How stigmas intersect: experiences of stigma and domestic violence in the lives of women living with HIV in India
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Thesis submitted for the degree of Doctor of Philosophy

UCL

Declaration:
I, Reshmi Mukerji, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.
Signature:

Date: .....

#### **Abstract**

**Background** An increasing number of women are diagnosed with HIV each year in India. Women living with HIV experience more domestic violence than others and both are stigmatized. This thesis explores experiences of intersectional stigma of HIV, domestic violence, and other marginalized identities in women's lives.

**Methods** An interpretive phenomenological approach was taken to understand Indian women's experiences and perceptions of intersectional stigma. Thirty-one semi-structured interviews were conducted with women living with HIV and sixteen with key informants in Kolkata, India. Photovoice work with eight women added to the interview findings. Data was analyzed using thematic network analysis.

Findings The findings show that HIV stigma often drives the domestic violence experienced by women living with HIV which is often temporal in nature. Multiple stigmas, such as that of HIV, combine with historic structures of discrimination, such as gender, to worsen the violence experienced by women. The additional marginalized identities are themselves contextual and can be identified through the application of an intersectional lens. The synergistic interaction of multiple stigmas that worsen violence against women has a negative impact on their health. One legal mechanism is the anti-discrimination 2017 HIV Act, but here too several barriers were identified before it could protect women from stigma-related violence.

Conclusions The thesis makes a theoretical and empirical contribution to understandings of intersectional stigma of HIV, domestic violence, and other marginalized identities by showing the importance of situating theories of intersectional stigma in particular social contexts. Since people are embedded in the history and culture of the place where they live, no understanding of HIV stigma is complete unless it is viewed intersectionally and placed within the deep rooted and interlocking structures of societal oppression. The thesis shows how such historic oppression combines with HIV stigma to affect women's lives and their health.

## **Impact Statement**

India has the third largest number of people living with HIV in the world. It also has some of the highest rates of domestic violence against women. As women living with HIV can experience high rates of violence, the primary motivation of this research was to understand experiences of intersectional stigma and related violence for women living with HIV and how such experiences impact their health. The aim was to use this information in improving services and further research so that ultimately women living with HIV can lead better lives.

The findings have practical impact for women living with HIV. Firstly, I identified a temporal trend in stigma-induced violence which can be used to inform and change practice. Women suffer heightened violence in the initial period after diagnosis and them and their families should be offered intensive stigma reduction counseling at this time. There is currently a lack of awareness of Undetectable=Untransmittable (U=U) approach and bringing this into counselling practice will help reduce both women's internalized stigma and enacted stigma (violence) towards them from partners and in-laws, while also improving mental health and adherence. Secondly, I found that intersectional stigma from multiple marginalized identities worsens violence experienced by women. This finding can be used to inform government policy, so that understandings of stigma address the broader social and historical contexts in which people live, rather than just treating it as an interpersonal issue. Thirdly, I found that poor mental health among women living with HIV experiencing violence leads to poor physical health. This finding can help inform counseling practice with strategies that allow women to focus on their positive identities and challenge stigma. Finally, I found that there was very little knowledge about the HIV Act among both women and key informants. This finding can be used to inform National AIDS Control Policy, which currently uses the Act as a measure of stigma eradication. Better success of the Act in reducing discrimination against women living with HIV can be ensured by addressing: (1) current legal frameworks that favor men, through unequal divorce and inheritance laws and (2) creating greater awareness of the HIV Act while also

recognizing its inherent flaws when used to protect women against HIV related discrimination.

Apart from impact on policy and practice, the findings also impact academic discourse by extending current understandings of intersectional stigma. There is a lack of academic literature on the intersectional stigma of HIV, domestic violence, and other marginalized identities and how such intersections impact women's lives. This work adds to the understanding of intersectional stigma by showing that manifestations of stigma are contextual (they differ in different settings), are temporal (they change over time), and impact women's lives in complex ways (both negative health effects and social impact).

Taken together, the findings from this work can be used to transform the lives of women living with HIV in India and elsewhere, through better understanding and improved practice.

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**Dedication** 

For Ma and Baba

6

## **Table of contents**

Chapter 1: General Introduction	13
1.1 HIV Global Epidemiology	14
1.2 HIV in India	14
1.3 Gender discrimination and domestic violence in India	15
1.4 Domestic violence stigma in India	
1.5 Domestic violence and HIV	
1.6 HIV stigma in India	
1.7 HIV stigma, domestic violence and the 2017 HIV/AIDS (Prevention and Control) Act	
1.8 Research questions	
1.9 Structure of thesis	22
Chapter 2: Literature Review	24
2.1 Introduction	
2.2 Methods	25
2.3 Search strategy and selection criteria	
2.4 Data extraction and synthesis	30
2.5 Results	31
2.5.1 Being affected by HIV increases domestic violence	31
2.5.2 Supportive reactions from partners	
2.5.3 HIV stigma is associated with domestic violence	
2.5.4 Domestic violence associated with HIV is gendered	
2.6 Discussion	
2.7 Limitations	
2.8 Conclusions	51
Chapter 3: Methodology	63
3.1 The interpretive position	63
3.2 The phenomenological approach	64
3.2.1 Husserl: Descriptive phenomenology	
3.2.2 Heidegger: Interpretative phenomenology	
3.2.3 The phenomenological approach compared with other approaches	
3.2.4 Limitations of the phenomenological method	
3.3 Theoretical frameworks	
3.3.1 Conceptualizations of stigma	
3.3.2 Domestic violence stigma framework	69
3.3.3 Feminist Theory	
3.3.4 Intersectionality	
3.3.5 Intersectional stigma framework	
3.3.6 Framework for coping with stigma	
3.3.7 Modifications made along the way	
3.4 Study setting	
3.5 Data collection methods	
3.5.1 Semi-structured interviews	
3.5.2 Photovoice	
3.6 Participants	
3.7 Inclusion and exclusion criteria	
3.8 Participant characteristics	82

3.9 Recruitment process	82
3.10 Covid-19 and challenges in recruitment	84
3.11 Supports for qualitative research	86
3.12 Feedback to participants	87
3.13 Research governance	87
3.13.1 Ethics	87
3.13.2 Informed consent	88
3.14 Data collection phases	88
3.15 Data analysis	89
3.15.1 Data management	89
3.15.2 Translation dictionary	90
3.15.3 Data analysis	91
3.16 Evaluation of the research	95
3.16.1 Timing of interview	95
3.16.2 Criteria for trustworthiness	95
3.16.3 Reflexivity and the researcher's position	97
3.17 Conclusions	99
Chapter 4: Intersectional stigma	100
4.1 Intersectional stigma of HIV and domestic violence amplifies stigma as a whole	
4.1.1 HIV stigma results in domestic violence against women living with HIV	
4.1.2 Perpetrators reinforce HIV stigma through abuse.	
4.1.3 HIV stigma worsens domestic violence stigma	
4.13 The stigma worsens domestic violence stigma	
4.2.1 "He is a man after all. Can a man's character be blemished?"- the intersection of H	
and gender discrimination	_
4.2.2 "Husband is the roof, husband is our shield"-the intersection of HIV and widowhoo	
	_
4.2.3 "You don't have boys, go, get lost"- the intersection of HIV, widowhood, and girl cl	
	•
4.2.4 "If we take her back our honor will be lost"-the intersection of HIV and sex work st	
4.2.5 "Neither is she getting any sympathy from trans people nor from people with HIV"	- the
intersection of HIV and transgender stigma	124
4.2.6 "People are afraid of the rich"-the intersection of HIV and poverty stigma	126
4.3 Stigma of HIV hides domestic violence	128
4.3.1 Women unable to share experience of violence with others	128
4.3.2 HIV stigma is a barrier to help seeking from informal sources	130
4.3.3 Women perceive reduced support from formal sources	132
4.4 Temporal domestic violence is triggered by HIV stigma	136
4.4.1 Reduction in enacted stigma over time	138
4.4.2 Reduction in internalized stigma over time	
4.5 Discussion	142
4.6 Conclusions	148
Chapter 5: Lived experiences of mental health due to intersectional stigma	150
5.1 Lived experiences of mental health as a result of HIV stigma in India	
5.2 Experiences of domestic violence and its impact on mental health among Indian wom	
5.3 Violence compounds the mental health effects of stigma, and vice versa	
5.3.1 Mental torture of stigma and violence	

5.3.2 Profound sadness due to stigma and violence	157
5.3.3 Hopelessness and wanting to die	
5.3.4 Mental disturbance of constant fear of people finding out	160
5.3.5 Intersectional stigma manifests as worries about children	
5.3.6 Distress of intersectional stigma of HIV and poverty	
5.4 The stress of stigma and violence on mental health contributes to poor physical health	
5.4.1 Poor mental health causes poor adherence to ART and non-linkage to care	
5.4.2 Effect of chronic stress on CD4 counts	
5.4.3 The physicality of stress	168
5.4.4 Stigma leads to poor health and vice versa	170
5.5 Discussion	170
5.6 Conclusions	175
Chapter 6: Coping with negative experiences of intersectional stigma	177
6.1 Women draw on their psychological resources to cope	
6.1.1 "Moner jor" or resilience	
6.1.2 "He gave it, He will make us better": Prayer	
6.1.3 "I feel like it is good I have this disease": Positive reframing	
6.1.4 "HIV is not as bad as blood sugar": Challenging stigma	
6.1.5 "I have cured so many people": Focusing on positive identities	
6.1.6 "When I feel upset I go to plants": Engaging in activity	
6.1.7 "Whatever has happened has happened": Acceptance and moving on	
6.2 Social resources strengthen psychological resources to cope	
6.2.1 "Our friends, they are positive. They are like us": Feeling included	
6.2.2 "When I come home, they come running to me": Feeling loved	
6.2.3 "I find my mental strength through work": Building financial independence	
6.2.4 Getting help with daily needs	
6.2.5 Seeking information	
6.3 Discussion	
6.4 Conclusions	
Chapter 7: The utility of the 2017 HIV Act in protecting women living with HIV fror	
violence	
7.1 Key anti-discrimination and domestic violence Acts in India	215
7.1.1 Hindu Marriage Act 1955, Hindu Succession Act 1956, and Hindu Succession (Am	
Act 2005	
7.1.2 Section 498A, Section 304B, and Protection of Women from Domestic Violence	-
7.1.3 Anti-Discrimination Laws	
7.1.4 Constitutional Protections and HIV Case Law in India	
7.2 Women's awareness and perceived effectiveness of the 2017 HIV Act	
7.2.1 Most women are unaware of the Act	
7.2.2 Stigma and ambivalence about using the Act	
7.3 Difficulty of access due to structural challenges.	
7.3.1 The police	
7.3.2 Legal aid services	
7.3.3 The courts	
7.3.4 Public offices	
7.4 Limited knowledge of the Act within the system	
7.4. i cimileo impiementación of the ACT	/ 3/4

7.4.2 Limited awareness among healthcare providers	234
7.4.3 Limited awareness among the police and judiciary	
7.4.4 Limited understanding of the Act among key service providers	238
7.5 Weaknesses in certain clauses of the HIV Act	242
7.5.1 Non-disclosure clause for women in conflict with existing laws	242
7.5.2 Inability to guarantee "Right to residence"	246
7.5.3 Penal clause too weak	248
7.5.4 Welfare measures not clearly defined	249
7.6 Discussion	252
7.7 Conclusions	257
Chapter 8: Conclusions and recommendations	259
8.1 Summary of research findings	
8.2 Contribution to existing literature	
8.3 Contribution to theory	
8.4 Implications for practice, policy, and recommendations	
8.5 Conclusions	
Bibliography	276
List of appendices	301
Appendix 1: Published mixed methods review	302
Appendix 2: Sociodemographic characteristics of women living with HIV	303
Appendix 3: Topic Guides	304
Key informant interview topic guide	
Topic guide for women living with HIV	
Appendix 4: Information Sheet and Consent form (Key Informants)	311
Appendix 5: Information sheet and consent form (Women living with HIV)	
Appendix 6: Audit trail for methodology	313
Appendix 7: HIV/AIDS Prevention and Control Act, 2017	314
List of Tables	
Table 1 Descriptions of different types of stigma	
Table 2 Ovid Medline example of search strategy and terms	26
Table 3 Summary of selected qualitative and mixed methods studies	
Table 4 Summary of selected quantitative studies	
women affected by HIV	
Table 6: Phenomenology compared with other qualitative approaches (adapted from Creswell 2016)	
Table 7 Description of key conceptualizations of stigma in general and in application to HIV and IPV	
stigma	
Table 8 Comparison of intersectional stigma frameworks	
Table 9 Key informant characteristics	82
Table 10 Characteristics of women living with HIV	8∠ 01
Table II Hallelation and incamine of sciedica delivation wild	

Table 12 Steps taken to ensure trustworthiness (Based on criteria developed by Bloomberg & Volp 2008)	
Table 13 Examples of themes on intersectional stigma	
Table 14 Descriptions of different forms of HIV related violence as reported by participants	
Table 15 Table showing severity and time point of violence at each stage of HIV trajectory	137
Table 16 Examples of themes on lived experiences of mental health	152
Table 17 Examples of themes on coping with intersectional stigma	179
Table 18 Examples of themes on the 2017 HIV Act	223
List of Figures	
Figure 1 PRISMA diagram for data extraction	
Figure 2 Intersectional stigma of HIV, domestic violence and other marginalized identities	
Figure 3 HIV stigma is a mediator of domestic violence for woman affected with HIV	
Figure 4 The Intimate Partner Violence Stigmatization Model (Overstreet & Quinn 2013)	
Figure 5 Health Stigma and Discrimination Framework (Stangl et al 2019)	
Figure 6 Map of India with location of West Bengal	
Figure 7 Exhibition of photographs	
Figure 8 Structure of a thematic network (Attride-Stirling, 2001).	
Figure 9 Conceptual framework of stigma amplification cascade	
Figure 10 Conceptual framework of intersectional stigma and health cascade	
Figure 11 Photovoice image	
Figure 12 Photovoice image	
Figure 13 Photovoice image	
Figure 14 Photovoice image	
Figure 15 Photovoice Image.	
Figure 16 Photovoice image	
Figure 17 Photovoice Image	
Figure 18 Photovoice image	
Figure 19 National policies on domestic violence and discrimination.	
Figure 20 Barriers to the HIV Act in protecting women from domestic violence and interventions that	
address these barriers	
Figure 21 Intersectional stigma framework for women living with HIV in India (adapted from Stangle 2019).	

#### **Abbreviations**

AIDS Acquired Immune Deficiency Syndrome

ANC Antenatal Care
ARR Adjusted relative risk
ART Antiretroviral therapy
CI Confidence interval
GBV Gender based violence

HIV Human Immunodeficiency Virus

HIV Act 2017 HIV/AIDS Prevention and Control Act IPA Interpretive phenomenological analysis

IPC Indian Penal Code
IPV Intimate Partner Violence
MSM Men who have sex with men
NFHS-5 National Family Health Survey-5
NACO National AIDS Control Organization
NACP National AIDS Control Program
NGO Non-governmental organization

OR Odds ratio

**aOR** Adjusted odds ratio

PMTCT Prevention of mother-to-child transmission

**PWN+** Positive Women's Network

SHGs Self Help Groups
TB Tuberculosis
US United States

WHO World Health Organization

## **Chapter 1: General Introduction**

This thesis examines experiences and perceptions of intersectional stigma in the lives of Indian women living with HIV. It explores how the stigma associated with HIV, domestic violence, and other marginalized identities intersect to shape the overall experiences of violence in women's lives, the impact of such intersecting stigmas on women's mental and physical health, how they cope with such experiences, and whether a law enacted to protect people living with HIV in India in 2017 is protecting women living with HIV from domestic violence.

The motivation for my research comes from my own personal experience of growing up in India and then moving abroad for several years. The experience of complete immersion in Indian society alongside time to reflect about it has made me acutely aware of the significance of the concept of "stigma" in Indian women's lives. We live our lives adhering to strict gender and societal norms and are at constant risk of being stigmatized for doing something "wrong". My interest in gender and stigma developed during my time volunteering and working at NGOs in Kolkata. While working on women's health and empowerment programs, I observed how restricted women were in making decisions about their own health and just how common violence was in their lives. This was never greater than when women were sick with an infectious disease such as TB or HIV. Specifically, my experience conducting research on TB stigma at a DOTS-TB clinic in Kolkata paved the way for the thesis as I learned the theories and concepts underlying the social process of stigma that I witnessed from clients' accounts at the clinic. Being trained in microbiology, I was intimately acquainted with the causative agents of disease and the body's response to it, but found it fascinating and equally frightening to see the havoc that an infectious disease could cause in a person's life because of the stigma attached to it.

When news of the enactment of the HIV/AIDS Prevention and Control Act (HIV Act) broke in the Indian media in 2018, I remember having mixed feelings of excitement and doubt.

On one hand, I thought of the relief that people living with HIV, particularly women, would have because of this Act, but I had a nagging sense of doubt about whether it would actually "work". This is what motivated me to research women's experiences of stigma and discrimination due to HIV and the experiences of violence and further stigmatization as a result of it and other marginalized identities.

I begin this introductory chapter with a brief examination of HIV epidemiology, both globally and in India, gender discrimination and domestic violence in India, the link between HIV and domestic violence, HIV stigma in India, and how domestic violence and HIV stigma intersect. This is followed by a summary of the key components of the 2017 HIV Act. I describe my research objectives and end with a brief description of the structure of the thesis.

#### 1.1 HIV Global Epidemiology

HIV is the second most deadly infectious disease in the world, with 690,000 people dying from AIDS-related causes in 2019 (WHO, 2019). Despite scale-up of antiretroviral therapy (ART) and consequent reductions in incidence from a peak of 3.16 million cases in 1999 to 1.7 million cases in 2019, there were still 38 million people living with HIV globally at the end of 2019 (Frank et al., 2019; WHO, 2019). About 19 million of them were women, 300,000 of whom died of AIDS-related causes in 2019 (WHO, 2019). The disease continues to be concentrated in sub-Saharan Africa, which carries 70% of the global burden of disease and accounts for 74% of the 1.5 million AIDS related deaths in 2013 (Kharsany & Karim, 2016).

#### 1.2 HIV in India

While there a lot is known about HIV stigma and how it manifests in parts of the world such as countries in Africa, relatively less is known about HIV stigma in India, where the social implications of HIV diagnosis are different. This is the focus of the thesis. India reported its first cases of HIV in 1986 when the virus was found among female sex workers in Chennai (Simoes et al., 2012). The epidemic grew to a peak in 1997 and has

since shown an 86% decline to its current incidence of 69,000 new infections in 2019, with over 2 million people currently living with the virus (NACO, 2019).

The nature of the epidemic in India is different from other regions of the world, in that it is driven mainly through heterosexual transmission among high risk groups, who have much higher rates of disease prevalence than the general population (Paranjape & Challacombe, 2016). High risk groups include female sex workers, men who have sex with men (MSM), injection drug users, and transpersons/hijras (hijras have been officially recognized as the third gender in India. They are considered neither male nor female and could be eunuchs, intersex, or transgender, who live in specific kinship communities). High risk groups and their partners, as well as 'bridge populations' (truck drivers, migrants), are key groups in which the HIV epidemic in India is concentrated.

My thesis explores the experiences of women living with HIV in India, as they are a group who have been increasingly impacted by the epidemic. Globally, women have been disproportionately affected, with AIDS-related illnesses being the leading global cause of death among women 15-49 years old (UNAIDS, 2019). This increased feminization of the epidemic has been witnessed in India as well, with 44% of new infections being found in Indian women aged 15 years or above (NACO, 2019). The global epidemic in women is primarily driven by heterosexual sex, but an unusual aspect of HIV in the general population of Indian women is that it is found almost exclusively among married monogamous women, with 90% of women reporting sex with their husbands as their only HIV risk behavior (Gangakhedkar et al., 1997; Newmann et al., 2000). It is important, therefore, to understand the specific challenges of stigma experienced by these women while living with HIV.

#### 1.3 Gender discrimination and domestic violence in India

The wide gender gaps in Indian society mean that women are particularly vulnerable to violence. The family, often headed by the oldest male, is the center of this patriarchal, patrilineal, and patrilocal society (Go et al., 2003; Jejeebhoy, 1998). Subordination of

women can be traced back to ancient India (c. 1500 BC). The sage Manu codified laws for society in the *Manusmriti*, in which he called for the absolute subservience of women to men (Menon & Kanekar, 1992). According to writings of the time, a husband was allowed absolute control over his wife's mind and body and had the "right to use physical corrective methods over his erring wife" (Mahajan, 1990). Texts from the time suggest that wife-beating was an everyday affair. The revered poet Tulsidas recommending regular beatings: "As part of a primitive, uncultured caste, animals and women deserve to be beaten regularly" (Mohan, 1990). The great Indian epic, the Ramayana, celebrates violence against women. Sita, the devoted wife of Lord Rama, is found guilty of unfaithfulness in the court of public opinion and is consigned to the flames by her silent husband (Radha, 2019). Over the years, violence against women continued with practices such as female infanticide, child marriage, purdah (hiding women from public gaze), jauhar (mass self-immolation of women to avoid capture, enslavement, and rape by Muslim invaders), sati (burning of wives on the husband's funeral pyre), devdasis (women dedicated to the worship of a temple for life), and dowry (Radha, 2019). Colonization by the British enforced Western patriarchal norms and Victorian values, such as women's subservience and sexual modesty, on Indian women (Chakraborty & Thakurata, 2013). Gender norms that tacitly sanction violence have continued. They have been perpetuated through colonial era laws on divorce, inheritance, and property rights that favor men (Chitnis & Wright), who continue to exert control over household, economic, and sexual decision making within their relationships (Jejeebhoy, 1998).

The latest Indian National Family Health Survey (NFHS-5) estimates that about one in three women were abused by their spouses in the 2019-21 period (IIPS, 2021). However, a systematic review of a decade of quantitative research from India estimates that about 40% of Indian women report experiencing domestic violence within their lifetimes and 30% report such experiences within the past year (Kalokhe et al., 2017). Traditional Indian wives are expected to be submissive to their partners and in-laws, and any disruption of this traditional gender role can result in violence. In the state of West Bengal, where my research was conducted, over half of all male and female respondents in a study reported

perpetrating or experiencing domestic violence, respectively (Babu & Kar, 2009). The definition of domestic violence in India, and for the thesis, includes violence from partners as well as in-laws, considering the structure of Indian joint families and the tradition of women living with their husbands' families after marriage (Kalokhe et al., 2015). Apart from husbands, mothers-in-law and other female relatives are often a significant source of violence in this setting, with some studies reporting as much as 33-40% of domestic violence being done by family members who either perpetrate or instigate it (Gangoli & Rew, 2011). While levels of wife-beating may be quite similar across the country, factors relating to women's autonomy such as education, marital age, economic activity and control of economic resources, decision making authority, and freedom of movement, may be more protective against violence in more gender equitable states in the South than in the North, where there are wider gaps in gender equality (Jejeebhoy, 1998). Overall, wife-beating in India is deeply entrenched and socially acceptable, with very few women willing to leave abusive marriages (Jejeebhoy, 1998). Despite changes in the Indian family structure, with more couples living in nuclear families and more educated women working in paid employment, the social stigma of divorce remains high, particularly for women, and forces them to stay in abusive relationships (Rangarao & Sekhar, 2002; Thadathil & Sriram, 2020). Apart from violence within marital relationships, widows are another group of women who experience significant disadvantage and discrimination. Widows generally experience greater poverty, social sanctions on movement, clothing and nutrition, and lack of property rights, all of which contribute to the violence they experience (Chen, 1997).

#### 1.4 Domestic violence stigma in India

Not only is domestic violence pervasive in India, it is also stigmatized just as it is in other geographic settings and cultures (Overstreet & Quinn, 2013). Although a common structural driver of stigma and domestic violence is a difference in positions of power between groups (men and women in the case of domestic violence) (Link & Phelan, 2001; Overstreet & Quinn, 2013), more complex multilevel factors drive domestic violence stigma. Evidence from the western literature has shown that interpersonal drivers of

domestic violence stigma include a combination of (1) domestic violence being considered a personal matter which happens and must remain behind closed doors (Gerbert et al., 2002; Taket et al., 2003) and (2) the victim's behavior and interpersonal relationship with the perpetrator that allow further victimization (Meyer, 2016). In India, however, the main interpersonal driver of this stigma is that domestic violence is considered a family affair that no one should know about (Paul, 2016). Reporting of domestic violence to formal sources or even talking to friends and family about it compromises the woman's and, more importantly, the family's honor (Menon & Allen, 2018). Dominant patriarchal cultural narratives mean that reaching out to formal sources such as the police can lead to victim blaming (Menon & Allen, 2018), which stigmatizes women further and fuels internalized stigma. Shame and guilt act as further barriers to help-seeking and asking for help outside the family may involve compromising the family's honor (Lee & Hadeed, 2009). This, combined with the cultural normalization of violence, works to silence survivors of domestic violence and trap them in abusive relationships.

#### 1.5 Domestic violence and HIV

My thesis examines the links between HIV stigma and domestic violence. Violence is commonly reported by married Indian women, both from their intimate partners (IPV) and their families (non-intimate partner domestic violence). These two forms of violence overlap in the lives of married women, given the strong role of family, arranged marriages, and the custom of living with in-laws after marriage. Domestic violence has been cited as a significant mediator of HIV risk for women in India and South Asia, with high levels being consistently reported from the region (Silverman et al., 2008). Domestic violence increases HIV risk by (1) taking away a woman's agency to refuse sex or negotiate safe sex with her partner and (2) increasing the risk of direct transmission due to cuts and lacerations during forced sex (Go et al., 2003). Domestic violence also presents an indirect risk to women, as abusive men are known to engage more in high risk behaviors such as unprotected extramarital sex, engagement with female sex workers, and greater alcohol and drug abuse (Dunkle et al., 2006). Domestic violence is not just a risk factor for HIV. Studies have shown that disclosure of HIV status can be a trigger for violence

and women with HIV may experience a commencement or escalation of violence after their diagnosis (Emusu et al., 2009; Maman et al., 2002; Zunner et al., 2015). Given this strong link between HIV and domestic violence, I explore the reasons for and the impact of domestic violence in the lives of women living with HIV in India.

#### 1.6 HIV stigma in India

Erving Goffman defined stigma as an "attribute that is deeply discrediting" which reduces the bearer "from a whole and usual person to a discounted, tainted one" (Goffman, 1963). Stigma has been classified into different dimensions and types, briefly described in Table 1 and discussed in more detail in Chapter 3.

Table 1 Descriptions of different types of stigma

Dimensions of stigma	Definition
Enacted stigma	Experiences of discrimination, stereotyping, or prejudice from others.
Internalized stigma	Endorsing negative beliefs about the stigmatized condition.
Anticipated stigma	Expectations of discrimination, stereotyping, or prejudice.
Perceived stigma	Perceiving that those without the condition view those with the condition negatively.
Vicarious stigma	Perceptions of stigma shaped by stories of discrimination against others living with HIV.
Symbolic stigma	Associations with morally devalued characteristics.
Instrumental stigma	Fears and misconceptions about transmission through casual contact.

Stigma and discrimination against people living with HIV/AIDS is a globally well-studied phenomenon (Mahajan et al., 2008). In India too, HIV remains a heavily stigmatized illness. A recent systematic review documenting knowledge and attitudes towards HIV found that 40% of people still have negative attitudes towards people living with HIV and 75% had correct knowledge about HIV (Bhagavathula et al., 2021). It has been argued that the drivers of HIV stigma in India include moral judgement, blame, and fear of contagion (Ekstrand et al., 2012; Panda et al., 2015). Stigma manifests in the form of physical violence and verbal abuse, ostracism, social distancing, rejection and breakdown

of marriage, denial of basic rights such as a proper cremation, unequal treatment in healthcare facilities, loss of employment, and dismissal from school (Ekstrand et al., 2012; Ekstrand et al., 2013; Krishna et al., 2005; Panda et al., 2015; Patel et al., 2012). Such behaviors can reinforce notions of untouchability associated with the Indian caste system. Non-disclosure or selective disclosure for fear of anticipated stigma is well documented in studies from India, and has been shown to be associated with depression and delays in healthcare seeking (Steward et al., 2013; Steward et al., 2008). While reports of perceived and internalized stigma are common in India, reports of enacted stigma are much fewer (Bharat, 2011), possibly because very few people disclose to extended family and community. The gendered nature of HIV stigma in India is obvious in studies, with women being blamed and shamed, abandoned, forcefully evicted from their marital homes, and denied their rights to property (Bharat, 2011). Although healthcare settings may be the most significant sites of stigma and discrimination for *all* people living with HIV in the Indian context, the marital home is where *women* experience the greatest discrimination (Bharat, 2011).

Although most studies from India come from the states in the South, a few studies from West Bengal have shown the persistence of social stigma towards people living with HIV (Biswas & Bandyopadhyay, 2019; Dasgupta et al., 2010; Ghosh et al., 2020; Sarkar et al., 2019; Sinha et al., 2020). In a study conducted with nurses in five tertiary care hospitals in Kolkata in 2020, although the majority held positive attitudes towards people living with HIV, about 7% still believed that people living with HIV should be isolated from the community and 16% believed their status should be made public (Ghosh et al., 2020). A study conducted with adolescent school girls in North Bengal in 2019 showed extremely stigmatizing attitudes, such as not wanting to shake hands or share a meal with people living with HIV, for the majority of students (Biswas & Bandyopadhyay, 2019). A study with men living with HIV in Kolkata showed that around 50% experienced stigma from the family and 20% from the community, with about 75% disclosing to the family and 30% to the community (Sarkar et al., 2019). A mixed methods study conducted in two districts of West Bengal described violence from the community towards people living with HIV, with

women being blamed and judged more than men (Panda et al., 2015). In sum, these studies show that there is still a considerable degree of stigma towards people living with HIV in India and West Bengal, and one manifestation of this stigma is increased violence against people living with HIV.

# 1.7 HIV stigma, domestic violence and the 2017 HIV/AIDS (Prevention and Control) Act

Living with HIV, then, can often result in domestic violence against women (Kouyoumdjian et al., 2013). In 2017, the Government of India passed the landmark HIV/AIDS (Prevention and Control) Act which prohibited discrimination against a person based on their HIV status. The Act was implemented nationally in 2018, at around the same time as the striking down of parts of Section 377 of the Indian Penal Code (which effectively decriminalized homosexual intercourse), and paved the way for progress in HIV control in India. In recognition of HIV being a trigger for domestic violence, the Act included special privileges for women, including the right to live in a shared household, which meant they could no longer be thrown out of the house because of their HIV status. The Act also specifically stated that, although people living with HIV must make every effort to reduce transmission, women (or their healthcare providers) are not obliged to disclose their HIV status to their partners if there is a reasonable expectation of violence (Ministry of Law and Justice, 2017). There have been no studies to date to show how effective the Act has been in preventing acts of stigma and discrimination, including domestic violence against women, and this thesis fill this gap.

#### 1.8 Research questions

Given the link between HIV and domestic violence, my thesis examines how the stigma of the two overlaps with other social identities through the following research questions:

(1) How do the stigmas of HIV, domestic violence, and other marginalized identities intersect in the lives of women living with HIV to shape their overall experience of violence?

- (2) What are the lived experiences of mental health and how it impacts physical health for women experiencing intersectional stigma and related violence?
- (3) How do women cope with experiences of intersectional stigma and related violence?
- (4) Does the 2017 HIV/AIDS (Prevention and Control) Act protect women from HIV stigma-related domestic violence?

#### 1.9 Structure of thesis

The thesis is divided into eight chapters.

Chapter One: an introductory chapter which details my motivation of study, a background on HIV epidemiology both globally and in India, the link between HIV and domestic violence, the stigma of HIV and domestic violence and brief description of the 2017 HIV Act, followed by the research questions that the thesis seeks to address.

Chapter Two: a systematic literature review to establish what is known about HIV stigma and domestic violence and to identify the gaps in the literature.

Chapter Three: Detailed methodology for the thesis. This includes a description of my epistemological position, my qualitative approach, a description of the theoretical frameworks that guide the research, methods of data collection, data analysis, ethical considerations, and issues of trustworthiness.

Chapter Four: Findings on the intersectional stigma of HIV and domestic violence, how they overlap with other marginalized identities, and how this worsens women's overall experience of violence.

Chapter Five: Findings on the lived experiences of mental health as a result of negative experiences of intersectional stigma and violence and how they affect physical health.

Chapter Six: Findings on women's coping mechanisms to overcome the negative experiences of stigma and violence.

Chapter Seven: Findings on the HIV Act and whether it is able to protect women living with HIV from domestic violence.

Chapter Eight: Summarizes the overall findings of the thesis in view of the current evidence and existing theories. It also provides recommendations about how the work can be used to inform policy and practice.

## **Chapter 2: Literature Review**

As this thesis is about the stigma in the lives of women living with HIV and experiencing domestic violence, I describe in this chapter the methods and findings of a systematic review I conducted to identify the gaps in the literature. The gaps that were identified were listed as research questions at the end of the previous chapter. The findings from the review have been published (with a few small changes because of the journal's word limit) in the journal AIDS Care (Mukerji et al., 2022) (published paper attached as Appendix 1). The methods, results, and discussion presented here give a detailed description of how the review was conducted, the evidence from the current literature, and a discussion of gaps that the thesis aims to fill.

#### 2.1 Introduction

HIV is as much a social disease as it is an infectious disease and people living with HIV are subject to widespread social stigma and discrimination (Parker & Aggleton, 2003). The stigma attached to HIV stems from moral judgement and fear of contagion, which often result in acts of discrimination against people living with HIV from family, friends, neighbors, healthcare providers, and others (Ekstrand et al., 2012).

Experiences of HIV stigma for women living with HIV are inextricably linked with gender discrimination and are often characterized by violence against them (Logie et al., 2011). According to the World Health Organization (WHO), almost 30% of women worldwide who have been in a relationship have experienced intimate partner physical or sexual violence in their lifetime, while 38% of all murders of women were committed by intimate partners (WHO, 2017). A recent systematic review and meta-analysis showed that 39% of people living with HIV experience intimate partner violence, but the numbers were neither disaggregated by sex nor whether the violence occurred before or after diagnosis (Cheng et al., 2022). There is a bi-directional link between HIV and domestic violence against women: domestic violence increases the risk of acquiring HIV and HIV increases the risk of domestic violence (Maman et al., 2000). We need to understand how these

two epidemics intersect in women's lives in order to design effective control measures for both.

While HIV stigma for women may manifest as physical and sexual violence from partners and in-laws, the stigma attached to domestic violence may prevent them from reporting or seeking help. Past reviews have examined the relationship between HIV and domestic violence (Campbell et al., 2008; Kennedy et al., 2015; Kouyoumdjian et al., 2013; Maman et al., 2000), but none have specifically examined the link between HIV stigma and domestic violence, despite both being stigmatized conditions. This review aims to fill this gap by synthesizing the evidence on violence experienced by women affected by HIV (defined here as women living with or testing for HIV), how it is linked to HIV stigma, and how the two stigmas intersect in their lives.

#### 2.2 Methods

I conducted a mixed-studies review of the literature to explore violence experienced by women affected by HIV and how it is linked to HIV stigma. A mixed studies review was conducted (instead of only a qualitative review) because the quantitative data would provide insights into the prevalence or risk of HIV stigma-related domestic violence in society, while the qualitative data would give a depth of understanding into women's lived experiences, perceptions, and the meanings they make of stigma-related violence. All women, either living with HIV or taking an HIV test, both cis- and transgender, were included in the review. Domestic violence was defined such that it included violence from either intimate partners or their families or both. The review had broad inclusion criteria which included peer-reviewed, original research articles that reported on experiences of stigma, discrimination, and domestic violence among women living with HIV in any country. There were no limits on date of publication and reports with qualitative, mixed methods and quantitative study designs were included. Studies reporting on experiences of men living with HIV, men who have sex with men, children and adolescents, mental health outcomes of HIV or domestic violence among women, and studies reporting on

gender-based violence committed by a non-partner were excluded. Studies focusing on domestic violence as a risk factor for HIV were also excluded. This was because the review focused only on domestic violence in relation to HIV serostatus or stigma experienced by women or those identifying as women.

#### 2.3 Search strategy and selection criteria

I searched Medline, Web of Science, PsycINFO and EMBASE databases without a starting date limit until March 2020. These databases were chosen so that articles from the broad array of biomedical, psychological, and public health literature that reported on women's experiences of living with HIV, stigma and domestic violence could be retrieved. A librarian provided guidance on the appropriate search strategy using keywords and MeSH (medical subject heading) terms. Search terms used to cover the three broad topic areas of HIV, stigma, and domestic violence included "social stigma" OR "discrimination" OR "prejudice" OR "disclosure" AND "intimate partner violence" OR "domestic violence" OR "spouse abuse" AND "HIV" OR "acquired immunodeficiency syndrome". No limits were placed on gender, form of violence, or study design during the search, but articles pertaining to women or those identifying as women and those reporting on intimate partner violence and domestic violence were selected from the search results for further review. Table 2 shows an example of the Medline search on which the other searches were based. Reference lists from included articles and reviews were hand-searched to identify relevant articles that may have been missed during the database search.

Table 2 Ovid Medline example of search strategy and terms

Sea	arch History	
	Searches	Result
1	prejudice/ or rejection, psychology/ or social discrimination/ or social distance/ or social isolation/ or social marginalization/ or socialstigma/ or stereotyping/	56407
2	stigma* or discriminat* or prejud* or marginal* or stereotyp* or reject*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary	573857

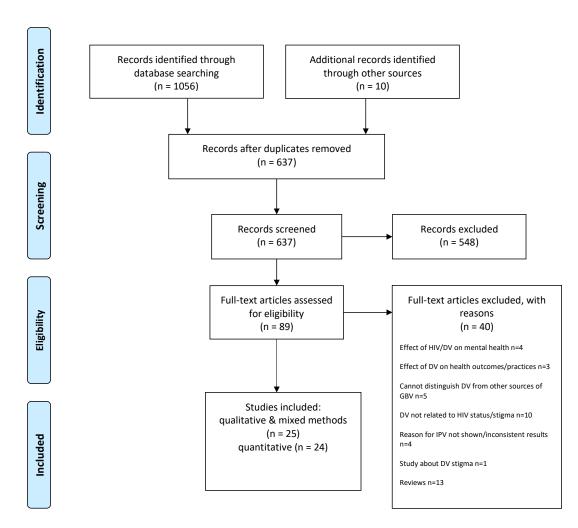
	concept word, unique identifier, synonyms]	
3	1 or 2	587150
4	domestic violence/ or gender-based violence/ or intimate partner violence/ or spouse abuse/ or physical abuse/	15503
5	(intimate partner violence or IPV or domestic violence or gender based violence or domestic abuse or spouse abuse or battered women).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	22490
6	Battered Women/	2613
7	4 or 5 or 6	22943
8	HIV/ or HIV Infections/	199461
9	(HIV or acquired immunodeficiency syndrome or human immunodeficiency virus).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating subheading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	402091
10	Acquired Immunodeficiency Syndrome/	76100
11	8 or 9 or 10	402091
12	Disclosure/	13419
13	disclosure.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keywordheading word, organism supplementary concept word, protocolsupplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	45393

14	12 or 13	45393
15	3 or 14	628667
16	7 and 11 and 15	265
17	limit 16 to (english language and journal article)	247

Articles were first screened by title and abstract to include articles that focused on women living with HIV and experiencing domestic violence. Studies that fit the inclusion criteria and reported findings of violence related to taking an HIV test, post-disclosure violence, or non-disclosure of HIV diagnosis due to fear of violence, studies showing violence increasing post-HIV diagnosis and violence in the lives of women living with HIV were included for full text screening. Studies that fit the exclusion criteria, such as studies that dealt with experiences of men or men who have sex with men, violence as a risk factor for HIV, lifetime prevalence of violence in women living with HIV (where violence occurring before HIV diagnosis could not be distinguished from violence happening after), violence from sources other than intimate partners or family, and studies focusing on the physical or mental health impact of HIV or violence were excluded. Review articles, intervention studies, conference abstracts, comments and editorials were also excluded. The full texts of the remaining articles were screened and those that did not fit the inclusion criteria were excluded. Figure 1 shows a summary flowchart of the screening process.



#### **PRISMA 2009 Flow Diagram**



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

Figure 1 PRISMA diagram for data extraction

#### 2.4 Data extraction and synthesis

Data such as number of participants, study design (e.g., cross sectional, longitudinal, qualitative research methods), geographical location, study settings (e.g., tertiary hospital, maternity clinic, HIV clinic), a summary of key findings and an analysis of stigma (whether or not stigma was specifically mentioned or measured in the study, although outcomes of violence were reported) were extracted from the selected qualitative and mixed methods (Table 3) and quantitative studies (Table 4).

Quality of the studies were assessed using the Mixed Methods Appraisal (MMAT) tool that has been developed for appraising qualitative, quantitative and mixed methods studies (Hong et al., 2018). The tool has five questions each for qualitative and quantitative studies and fifteen questions for mixed methods studies, but the lowest score of either the qualitative or the quantitative portion becomes the score for mixed methods studies. None of the selected studies was excluded on the basis of quality as I wanted to explore the link between domestic violence and HIV stigma experienced by women using all of the evidence available from the published literature.

I used a convergent approach to synthesize the data, such that qualitative and quantitative data were analyzed together, so as to understand the broad question of how domestic violence among women living with or testing for HIV is linked to HIV stigma (Gough, 2015; Pluye & Hong, 2014). I did not convert qualitative data to quantitative data or vice versa. I used a narrative synthesis approach to analyze the data, where data from all study types were analyzed thematically (Pluye & Hong, 2014). Patterns in findings across studies were analyzed inductively and iteratively to develop broad conceptual themes that were organized around the findings from the diverse set of included studies (Popay et al., 2006). For the preliminary analysis, studies were grouped according to the timing of violence during the course of the HIV trajectory; for instance, testing, disclosure, and lived experience of women living with HIV. Re-analysis of this grouping revealed significant overlap between groups and identified new patterns within the findings. This led to the final development of broad themes, based on the concepts identified from

studies within the groups. Four themes emerged from the analysis: (1) being affected by HIV increases domestic violence, (2) supportive reactions from partners, (3) HIV stigma is associated with domestic violence, and (4) domestic violence associated with HIV is gendered. Gaps in the literature were also identified through the same analytical process.

#### 2.5 Results

A total of 49 studies were selected for analysis, of which 18 used qualitative and 7 mixed methods (Table.2), while 24 were quantitative (Table. 3). Thirty-four studies were from Africa (Abuogi et al., 2019; Adeniyi et al., 2017; Ashaba et al., 2017; Chilemba et al., 2014; Colombini et al., 2016; Emusu et al., 2009; Ezeanochie et al., 2011; Ezechi et al., 2009; Fiorentino et al., 2019; Hardy et al., 2020; Hatcher et al., 2016; Hatcher et al., 2014; Hyginus et al., 2012; Iliyasu et al., 2011; Kabwama et al., 2019; Knettel et al., 2019; Malaju & Alene, 2013; Maman et al., 2016; Marais et al., 2019; Matseke et al., 2016; Mepham et al., 2011; Mulrenan et al., 2015; Odiachi et al., 2018; Olowookere et al., 2015; Onono et al., 2014; Osinde et al., 2011; Pool et al., 2001; Ramlagan et al., 2019; Rujumba et al., 2012; Shamu et al., 2014; Turan et al., 2011; Turan et al., 2016; Zamudio-Haas et al., 2012; Zunner et al., 2015), one that studied sub-Saharan African immigrants in Belgium (Arrey et al., 2015), six from North America (Gielen et al., 2000; Gielen et al., 1997; Koenig et al., 2002; Logie et al., 2011; Maher et al., 2000; Moreno, 2007), four from Asia (Aryal et al., 2012; Chakraborty et al., 2016; Hershow et al., 2017; Mehta et al., 2019), one from central Asia (Jiwatram-Negron et al., 2018), one from South America (Derose et al., 2017), and two were multi-country studies (Ojikutu et al., 2016; Orza et al., 2015).

### 2.5.1 Being affected by HIV increases domestic violence

Having HIV can increase the risk of domestic violence for women at every stage of the HIV trajectory. The studies described below provided evidence of a higher risk of violence as a consequence of undertaking an HIV test and disclosure of a positive diagnosis, with violence starting for the first time or pre-existing violence worsening after disclosure. As

a result, some women chose not to disclose positive test results for fear of ensuing violence.

Four studies described how HIV testing could increase the risk of domestic violence and how anticipation of violence could cause women to refrain from disclosing positive test results. Testing for HIV could raise suspicions of infidelity and the stigma attached to an HIV diagnosis could lead to fears of violence which deterred women from undertaking an HIV test. A qualitative study showed that HIV negative women attending a maternity clinic in south-west Uganda were ambivalent about taking an HIV test: some were willing to take the test, while others were hesitant due to fears of negative consequences and stigma associated with a positive test result. Women were unwilling to inform their husbands, if they tested positive, "because he would say I am the one who brought it, and he can send me away as well" (Pool et al., 2001). A study from Kenya mentioned that women could "be sent packing" if they were found to have taken an HIV test (Turan et al., 2016). A Zimbabwean study reported high levels of domestic violence associated with taking an HIV test. Although the risk of violence was almost six times greater for women who tested positive (OR: 5.83 95% CI: 4.31-7.9), high levels of violence were also reported by women who tested negative, showing that HIV testing irrespective of outcome can be a risk factor for violence towards women (Shamu et al., 2014). Although 28% of women declined to take an HIV test in a study conducted in two cities in the U.S., this decision was not strongly associated with their fear or history of partner violence or experiences with partner notification (p>0.05). But 12% of participants felt that they would be threatened with violence if they tested positive and 31% felt they might be humiliated or rejected if they tested positive (Maher et al., 2000).

Thirty-one studies showed how disclosure of positive HIV test results could increase risk of actual violence or the fear of violence could lead to non-disclosure for women living with HIV. Twelve quantitative (Abuogi et al., 2019; Ezechi et al., 2009; Hardy et al., 2020; Iliyasu et al., 2011; Koenig et al., 2002; Malaju & Alene, 2013; Maman et al., 2016; Ojikutu et al., 2016; Olowookere et al., 2015; Onono et al., 2014; Shamu et al., 2014; Turan et

al., 2011), twelve qualitative (Arrey et al., 2015; Ashaba et al., 2017; Colombini et al., 2016; Derose et al., 2017; Gielen et al., 1997; Hatcher et al., 2016; Hatcher et al., 2014; Mulrenan et al., 2015; Pool et al., 2001; Rujumba et al., 2012; Zamudio-Haas et al., 2012; Zunner et al., 2015), and seven mixed methods (Adeniyi et al., 2017; Gielen et al., 2000; Knettel et al., 2019; Mepham et al., 2011; Odiachi et al., 2018; Orza et al., 2015; Turan et al., 2011) studies reported on actual or anticipated post-disclosure violence. The most frequently reported experiences of violence were associated with the disclosure of HIV test results, including blame for "bringing virus" due to suspicions of infidelity, verbal hostility, physical, sexual and emotional violence, breakdown of marriage, rejection, abandonment, forced interruption of treatment and financial withdrawal.

Generally, women were afraid to disclose positive test results for fear of a violent backlash, illustrated by a quote from a Kenyan study: "I'm scared to tell him, I don't have the guts to tell him, he is a big bully and rude" (Adeniyi et al., 2017). Fears of disclosure were even greater for women in polygamous marriages as a positive diagnosis could lead to the husband returning to the other wife:

"If I tell him, he may never come back to my place and shift forever to the second wife. How will I and my children survive? He can even send me away or say I brought HIV yet I have been faithful to him; I feel bad that I have HIV yet I have not been having other men" (Rujumba et al., 2012).

There were also reports of actual experiences of violence following disclosure, as reported by a study from South Africa where severe violence followed HIV status disclosure at the time of pregnancy:

"He started telling me things, hurting me emotionally, telling me that I'm a fool, and stupid, I'm an idiot. And then he strangled me, That's when it started . . . Maybe it's pregnancy, I don't know. I told him that I am HIV positive, so I don't know if that's what made him to do all these things" (Hatcher et al., 2014).

Similar reports came from high-income countries such as the US, where women often experienced blame and violence as a result of disclosure, as described by one respondent living with HIV:

"One day, he kicked the TV . . . and knocked up all the furniture, and took soap and wrote "AIDS" b\_\_\_\_ on the mirror. ..Every time we would have an argument, that's what it would be, you know, "You b\_\_\_ you gave me AIDS" (Gielen et al., 1997).

Fifteen studies described how domestic violence started or worsened following HIV diagnosis, and provided the strongest evidence of how being affected by HIV increases risk of domestic violence (Aryal et al., 2012; Emusu et al., 2009; Ezeanochie et al., 2011; Ezechi et al., 2009; Gielen et al., 2000; Hardy et al., 2020; Hatcher et al., 2016; Hyginus et al., 2012; Iliyasu et al., 2011; Marais et al., 2019; Mulrenan et al., 2015; Olowookere et al., 2015; Orza et al., 2015; Shamu et al., 2014; Zunner et al., 2015). Due to the large number of studies showing violence following an HIV diagnosis emerging from Africa, these are discussed first, before studies from other parts of the world.

There were two studies from South Africa, of which one reported recent domestic violence that started or worsened immediately after HIV testing among 81% study participants (Hatcher et al., 2016), while women living with HIV from the second South African study attributed their experiences of abuse or worsening of abuse to their HIV diagnosis (Marais et al., 2019). For Zimbabwean women who had disclosed, 11% reported experiencing domestic violence for the first-time after disclosure, with 22% of these women living with HIV (Shamu et al., 2014). A study from Kenya reported that, for 79% participants, violence started only after disclosing their HIV status to their male spouse and 50% reported that their in-laws were the perpetrators of abuse (Zunner et al., 2015). Although a small number of women from Ghana answered questions on post-disclosure violence, for 76% of them violence started after disclosure and escalated for 67% (Hardy et al., 2020). In a

study from Uganda (Emusu et al., 2009), women living with and without HIV in serodiscordant relationships reported violence in their relationships, with violence either commencing or doubling after a positive diagnosis:

"Yes, the sexual violence which used not to be there started and increased in frequency over time after the disclosure of our test results. It started by him being rude to me, then it reached a stage whereby every time he wants sex, he would use force to get me to play sex with him against my will, especially when he was drunk" (Emusu et al., 2009).

Five quantitative studies from Nigeria reported similar findings of worsening violence after an HIV diagnosis. In one study, domestic violence started after their HIV diagnosis for 22% of respondents, with women who had disclosed to their partners being three times as likely to experience violence (28.4% vs 9.5%, p=0.0003) (Iliyasu et al., 2011). A second study showed that only 24% women had disclosed their HIV status to their partner, and almost all had experienced domestic violence after disclosure (Olowookere et al., 2015). A third study, which compared violence in the lives of women living with and without HIV, showed that women living with HIV experienced six times more physical violence and four times more sexual violence, with 75% of women living with HIV also experiencing an increase in violence following disclosure of their diagnosis to partners (Hyginus et al., 2012). A fourth study reported similar findings, where 74.1% women reported abuse only after HIV diagnosis and 53% reported a worsening of abuse after diagnosis (Ezechi et al., 2009). The fifth study showed that multiparous women living with HIV had a higher likelihood of experiencing violence (OR 9.4; CI 1.23–71.33), as did those with a child who had acquired HIV vertically (OR 9.2; CI 4.53-18.84). But women who experienced violence before diagnosis had 45 times higher likelihood of experiencing violence after diagnosis (OR 44.4; 10.33–190.42) (Ezeanochie et al., 2011).

Domestic violence commencing or worsening after an HIV diagnosis was also reported by studies with women from other parts of the world. A global participatory mixed methods study with participants from 94 countries found that, although domestic violence was most common before HIV diagnosis, it became worse for some after diagnosis, with 31% of participants reporting violence from an intimate partner because of their HIV diagnosis (Orza et al., 2015). A study from the US. reported that 67% of women living with HIV experienced some form of domestic violence: 16% experienced violence only after diagnosis and 4% reported violence immediately after disclosure. In the words of one woman,

"HIV, the abuse started then . . . He didn't want to accept the blame for it and he wanted to throw it on me. So, he used to do things mentally to try to make me feel like I was responsible. Then he started disrespecting me in public, especially in front of his family" (Gielen et al., 2000).

A small cross-sectional study from Nepal reported a sharp rise in domestic violence following HIV diagnosis (53.5% vs 93.02%), with 40% reporting economic violence commencing only after diagnosis. Husbands were the main perpetrators (45%), followed by mothers-in-law (42.5%) and maternal relatives (35%) (Aryal et al., 2012). Finally, a study from India showed that a significantly higher proportion of women living with HIV reported "quarrels" with their spouse compared to those without HIV (79.8% vs 67%), with 28% of women attributing HIV status as the reason for quarrels. Women living with HIV were also three times (CI= [1.1, 7.6], p=0.023) more likely to experience recent sexual violence than women without (Chakraborty et al., 2016).

#### 2.5.2 Supportive reactions from partners

There were, however, 14 studies that reported supportive reactions from partners (Abuogi et al., 2019; Adeniyi et al., 2017; Ashaba et al., 2017; Derose et al., 2017; Gielen et al., 2000; Gielen et al., 1997; Hershow et al., 2017; Iliyasu et al., 2011; Kabwama et al., 2019; Mulrenan et al., 2015; Odiachi et al., 2018; Rujumba et al., 2012; Shamu et al., 2014; Zamudio-Haas et al., 2012). Some studies showed that violence was a function of behavioral or relationship characteristics rather than HIV status. A study from South Africa found no association between disclosure of HIV status and domestic violence between women living with and without HIV, but for those who had not disclosed, women living

with HIV were five times (95% CI: 1.25-21.0) more likely to experience violence, indicating that non-disclosure could be a marker of an unhealthy relationship with a violent partner (Maman et al., 2016). In a US study, violence was present in all partnership categories (abusive and non-abusive partners) and violence did not differ significantly by serostatus (6% diagnosed during current pregnancy, 11% for seronegative women, and 9% diagnosed prior to current pregnancy)(Koenig et al., 2002). A Ugandan study indicated that, although women living with HIV experienced high levels of domestic violence, this was similar to that experienced by the general population of women, although a surprising finding was that women in serodiscordant relationships were less likely to experience violence (PRR = 0.87 95% CI: 0.78-0.98) (Kabwama et al., 2019). One reason that the authors gave for this was that serodiscordant couples were provided with better counseling and disclosure-related assistance in anticipation of the possibility of violence. None of the participants in a study from Vietnam were afraid of disclosing their positive status to their husbands, mainly because they were wives of injection drug users who knew that their husbands were the source of the virus (Hershow et al., 2017). 88% of women from Western Kenya reported positive male partner reactions upon disclosure of HIV status. Women in concordant relationships were six times more likely to report a positive reaction (aOR 6.7, 95% CI 1.7-26.6, p=0.01), those using couples HIV testing and counseling assisted disclosure were 20 times more likely to report a positive reaction (aOR 20.2, 95% CI 1.8-221, p=0.01), and those in emotionally abusive relationships less likely to report a positive reaction (aOR 0.21, 95% CI 0.1-0.8, p=0.02) (Abuogi et al., 2019).

#### 2.5.3 HIV stigma is associated with domestic violence

In synthesizing the literature, we can see that HIV-related stigma can manifest in many different ways. These include physical and sexual violence, verbal abuse, rejection and humiliation, shame and blame for bringing the disease (enacted stigma), gossip, labeling as promiscuous (perceived stigma), isolation, feelings of worthlessness and guilt (internalized stigma), and fear of violence and rejection once people find out about the disease (anticipated stigma). Some of these manifestations of enacted stigma overlap

with the different forms of domestic violence, such as physical violence (beatings), sexual violence (forced sex, deliberately infecting partner), and psychological violence (verbal abuse, blame, shame, rejection, and humiliation). A selection of quotes from qualitative studies illustrates this overlap of violence with the different dimensions of HIV stigma (Table 5).

Violence is rarely described as a form of stigma in the literature; instead, it is described as physical, sexual, or emotional abuse due to HIV status (Adeniyi et al., 2017; Aryal et al., 2012; Ashaba et al., 2017; Chakraborty et al., 2016; Chilemba et al., 2014; Emusu et al., 2009; Ezeanochie et al., 2011; Ezechi et al., 2009; Gielen et al., 2000; Gielen et al., 1997; Hardy et al., 2020; Hatcher et al., 2014; Hershow et al., 2017; Hyginus et al., 2012; Iliyasu et al., 2011; Kabwama et al., 2019; Koenig et al., 2002; Maher et al., 2000; Maman et al., 2016; Mepham et al., 2011; Moreno, 2007; Mulrenan et al., 2015; Odiachi et al., 2018; Olowookere et al., 2015; Orza et al., 2015; Osinde et al., 2011; Rujumba et al., 2012; Shamu et al., 2014; Zamudio-Haas et al., 2012; Zunner et al., 2015). Several studies reported fears or acts of physical violence, blame and abandonment due to suspicions of infidelity rather than enacted stigma. For instance, a study in Malawi described women's experiences as emotional abuse due to HIV status rather than stigma: "He told me since you have the disease you are already dead" (Chilemba et al., 2014). Studies described feelings of worthlessness and guilt as types of emotional problems experienced by women living with HIV, rather than being described as manifestations of internalized stigma: "They [HIV+GBV+ women] feel as if they just don't add value. Others feel like even dying because they are so valueless in the eyes of everyone" (Zunner et al., 2015).

On the contrary, 18 studies explicitly showed that HIV-related stigma was associated with domestic violence (Abuogi et al., 2019; Arrey et al., 2015; Colombini et al., 2016; Derose et al., 2017; Fiorentino et al., 2019; Hatcher et al., 2016; Jiwatram-Negron et al., 2018; Knettel et al., 2019; Logie et al., 2011; Marais et al., 2019; Matseke et al., 2016; Mehta et al., 2019; Ojikutu et al., 2016; Onono et al., 2014; Pool et al., 2001; Ramlagan et al., 2019;

Turan et al., 2011; Turan et al., 2016). Women were afraid to take an HIV test or disclose their status due to HIV stigma-related violence or fears of it (anticipated stigma). Two studies from Kenya and one from Uganda described how fear of HIV stigma and discrimination was associated with avoidance of HIV testing (Pool et al., 2001; Turan et al., 2011; Turan et al., 2016), and could lead to forced migration and violence in some cases (Turan et al., 2016). One of the studies from Kenya showed that women who anticipated male partner stigma (measured as breakup of relationship and physical abuse from partner) were twice as likely to refuse an HIV test, after adjusting for other individual factors (OR=2.10, 95% CI: 1.15-3.85) (Turan et al., 2011). This anticipation of male partner stigma and discrimination was a greater negative influence on the decision to forego an HIV test than anticipation of stigma from other sources, such as family, friends, neighbors, or health workers (Turan et al., 2011).

The following five studies (Abuogi et al., 2019; Arrey et al., 2015; Knettel et al., 2019; Ojikutu et al., 2016; Onono et al., 2014) described how anticipated stigma (measured as fears of breakup of marriage or relationship and fear of physical abuse from intimate partner) and internalized stigma (measured using the modified self-stigma subscale from People Living with HIV Stigma Index (International Planned Parenthood Federation, 2008)) were important reasons for non-disclosure of status. In other words, nondisclosure was a strategy used by women to avoid domestic violence related to HIV stigma. Two Kenyan studies described non-disclosure of status for fear of violence due to HIV stigma. In one study, 61% of women anticipated stigma upon disclosure and only 31% chose to disclose to their partners (Onono et al., 2014). A second Kenyan study showed that, for the small proportion of women who chose not to disclose, non-disclosure was associated with both internalized (p<0.01) and anticipated stigma (p<0.001) (Abuogi et al., 2019). Similar findings were also reported from a multisite study from Thailand, Brazil and Zambia, where women living with HIV who reported greater anticipated stigma (measured using questions such as fears of violence upon disclosure of status, fears of being thrown out of the house, fears of being thrown out of community, and so on) were less likely to disclose their status to male partners [aOR 0.30 (0.18, 0.50)] (Ojikutu et al.,

2016). Similarly, anticipated stigma (conceptualized as mocking, exclusion, and gossip), the fear of abandonment, rejection and violence, and self-stigma (conceptualized as shame, avoidance, and silence) were the main reasons for non-disclosure for Sub-Saharan African migrant women in Belgium (Arrey et al., 2015):

"It is shame because HIV is contracted through sex and sex is a taboo for some Africans. There is no other reason. If I tell him/her, she/he will spread it aeverywhere. We have not yet reached that stage of removing the shame of being HIV infected. It is shame and shame kills" (Arrey et al., 2015).

A study from Kenya concluded that status disclosure increased risk of partner stigma and violence (Colombini et al., 2016). Similarly, a study from Tanzania reported that stigma, violence, and abandonment were the most common reasons for non-disclosure:

"The first thing that came to my mind (when I tested positive) was that my husband would leave me or stigmatize me" (Knettel et al., 2019).

Women living with HIV also experienced HIV stigma-related domestic violence as described in the nine studies below, and this finding was true for several countries around the world. Since the majority of studies describing domestic violence related to HIV stigma came from sub-Saharan African countries (Fiorentino et al., 2019; Hatcher et al., 2016; Marais et al., 2019; Matseke et al., 2016; Ramlagan et al., 2019), these have been described separately from studies emerging from other countries, namely the Dominican Republic, Canada, Kazakhstan, and India (Derose et al., 2017; Jiwatram-Negron et al., 2018; Logie et al., 2011; Mehta et al., 2019).

Three quantitative studies from sub-Saharan Africa found an association between HIV stigma and domestic violence (Fiorentino et al., 2019; Matseke et al., 2016; Ramlagan et al., 2019). A study from Cameroon showed that 73% of women experienced HIV-related stigma, which was associated with twice the risk of frequent physical domestic violence (2.53 (1.58; 4.02), p<0.001) and frequent physical domestic violence was associated with

ART interruption for greater than one month (Fiorentino et al., 2019). In a South African study, 56% of participants reported either physical or psychological violence, with higher levels of internalized stigma (1.392 (1.193 – 1.624), p<0.001) and depression (1.055 (1.026 – 1.085), p<0.001) associated with both types of domestic violence (Matseke et al., 2016). A second study from South Africa showed that women who experienced domestic violence (aOR 7.92 (1.06-59.09), p=0.043) and whose male partners were not involved in their pregnancy were more likely to experience personalized stigma (aOR 0.13 (0.05-0.38), p<0.000). Negative self-image was also associated with no male involvement in pregnancy (aOR 0.15 (0.06-0.37), p<0.000) and HIV-related stigma (aOR 1.47 (1.00-2.15), p=0.052) (Ramlagan et al., 2019). Two qualitative studies from South Africa (Hatcher et al., 2016; Marais et al., 2019) briefly reported on the dual burden of HIV and domestic violence stigma which led to a reduced ability among women living with HIV to seek support and greater social isolation. Results from one study highlighted this lack of social support in the lives of women living with HIV who also experience domestic violence:

"It's hard to tell people I've got a problem, I'm not living a good life, with a partner that I'm worried, we're always fighting, things like that. You just pretend, like now pretending that I'm ok but I'm not ok" (Hatcher et al., 2016).

Abusive and controlling partners of women with HIV may create HIV shame which compounds their burden, as described by a pregnant woman living with HIV from a second South African study:

"You're still strong, but you know you are HIV positive, and you are being abused. Maybe you're like me—maybe you are being abused because you're HIV-positive . . . so you feel very bad" (Marais et al., 2019).

Studies from other parts from the world also reported similar findings of HIV stigmarelated domestic violence for women living with HIV. Women in the Dominican Republic experienced enacted HIV stigma at places of employment and from family, neighbors, and partners, which rendered them vulnerable to food insecurity, while internalized stigma led to social isolation and loss of social support (Derose et al., 2017). Canadian women living with HIV, some with multiple stigmatized identities such as sex work, sexual orientation, drug use, and ethnicity, described how HIV stigma intersected with other stigmas to create systems of oppression. The combination of HIV stigma and gender discrimination caused women to be trapped in abusive relationships (Logie et al., 2011). Kazakh women's experiences of intimate partner, non-intimate partner violence, and HIVstatus-specific abuse showed that women reporting HIV-related stigma had almost twice the risk of experiencing intimate partner violence (aRR 1.59 (1.10, 2.31), p<0.05), with 10% of participants experiencing HIV-specific abuse (Jiwatram-Negron et al., 2018). Finally, a study from India described an association between domestic violence and HIV stigma (Mehta et al., 2019). Stigma was perceived by 82% of women, 42% experienced discrimination (enacted stigma), and 50% experienced domestic violence (which overlapped with measures of enacted stigma), all of which were significantly associated with unsafe sex (p<0.05) (Mehta et al., 2019).

#### 2.5.4 Domestic violence associated with HIV is gendered

According to the WHO, gender is defined as "the characteristics of women, men, girls and boys that are socially constructed. This includes norms, behaviors and roles associated with being a woman, man, girl or boy, as well as relationships with each other" (WHO, 2018). Although all people living with HIV may experience violence, the experiences may differ for men and women, often due to unequal social structures that position women as inferior to men. The studies discussed below provide evidence that domestic violence associated with HIV is gendered.

Women are often the first to be tested for HIV during pregnancy and may come home to report their diagnosis to their male partners, who could be HIV-negative, mainly because they have not been tested. Serodiscordance or male partners of unknown status and

disclosure asymmetry can be triggers for male partner violence which includes blame for bringing the disease into the relationship (Abuogi et al., 2019; Colombini et al., 2016; Ezechi et al., 2009; Hatcher et al., 2014; Mulrenan et al., 2015; Turan et al., 2016; Zunner et al., 2015). A key informant from a Kenyan study said:

"... you might have a husband who has not gone for a HIV test. They can never go. It is almost impossible to convince them to go. You come back home to tell your husband that you are HIV positive. This man will hurt you. You will be beaten. You might even be sent away from your home. You will leave the kids behind or be forced to go with the kids. Your husband might also die and your in-laws will want to inherit you [forced marriage to a brother of the late husband]. This happens a lot in Dholuo land. You will have to tell them that you cannot be inherited because of one, two or three. They will start saying, 'You have killed our son.' They will beat you up and send you away from that home. They believe that it is you who brought them the disease" (Zunner et al., 2015).

Women living with HIV experienced multiple forms of violence from different sources after disclosure. They were humiliated by partners and in-laws who publicized their serostatus and labeled them as prostitutes (Chilemba et al., 2014; Zunner et al., 2015).

"He was saying I am a whore and it is because of that, that I got infected" (Chilemba et al., 2014).

Family members and neighbors encouraged men to abandon their wives' due to suspicions of infidelity and HIV reflecting badly on the family and community (Chilemba et al., 2014; Turan et al., 2016; Zamudio-Haas et al., 2012; Zunner et al., 2015). One participant from Zimbabwe said:

"My husband kept saying things to me like, 'Pack your things and go, I don't love you anymore.' His relatives told him, 'How can you stay with a snake in your house?... Leave her at the roundabout close to the taxi rank; she will figure out where to go" (Zamudio-Haas et al., 2012).

Children testing positive for HIV can also be a trigger for violence (Ezeanochie et al., 2011; Marais et al., 2019; Mulrenan et al., 2015), as described by a participant from Swaziland:

"He would have killed me if his mother was not there, because he got very angry when he found out that even the baby had HIV passed on to her... He was carrying a bush knife saying he was going to hack me with it" (Mulrenan et al., 2015).

Controlling behaviors and deliberate infections from male partners were other forms of abuse. Latina women living with HIV and residing in the Los Angeles area described how they felt that men did not want to be with women who had HIV: "He told me that I had all the qualities that he needed but he could not deal with me because of the virus." Women also felt that the virus "determined the quality of their relationships, giving men an excuse to be controlling and domineering" (Moreno, 2007). Women also reported being deliberately infected by husbands or partners with HIV (Emusu et al., 2009; Moreno, 2007), some of whom turned around to blame their wives for infecting them:

"He feels very bad knowing that he is HIV positive and I am not. I think his intention was to make sure that I get the disease; so he could then say that I infected him" (Emusu et al., 2009).

Forceful interruption of clinic visits or medication adherence was another form of violence reported by women. Women who were currently on ART were three times (ARR 3.04 (95% CI 1.15-8.45, p=0.032) more likely to report domestic violence, which could make it difficult for women living with HIV to adhere to treatment (Osinde et al., 2011). Women who did not disclose hid their medications for fear of violent reprisals from male partners if they found out (Hatcher et al., 2014; Marais et al., 2019; Mepham et al., 2011; Zunner et al., 2015). A South African woman said:

"On one occasion, he found them and threw them away. I told him they were vitamins" (Mepham et al., 2011).

Controlling partners became suspicious during clinic visits, becoming physically abusive, and actively prevented women from picking up medications (Ashaba et al., 2017; Hatcher et al., 2016; Marais et al., 2019) or interfered with ART intake (Hardy et al., 2020; Zunner et al., 2015). Frequent physical violence was associated with ART interruption of greater than one month (Fiorentino et al., 2019). Internalization of abuse led to hopelessness which made it burdensome for women to engage in regular HIV care (Hatcher et al., 2016; Marais et al., 2019; Zunner et al., 2015), and caused some to contemplate suicide (Chilemba et al., 2014; Hardy et al., 2020; Hatcher et al., 2016; Zunner et al., 2015). A woman from Uganda who became pregnant despite knowing her positive status said:

"After giving birth he started treating me badly. He knew that he had finished me off because he had already infected me with HIV. I no longer had anywhere to go. He stopped me from working and stopped me from coming to hospital to pick my medications" (Ashaba et al., 2017).

Financial abuse is a form of domestic violence where an intimate partner has control over the other partner's resources, making them financially dependent on the abuser. Withdrawal of financial support after an HIV diagnosis was reported by women in multiple studies, (Aryal et al., 2012; Ashaba et al., 2017; Chilemba et al., 2014; Colombini et al., 2016; Derose et al., 2017; Hardy et al., 2020; Hyginus et al., 2012; Malaju & Alene, 2013; Odiachi et al., 2018; Turan et al., 2016; Zunner et al., 2015) and is illustrated by a quote from a Kenyan social worker:

"Before you told him that you were HIV positive, maybe he [your husband] used to give you 500 shillings per day. Now that you are HIV positive, he starts frustrating you. He will give you 200 shillings and you are supposed to use that for the whole day" (Zunner et al., 2015).

Fears of withdrawal of financial support became a barrier to disclosure (Knettel et al., 2019; Odiachi et al., 2018; Pool et al., 2001; Rujumba et al., 2012; Turan et al., 2016). Women were also forced to tolerate their partners' risky behaviors and abuse because of their financial dependence on them (Arrey et al., 2015; Chilemba et al., 2014; Emusu et

al., 2009; Marais et al., 2019; Moreno, 2007; Orza et al., 2015). Lack of financial support could lead to food scarcity among women living with HIV (Chilemba et al., 2014; Colombini et al., 2016; Derose et al., 2017; Zunner et al., 2015), and result in interruption of treatment (Odiachi et al., 2018). A Nigerian woman with HIV who was currently non-adherent to treatment said:

"I was sick so he brought me to the clinic. That's how he knew my status. So, as we were going home he told me he could not live with me anymore. He then sent me away to my father's house. I was there for four months. He came back six days after I delivered...He refused to give me money for transport to come for my drugs here [clinic]... That's why I was not taking the drugs" (Odiachi et al., 2018).

Negotiation of safe sex is associated with higher risk of domestic violence against women, regardless of cultural setting. Since women living with HIV are more likely to negotiate safe sex, they are at greater risk of violence (Chakraborty et al., 2016; Chilemba et al., 2014; Colombini et al., 2016; Emusu et al., 2009; Gielen et al., 1997; Hatcher et al., 2014; Marais et al., 2019; Mehta et al., 2019; Mepham et al., 2011; Moreno, 2007; Mulrenan et al., 2015; Zamudio-Haas et al., 2012; Zunner et al., 2015). Women living with HIV found it difficult to find partners who would be willing to use condoms. As a Latina woman said, "[Condoms] inhibit, so it is hard finding a man that is ok with it" (Moreno, 2007). Traditional gender norms set expectations around childbearing forcing women to engage in condomless sex (Emusu et al., 2009; Mulrenan et al., 2015; Ojikutu et al., 2016; Zunner et al., 2015). Studies from India found associations between domestic violence and negotiation of safe sex (Chakraborty et al., 2016; Mehta et al., 2019). In one study, women who used contraception had an 8-fold greater risk of experiencing domestic violence, with 12% women living with HIV using contraception and more likely to negotiate safe sex compared to 3% women who were not living with HIV (Chakraborty et al., 2016).

Women also reported being trapped in abusive relationships due to their HIV status (Derose et al., 2017; Logie et al., 2011; Marais et al., 2019; Moreno, 2007). They were afraid to report violence for fear of making their status public, as shown by two studies

from Africa (Ezechi et al., 2009; Hardy et al., 2020). One study found that almost half of women did not report violence (Iliyasu et al., 2011) and another that women living with HIV were more likely to report violence to formal and informal sources (Hyginus et al., 2012), although the reasons for such behaviors were not explored. Women feared not finding another partner because of their serostatus and this was a reason to stay in violent relationships (Derose et al., 2017; Logie et al., 2011). Internalization of emotional abuse from partners also prevented women from leaving such relationships:

"...because there is no one to tell, you don't talk to anyone and then you just tell yourself, maybe my boyfriend is right about those things he's saying to me. He said, "I did you a favor by being with you, no one is going to want you on the street because you are HIV-positive." ... No one wants me, so this is the only person who wants me" (Marais et al., 2019).

#### 2.6 Discussion

The review examined the evidence around HIV stigma and domestic violence in the lives of women affected by HIV. All studies that examined the relationship between HIV, violence and stigma experienced by women due to HIV testing, disclosure of HIV status, and violence related to an HIV diagnosis were included in the analysis. The review provides evidence that HIV increases the risk of violence against women at every stage of the HIV trajectory, such as taking a test, disclosing results, and life after a positive diagnosis. Although most studies came from Africa, this finding held across both high and low-income countries. Some studies associated the violence with HIV stigma, but most studies did not. Several studies showed supportive reactions from partners, which highlighted the importance of interventions such as couples counselling in reducing violence following an HIV diagnosis.

The review captured how violence in the lives of women living with HIV was gendered. Women are often blamed for bringing the virus into the relationship as they are usually the first to be tested, during pregnancy, which in itself is not a biological necessity but rather a manifestation of gender norms that medicalize women's natural life processes,

particularly reproduction (Conrad, 1992). Those without HIV may have been coercively infected by their seropositive partners as a form of violence. Once known to have HIV, women were seen to be abandoned and denied financial and nutritional support and their treatment forcefully interrupted. People living with HIV are advised to negotiate safe sex, but for women this too could result in violence. Women living with HIV were not only more likely to end up in violent relationships, but were often trapped in such relationships and were helpless when it came to reporting violence. Women living with HIV ended up isolated and often suffered abuse in silence.

Although both HIV and domestic violence are both stigmatized, few studies reported on the intersectional stigma of the two. It is important to understand how these two stigmas intersect in the lives of women living with HIV because, as shown in the case of women living with HIV who have other stigmatized identities, such as transgender women or female sex workers, the interaction of multiple stigmas can serve to amplify the stigma experienced by women as a whole (Logie et al., 2011). For instance, in the case of HIV and domestic violence stigma, a woman living with HIV who is also a survivor of domestic violence may find it difficult to report violence to the police for fear of revealing her HIV status. Only two studies showed that women living with HIV were unlikely to report violence due to fears of making their HIV status public, although the association with stigma was not explored (Ezechi et al., 2009; Hardy et al., 2020). However, one study showed that women living with HIV were more likely to report violence to formal and informal sources than women without HIV, but reasons for the difference were not provided (Hyginus et al., 2012). HIV stigma may also worsen domestic violence stigma, as women living with HIV who experience domestic violence may not be able to seek support from family, friends, or neighbors after an episode of domestic violence, unlike a woman without HIV, due to the compounded shame of having HIV and experiencing domestic violence. The expectation that others might be unsympathetic and somehow think that she deserves the violence due to her HIV status may also act as a deterrent to help-seeking for a woman living with HIV. This means that abusive partners may exploit the stigma of HIV and the internalization of this stigma can cause women living with HIV

to be trapped in abusive relationships, as is often the case (Logie et al., 2011; Marais et al., 2019).

Only two studies reported on the intersectional stigma of HIV and domestic violence. This dearth of evidence to show how domestic violence stigma, such as public shaming or non-reporting of violence, intersects with HIV stigma among women living with HIV suggests that there is an important gap in the literature regarding the dual stigma of HIV and domestic violence. My PhD aims to fill this important research gap by exploring how domestic violence stigma and HIV stigma intersect with other marginalized identities in women with HIV, and how these stigmas amplify themselves so that the whole is more powerful than its constituent parts (Figure 2).

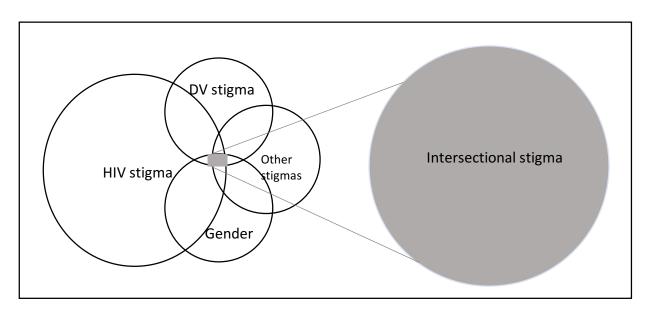


Figure 2 Intersectional stigma of HIV, domestic violence and other marginalized identities

The review showed that violence can be a manifestation of HIV stigma for women affected by HIV. This has also been recognized in the theoretical literature where authors have described violence against people living with HIV as a form of enacted stigma (Earnshaw & Chaudoir, 2009; Herek, 1999; Holzemer et al., 2007). For example, Herek describes physical violence as "stigma manifested in its most extreme form" (Herek, 1999) and

Earnshaw and Chaudoir discuss how discrimination may be experienced by people living with HIV "in the form of job loss, social rejection, or even physical violence (i.e., enacted stigma) and may also increase their expectations of future experiences of discrimination (i.e., anticipated stigma)" (Earnshaw & Chaudoir, 2009). In this review, several empirical studies showed how the violence experienced by women with HIV was related to HIV stigma. However, most studies described violence as a function of HIV serostatus and not HIV-related stigma. I argue that it is important to acknowledge the critical role of HIV stigma in order to fully understand the violence experienced by women affected by HIV. Domestic violence in the lives of women living with HIV may start or escalate upon HIV diagnosis and violence has been shown to be greater for women living with HIV than the general population of women. While all women may experience domestic violence, women living with HIV may experience abuse solely due to their HIV serostatus. In addition, the expectation of violence may cause women to avoid taking an HIV test or not disclose their HIV status. This essentially means that HIV makes the violence happen. But the presence of a virus in a woman's body is not the reason for the violence, but rather what people think of the woman when she has the virus in her body. This is HIV stigma and HIV stigma essentially drives the violence that occurs in the lives of women with HIV (Figure 3). However, this mediating role of HIV stigma in outcomes of violence against women with HIV has not always been described in the literature. I argue that this gap in the literature is important to address because (1) failing to recognize the mediating role of stigma in violence provides us with an incomplete picture of the stigma experiences of women living with HIV and (2), more importantly, it has practical implications because the underlying role of stigma must be taken into account in designing violence reduction interventions for this population. The symbolic stigma attached to HIV, such as an association with poor moral character or sex work, and the instrumental stigma of HIV transmission (Herek, 2002), must be eradicated from people's minds and only then can there be a reduction in the violence (Figure 3). This can be done if the mediating role of HIV stigma in violence experiences is recognized and addressed. If domestic violence against women living with HIV is treated as 'just' domestic violence and regular domestic violence reduction interventions applied, rather than being accompanied with HIV stigma

reduction interventions, the violence can never be effectively reduced.

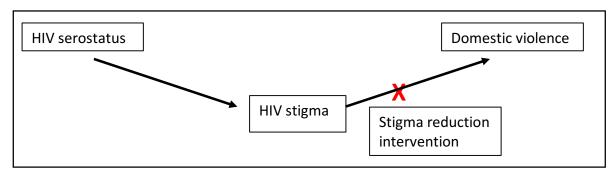


Figure 3 HIV stigma is a mediator of domestic violence for woman affected with HIV

#### 2.7 Limitations

Only one reviewer screened all articles. The inclusion of both qualitative and quantitative articles led to a deeper understanding of the links between stigma and domestic violence as qualitative articles described stigma experiences and quantitative studies measured stigma using validated scales, which were used to show associations between stigma and violence. The articles that were selected had limitations around comparability as the studies included diverse populations and study designs. Most of the quantitative literature was cross-sectional, some with small sample sizes, which meant that causation could not be established. The search terms used for the review were such that they captured the three broad concepts of domestic violence, HIV, and stigma. However, as studies often showed violence as an outcome of HIV status, which is not always shown as related to HIV stigma, some studies may have been missed. Hand-searches of reference lists minimized this limitation as far as possible.

#### 2.8 Conclusions

The review synthesized the evidence on domestic violence and HIV stigma or serostatus. The findings suggest that HIV increased the risk of domestic violence for women affected by HIV, although some women did receive support from partners, that the violence was associated with HIV stigma, and that HIV-related domestic violence was gendered. Two important gaps in the literature were also identified, both of which were shown to have practical implication for domestic violence in women's lives and HIV control. Firstly, there

was a lack of studies that examined the intersectional stigma of HIV and domestic violence, which meant that the additional burden of the two intersecting stigmas was not fully understood. Secondly, the role of HIV stigma as a mediator of domestic violence for women affected by HIV was not always recognized, which meant that the full stigma experience of women living with HIV was not captured and that domestic violence reduction interventions could be ineffective for women with HIV, unless accompanied by stigma reduction interventions. This PhD aims to fill both gaps through qualitative interviews with women living with HIV who are also survivors of domestic violence as well as with key service providers in Kolkata, India.

Table 3 Summary of selected qualitative and mixed methods studies

Author/Year	Sample size and characteristics	Study design/qualitative methods	Location	Study setting	Stigma analysis
Adenyi et al 2017	1709 HIV+ pregnant women	Cross sectional interviews with section to elaborate on reason for non-disclosure	South Africa	Maternity clinics	Although stigma not specifically mentioned as reason for DV, possible violent backlash, blame and rejection can be classified as forms of enacted HIV stigma.
Arrey et al 2015	28 HIV+ Sub- Saharan African women; 4 HIV/AIDS physicians; 1 therapist nurse, 5 observations.	In-depth interviews with HIV+ women (initial and at 4 months follow up), key informant interviews, observations of physician's consultations.	Belgium	University teaching hospital/AID S Conferences	Stigma was rampant in the Sub-Saharan African community in Belgium so most women kept their HIV status a secret. Anticipated or actual experiences of partnership breakdown, rejection, violence and abandonment were reasons for non-disclosure (could be classified as enacted stigma). Discussion mentions anticipated, perceived and most importantly self-stigma which manifested as shame, denial, silence and avoidance were barriers to disclosure.
Ashaba et al 2017	20 HIV+ pregnant women	In-depth interviews	Uganda	HIV clinic	Stigma and discrimination was reported from healthcare settings which fueled self-stigma for being pregnant while being HIV+. Non-disclosure was associated with fear of gossip and discrimination from the community and DV and abandonment from partners. Women also reported actual experiences of violence included forced treatment interruption by partners after disclosure. Negative reactions from partners were not characterized as forms of stigma although this could be interpreted as such.
Chilemba et al 2014	12 HIV+ women	In depth interviews	Malawi	Public health clinics	The paper does not mention stigma but the actions they describe as emotional abuse overlap with acts of enacted stigma (humiliation, verbal abuse, abandonment, social exclusion, blame and shame). Internalization of abuse/blame leading to feelings of worthlessness is mentioned and can be characterized as internalized stigma.
Colombini et al 2016	30 HIV+ women	In-depth interviews	Kenya	Sexual and reproductive health clinics	HIV status disclosure was seen as a period of heightened risk for partner stigma and abuse including physical, emotional and economic abuse and separation. Health providers were seen as a means to reduce some of the fear of anticipated partner stigma and violence and so reduce DV post disclosure.
Derose et al 2017	30 HIV+ women	In-depth interviews	Dominican Republic	Women registered with HIV study clinics	Study specifically mentions enacted stigma from family, friends, and neighbors manifested as gossip and rejection while that from intimate partners resulted in emotional, physical and sexual abuse which together left women vulnerable to food insecurity and support. The experiences led to internalized stigma which made women hesitant to disclose their status and further isolated them.
Emasu et al 2009	26 HIV+ serodiscordant couples (~50% HIV+ women; 50% HIV- women); only women interviewed	Critical incident technique	Uganda	AIDS Information Centers	Sexual violence in serodiscordant unions (where either the male or female partner was positive) escalating after diagnosis shows that violence was due to HIV status. Although not mentioned as stigma, blame and sexual violence including deliberate infection of partners can be interpreted as forms of enacted stigma.

Gielen et al 1997	50 HIV+ women	In-depth interviews	United States	Urban teaching hospital outpatient clinic	For a quarter of women actual experiences of violence or fears of violence was associated with status disclosure but this was not specifically characterized as a result of HIV stigma. But paper mentions that destigmatizing the disease could reduce violence experienced by women living with HIV.
Gielen et al 2000	301 HIV+ women	Mixed methods (cross sectional interviews and 43 in- depth interviews)	United States	Urban teaching hospital HIV primary care clinic	About half of women experienced both intimate and non-intimate partner violence directly due to their HIV status. Blame and violence due to HIV status can be seen as forms of enacted stigma although not characterized as such in the study.
Hatcher et al 2014	13 pregnant women, 28 key informants	Focus groups with 13 pregnant women, and in-depth interviews with 10 policy makers, 8 health providers, 6 NGOs, 4 community leaders, and 5 abused pregnant women (chosen from focus groups).	South Africa	ANC clinics	Although stigma not specifically mentioned in this study, blame and subsequent physical, sexual and emotional violence following disclosure could be considered a form of enacted stigma.
Hatcher et al 2016	32 HIV+ women who experienced DV	In-depth interviews	South Africa	ANC clinics	Study investigates the hidden nature of HIV and DV and the two stigmatized conditions make it harder for women to find support for either condition causing women to suffer in silence.
Hershow et al 2017	20 HIV+ women	In-depth interviews	Vietnam	Outpatient ART clinic	Participants were mostly infected by the husbands and so were not afraid to disclose to them. Role of stigma in DV not mentioned. Women were fearful of disclosing to husband's family or to the community for bringing stigma to themselves and their families.
Knettel et al 2019	200 HIV+ pregnant women for quantitative survey, 20 qualitative interviews	Prospective cohort survey (at pregnancy n=200 and postpartum n=168) and in-depth interviews (at pregnancy n=24 and 3 months postpartum n=18)	Tanzania	HIV clinics	For quantitative part, HIV shame and internalized stigma measured using Scale A (HIV-Related Shame) of the HIV and Abuse Related Shame Inventory (HARSI-A) and non-disclosure was not associated with internalized stigma. But in qualitative interviews, women's fear of negative consequences following disclosure included partner violence, withdrawal of support, and abandonment and fears of stigma (gossip, social exclusion and labeling) from the family and community. Although violence, withdrawal of support and abandonment treated separately from stigma, the former may also be considered forms of enacted stigma.
Logie et al 2011	104 HIV+ women (69% ethnic minority; 23% lesbian/bisexual; 22% transgender	Focus groups	Canada	Community agencies	Study examines intersectional stigma and several forms of stigma discussed. Findings include gender discrimination and HIV stigma can result in violence from intimate partners while internalized stigma cause women to be trapped in abusive relationships.
Marais et al 2019	12 HIV+ women	In-depth interviews	South Africa	HIV maternity clinic at a tertiary hospital	HIV diagnosis and disclosure was a trigger for DV. Study findings showed that HIV stigma was exacerbated in the context of DV through partner blaming and shaming. Dual stigma of HIV and DV caused women to isolate themselves thus leading to depression and mental stress leading to poor engagement in care.
Mepham et al 2011	100 HIV+ women	Clinical and counselling notes (100 HIV+ women) unstructured interviews (n=43)	South Africa	Trial clinic	Threats or actual experiences of violence as a result of status disclosure was cited by a number of women. Stigma not specifically mentioned but acts of domestic violence or threats of violence can be interpreted as enacted or anticipated stigma.

Moreno 2007	42 HIV+ women	3 focus groups (n=32), in-depth interviews (n=5 from focus groups), community meetings (n=30 including 20 from focus groups)	United States	Latino community agencies	No discussion of stigma as such in relation to DV, but findings showed that infecting partner often left women once they were infected. The virus also defined the quality of their relationships, with men being more controlling or domineering because of the woman's serostatus, which could be interpreted as acts of enacted stigma.
Mulrenan et al 2015	19 HIV+ women	In-depth interviews	Swaziland	Public health facilities	Violence as a result of interpersonal triggers (eg status disclosure, vertical transmission) and normative tensions (eg opposing contraception and fertility intentions) discussed. However, blame, physical violence and coercive control could be seen as forms of enacted stigma, although not mentioned in this analysis.
Odiachi et al 2018	100 HIV+ women (25 newly diagnosed, 26 in PMTCT care, 28 postpartum ART, 21 lost to follow up (not on ART)	Cross sectional mixed methods interview	Nigeria	Primary and secondary healthcare facilities	Worries about disclosure to intimate partners resulting in DV or divorce was common for all four groups. 20% did not plan to disclose due to fears of negative reactions and stigma (where stigma was more from family rather than partners). However, actual acts and fears of blame, verbal abuse, physical violence, abandonment and financial abuse could be seen as forms of enacted or anticipated stigma.
Orza et al 2015	945 HIV+ women (832 web survey from 94 countries, 113 in focus groups from 7 countries)	Mixed methods participatory survey	94 countries	Global listservs and clinical networks of women living with HIV	Study reported that for a third of women reported violence from an intimate partner since HIV diagnosis and that DV escalated for some after diagnosis. Recommended that stigma and discrimination should be recognized as gender based violence (IPV/violence from family/community/health settings) for women living with HIV and gender based violence is common for women living with HIV.
Pool et al 2001	208 pregnant women	Focus groups	Uganda	Maternity clinics	Stigma and discrimination was a real fear among women if they had to undergo voluntary counseling and testing. Husbands finding out could possibly lead to blame, conflict and breakdown of marriage which could be interpreted as acts of enacted stigma and the fear of it as anticipated stigma.
Rujumba et al 2012	15 HIV+ and 15 HIV- pregnant women, 6 key informants	In-depth interviews with women and key informant interviews	Uganda	ANC clinics	All those who tested positive disclosed to their partners while most women testing positive did not for fear of violence, abandonment, and blame. The fear of such negative consequences could be seen as forms of anticipated stigma but this was not described as such in this study.
Turan et al 2016	Quantitative (pregnant women n=614), qualitative (pregnant women n=29, male partners n=32, service providers n=20, post intervention FGDs, 2 groups with n=17, IDIs n=25), IPV screening data (n=134)	Baseline and follow up quantitative interviews, in-depth interviews and focus groups, key informants, clinic IPV screening data (part of a larger IPV/GBV study)	Kenya	ANC clinics	HIV testing and disclosure could be a reason for women to be 'sent packing'. Study shows that such acts of forced migration results in shame, stigma and loss of status (stigma of being thrown out of the house) while also being a consequence of HIV stigma.
Zamudio et al 2012	28 HIV+ women	In-depth interviews	Zimbabwe	Hospital with HIV, ANC and reproductive health clinic	Women living with HIV could be stigmatized for having children. For almost half the participants disclosure resulted in physical and verbal abuse/humiliation, threats of being thrown out of the house and abandonment, all of which can be interpreted as acts of enacted stigma, although not specifically mentioned in the study.

Women and key informants described acts of physical, sexual, psychological and financial abuse due to HIV status which could be Zunner et al participants In-depth interviews Kenya HIV clinic 2015 (HIV+ (n=30), focus groups women, interpreted as manifestations of enacted HIV stigma. Feelings of hopelessness leading to depressive symptoms including suicidal healthcare (n=4) providers, community leaders) ideation could be seen as an outcome of internalized stigma.

Table 4 Summary of selected quantitative studies

Author/year	Sample size & characteristics	Study design	Location	Study setting	Stigma Analysis
Abuogi et al 2019	200 HIV+ women, 12 months postpartum	Cross sectional survey	Kenya	Primary healthcare facilities	Stigma measured using (i) anticipated stigma scale (adapted from relevant research) and (ii) internalized/self-stigma (modified self -stigma subscale from PLHIV Index). 55% reported internalized HIV stigma and 57% reported anticipated HIV stigma. And non-disclosure was associated with both.
Aryal et al 2012	43 HIV+ women	Cross sectional survey	Nepal	HIV care organizations	Emotional violence escalated upon diagnosis while economic abuse started only after diagnosis. Definition of emotional violence included isolation, discrimination, humiliation, shame which can also be seen as forms of enacted stigma although not described as such in this study. Self-humiliation or internalization of abuse was a major consequence of violence.
Chakraborty et al 2016	99 HIV+ couples, 100 HIV- couples (only responses of wives analyzed; if man is positive and wife negative, wife is analyzed in the HIV+ group)	Cross sectional survey	India	HIV care organization (HIV+ group), hospital (HIV- group)	HIV stigma was not mentioned specifically as a reason for violence but over a quarter of women attributed their HIV status as a reason for their quarrels. Women in the HIV+ group reported significantly higher levels of recent sexual DV. Discussion mentioned that quarrels due to HIV possibly escalated into physical and sexual DV, which could be one cause of higher levels of domestic violence in the group.
Ezeanochie et al 2011	305 HIV+ pregnant women	Cross sectional survey	Nigeria	ANC clinic at a university teaching hospital	Stigma not mentioned in this study, but those experiencing violence before diagnosis were at greater risk of experiencing violence after. Authors mention that HIV+ status is not just a predictor of DV but worsens pre-existing DV.
Ezechi et al 2009	652 HIV+ pregnant women	Cross sectional study	Nigeria	Large comprehensive HIV treatment centre	Although stigma not mentioned, for 74% of women, violence started after diagnosis and for those who experienced violence before, about half reported an escalation of violence after diagnosis. Non-disclosure was due to fear of stigma, violence and rejection. Most women were afraid to report violence for fear of making status public.
Fiorentino et al 2019	894 HIV+ women	Cross sectional survey	Cameroon	Hospitals	73% of women had experienced HIV related stigma as measured by the Berger HIV Stigma Scale. Frequent physical DV was significantly associated with experiencing HIV related stigma and ART interruption for over 1 month.
Hardy et al 2020	129 HIV+ women in discordant relationships.	Cross sectional survey	Ghana	HIV clinic of a tertiary health facility	Although stigma not specifically mentioned, study shows high proportion of post-disclosure violence among sero-discordant couples with violence escalating post-disclosure in relationships where violence was already present. Reasons for non-reporting of DV included fear of status disclosure.
Hyginus et al 2012	110 HIV+ and 110 HIV- pregnant women	Comparative cross- sectional survey	Nigeria	University teaching hospital	Although stigma not studied, women with HIV suffered more violence than HIV- women in the year prior to pregnancy. Of women experiencing violence, 75% women reported increased violence after disclosure of status to partners. Reporting of violence more for women with HIV. Discussion mentions women with HIV were being abused probably due to the stigma associated with HIV.

Illiyasu et al 2011	289 HIV+ women	Cross sectional survey	Nigeria	Teaching hospital	Although role of stigma not explored in the study. Higher prevalence of violence was seen for women living with HIV compared to that in the general population in the same region. Women who had disclosed to partners were twice as likely to experience violence compared to those who did not.
Jiwatram- Negron et al 2018	249 HIV+ women	Cross sectional survey	Kazakhsta n	AIDS centers, HIV health clinics, HIV NGOs, snowballing participants.	Women reporting HIV related stigma, as measured by the Berger Stigma Scale, were significantly more likely to report DV and also HIV-status specific abuse. Women experiencing HIV related abuse were more likely to be depressed possibly due to internalized HIV stigma. HIV+ women who also traded sex had a higher relative risk of HIV-specific abuse possibly representing the dual stigma from this status.
Kabwama et al 2019	5198 HIV+ women	Secondary data analysis from a national cross sectional survey	Uganda	HIV clinics	Study shows high level of DV for women with HIV in care but this is similar to levels in general population. Also, women in serodiscordant relationships experience less DV than women in seroconcordant relationships. Study indicates that DV is not related to HIV status or stigma.
Koenig et al 2002	336 HIV+ and 298 HIV- at risk pregnant women	Cross sectional survey	United States	Health departments and clinics	Violence was reported by about 9% women, and violence was not associated with relationship type (abusive and non-abusive partners) and did not differ significantly between women with and without HIV. Role of stigma not explored and disclosure related violence was reported rarely and included relationship termination, anger and physical assault.
Maher et al 2000	490 at risk women	Cross sectional survey	United States	STD clinics	Stigma not specifically discussed but there was no association on test non-uptake with partner violence/fear of partner violence or experiences/fears of partner notifications. 12% participants reported taking the test feared partner violence, humiliation or rejection if they tested positive which can be interpreted as forms of anticipated stigma.
Malaju et al 2013	400 pregnant women	Cross sectional survey	Ethiopia	ANC clinics in public health facilities	79% of women expected negative reactions from male partners upon disclosing positive test results. Women who did not have stigmatizing attitudes towards people living with HIV were twice as likely to anticipate positive reaction from male partners upon disclosure of HIV status but reasons for findings not explored.
Maman et al 2016	403 HIV+ and 689 HIV- pregnant and postpartum women	Prospective cohort study	South Africa	Primary health clinic	For women who disclosed their status, HIV was not associated with DV. But for women who had not disclosed, there was a five-times higher likelihood of reporting DV. Findings, suggest post-disclosure DV is not a result of HIV stigma but rather a marker of a violent relationship.
Matseke et al 2016	673 HIV+ pregnant women	Cross sectional survey	South Africa	Community health centers	Internalized stigma was measured using the Kalichman AIDS-related Stigma Scale. Higher level of internalized stigma and depression was associated with physical and psychological DV.
Mehta et al 2019	135 HIV+ women	Cross sectional survey	India	ART center at tertiary care hospital	Perceived stigma and discrimination (enacted stigma) was measured in the study. 41% participants reported discrimination including rejection, shifting of home, and divorce from spouse while 50% reported domestic violence (treated separate from discrimination). 82% reported perceived stigma including blame, shame and fear of family rejection.
Ojikutu et al 2016	299 HIV+ women (100 Thailand, 100 Brazil, 99 Zambia)	Multi-site longitudinal, observational cohort	Thailand, Brazil, Zambia	HIV clinics	Perceived community stigma and anticipated stigma were measured using Likert scales. For all women in this study, anticipated stigma and severe depression were predictors of non-disclosure of HIV status to partners. Among the subset of unmarried or non-cohabiting women, perceived community stigma was a further predictor of non-disclosure to intimate partners.
Olowookere et al 2015	360 HIV+ women	Cross sectional survey	Nigeria	ART clinic in secondary health care facility	Disclosure of HIV status was a predictor of DV with about a quarter experiencing violence since diagnosis. Almost half reported non-disclosure as a means to reduce DV. Although role of stigma not explored authors recommend reducing stigmatization as a means of reducing DV among women living with HIV.

Onnono et al 2014	281 postpartum women (104 HIV+, 123 HIV-, 54 unknown HIV status)	Post-hoc analysis of data from subset of participants from a prospective study	Kenya	ANC clinics	High levels of anticipated stigma (measured using stigma scale adapted from relevant research) and fears of negative male partner reaction, including DV was observed and this was associated with non-disclosure of HIV status.
Osinde et al 2011	317 HIV+ pregnant women	Cross sectional survey	Uganda	HIV treatment center at regional hospital	Almost 30% of women reported DV in the last 12 months. Although HIV stigma not mentioned as possible reason for DV, women who were on ART were twice as likely to report DV in the last 12 months.
Ramlagan et al 2019	673 HIV+ pregnant women	Cross sectional survey	South Africa	Community health centers	Perceived HIV Stigma Scale and the Kalichman AIDS Related Stigma Scale was used to measure HIV/AIDS stigma. DV was significantly associated with experiencing personalized stigma which possibly leads to greater perceived HIV-related stigma.
Shamu et al 2014	1951 postpartum women (299 HIV+ and 1652 HIV-)	Cross sectional survey	Zimbabwe	Public clinics	Women disclosing test results, both positive and negative experienced violence, but more women testing positive experienced violence (41%) than those testing negative (32%). Also, significant portion these women experienced violence for the first time after disclosure, with those testing positive more likely to experience violence. Role of stigma in violence not measured.
Turan et al 2011	1525 pregnant women (94 refused testing, 1431 accepted testing (254 HIV+ and 1177 HIV-)).	Cross sectional survey	Kenya	ANC clinics	Anticipated stigma scale was adapted from relevant research and perceived community stigma measured using a scale from National Institute of Mental Health Project Accept. Women who anticipated male partner stigma were twice as likely to refuse an HIV test and as were women with a lack of knowledge about male partner's HIV testing status. Anticipated stigma from others and perceived community stigma was not associated with refusal of HIV testing.

Table 5 Illustrative quotes showing overlap of types of violence and dimensions of stigma experienced by women affected by HIV

Violence	Abuse type	Dimensions of stigma	Illustrative quotes	Reference
Blame, revealing status to others, forcefully preventing clinic visits/medication adherence	Psychological abuse	Enacted stigma	"He takes the medicine and shows it to them"" They started publicizing to others outside our household."	Chilemba et al 2014
adileterice			HIV, the abuse started then He didn't want to accept the blame for it and he wanted to throw it on me. So he used to do things mentally to try to make me feel like I was responsible. Then he started disrespecting me in public, especially in front of his family".	Geilen et al 2000
			"Sometimes when I go to the clinic he say hey you are not going to the clinic. He asked me too many questions But I refuse. I tell him I can't stop going to clinic because this is my life! I have children. I have to live to take care of my babies. Sometimes when I come back to the house he beats me, accusing that I'm not coming from the clinic".	Hatcher et al 2016
Fear of blame/violence/abandonment/	Psychological abuse	Anticipated stigma	"If I tell him, he may never come back to my place and shift forever to the second wife. How will I and my children survive? He can even send me away or say I brought HIV yet I have been faithful to him; I feel bad that I have HIV yet I have not been having other men".	Rujumba et al 2012
Beatings, verbal abuse, women "sent packing "or abandonment	Physical abuse	Enacted stigma	"He was abusive before I told him I was HIV-positive, and afterwards, well, the beatings got worse and more they happened more regularly. I say that because I remember him making the statement, "I should kill you since you are trying to kill me."	Geilen et al 2000
			One day, he kicked the TV and knocked up all the furniture, and took soap and wrote "AIDS" b_ on the mirrorEvery time we would have an argument, that's what it would be, you know, "You b_ you gave me AIDS."	Geilen <i>et</i> <i>al</i> 1997
			The relatives if they know that their daughter- in-law who is pregnant is HIV- infected then they will talk about it. And if the man hears that, he would take steps to send his wife packing. But even if you send her away you are still HIV- infected!"	Turan <i>et al</i> 2016
			"you might have a husband who has not gone for a HIV test. They can never go. It is almost	Zunner et al 2015

impossible to convince them to go. You come back home to tell your husband that you are HIV positive. This man will hurt you. You will be beaten. You might even be sent away from your home. You will leave the kids behind or be forced to go with the kids. Your husband might also die and your in-laws will want to inherit you [forced marriage to a brother of the late husband]. This happens a lot in Dholuo land. You will have to tell them that you cannot be inherited because of one, two or three. They will start saying, 'You have killed our son.' They will beat you up and send you away from that home. They believe that it is you who brought them the disease".

Forced sex, infecting on Sexual abuse Enacted purpose stigma

"He feels very bad knowing that he is HIV positive and I am not. I think his intention was to make sure that I get the disease; so, he could then say that I infected him. The sexual abuse took place under sadistic intentions, and also under the influence of alcohol. I think he also thought that doing all that he was doing would stop me from having extra-marital sexual affairs".

"Being infected by men who know that they have the virus is not only a form of domestic violence but a crime'.

Humiliation, neglect, rejection

Psychological Enacted abuse stigma

"He even brings prostitutes in our house when I am there...Every time I serve food for him he would break the plates, throwing away the food"

"He told me that I had all the qualities that he needed but he could not deal with me because of the virus".

Financial Withdrawal

Financial abuse

Enacted Stigma "Before you told him that you were HIV positive, maybe he [your husband] used to give you 500 shillings per day. Now that you are HIV positive, he starts frustrating you. He will give you 200 shillings and you are supposed to use that for the whole day".

"I was sick so he brought me to the clinic. That's how he knew my status. So, as we were going home he told me he could not live with me anymore. He then sent me away to my father's house. I was there for four months. He came back six days after I delivered...He refused to give me money for transport to come for my drugs here [clinic]... That's why I was not taking the drugs".

Internalization of blame, self-isolation, worthlessness

Psychological Infabuse sti

Internalized stigma

"Sometimes you think, this is the partner who made me HIV-positive so he already knows, and he is not telling me. He wants me to get sick. . . . but your partner is going to say, you're the one who is HIV-positive, and you're the one who made me to be HIV-positive. . . . . All those things your boyfriend said about you, when you look at yourself sometimes you say, maybe he is right . . . because there is no one to tell, you don't talk to anyone and then you just tell yourself, maybe my boyfriend is right about those things he's saying to me. He said, "I did you a favour by being with you, no one is going to want you on the street because you are HIV-positive.". . . No one wants me, so this is the only person who wants me".

"a lot of the times people blame themselves for being abused".

"Women who are productive before their HIV status is known, tend to shy away when their status is known and there is that violence in the family. They tend to shy away from the community activities that they were participating before" (Radhi, participant in focus group of healthcare providers).

# **Chapter 3: Methodology**

In this chapter I describe the methodology for investigating the gaps in the literature identified through the literature review described in the previous chapter. I start with an outline of my epistemological position for understanding women's experiences and perceptions of intersectional stigma. An epistemological position is the meaning or process of obtaining knowledge, and helps to inform the methodological decisions of the research (Hathcoat et al., 2019). I then describe the methodological approach I used to conduct the study and why it is suitable for answering my research questions, compared to other approaches, particularly the narrative approach and grounded theory. I go on to describe the methods used for data collection, the recruitment process, and data analysis, and address ethical issues and criteria for trustworthiness. I end by summarizing the methods used and then go on to the presentation of results.

## 3.1 The interpretive position

I chose a broadly interpretive epistemological position because it allowed me to understand the experiences of participants who have been marginalized by their HIV diagnosis, gender, experiences of domestic violence, class, and other identities. The interpretive position has been used to answer research questions that seek to understand conditions that exclude and marginalize individuals, such as racism, sexism, and other unequal power relations in society (Creswell & Poth, 2016). An interpretive stance was also applied to methods of data collection, in which the researcher is careful not to further marginalize participants, respect their viewpoints by focusing on their differing perspectives, being aware of the power differential in the research process, and acknowledging their own subjectivity (Creswell & Poth, 2016). Critical theory calls for empowering people to overcome the constraints placed on them by class, race, and gender and often calls for action to do so (Creswell & Poth, 2016). As a critical social theory, intersectionality may be considered a tool for social change that calls for action

(Earnshaw et al., 2022). It was important for me to take a critical stance in my research, although the main aim of the project was to understand women's experiences and perceptions of intersectional stigma, rather than bring about changes in their circumstances. A critical stance, however, was needed to ensure that the project gave women a space to describe their experiences of intersectional stigma and express their views on how they would like society to change.

## 3.2 The phenomenological approach

I took a phenomenological approach as the thesis describes the lived experiences of individuals with regard to a specific concept or phenomenon. Phenomenology, particularly interpretive phenomenology, fits within the interpretive epistemology as it emphasizes the importance of interpretation, influenced by context and history, for understanding the lived world. Phenomenologists describe what all participants have in common as they experience a phenomenon (Creswell & Poth, 2016), in this case stigma of HIV as it intersects with the stigma of other identities. Basically, the purpose of phenomenology is to reduce individual experiences of a phenomenon to that of a universal "essence" or "object" of human experience (Van Manen, 1990). The researcher collects data from people who have experienced the phenomenon and develops an overall description of the essence of the experience for all the respondents (Moustakas, 1994).

#### 3.2.1 Husserl: Descriptive phenomenology

The roots of phenomenology can be traced back to the work of German mathematician Edmund Husserl. Husserl's philosophical assumption was that experience as perceived by the human consciousness has value and should be an "object" of scientific study. This led to his descriptive approach to phenomenological enquiry. A key aspect of Husserl's phenomenology was that the researcher must let go of all prior knowledge of the phenomenon being studied in order to truly understand the lived experiences of participants. Descriptive phenomenologists believe that researchers should not conduct a detailed literature review, nor have clearly defined research questions when they start

their study. The researcher must achieve transcendental subjectivity, which essentially means that researchers must be constantly aware of the impact of their own biases and make an attempt to remove them so that they do not have an impact on the "object" of study. Another key assumption of Husserl's phenomenology is that there are features of lived experience that are common to everyone who has undergone an experience. This is known as "universal essences" or eidetic structures. The commonalities must be identified in order to develop the description. In this view, reality is objective, independent of history and context (Husserl in Lopez & Willis, 2004). It involves the philosophical concept of epoche or bracketing, whereby the researcher sets aside as much of their own experience as they can in order to take a fresh view of the phenomenon under investigation (Moustakas, 1994).

## 3.2.2 Heidegger: Interpretative phenomenology

Martin Heidegger was Husserl's student and challenged his approach to phenomenology. Heidegger's ideas take on an interpretive or hermeneutic approach to research. Hermeneutics has been identified as a process of bringing out what is normally hidden in human experience (Spiegelberg, 1975). These meanings may not always be obvious to participants but must be interpreted from their narratives. A key aspect of Heidegger's thought was that the relationship between the individual and his "lifeworld" should be the focus of phenomenological enquiry. He used the word "lifeworld" to show that an individual's reality is inextricably linked to the world in which they live. Another key concept is that of "situated freedom," whereby Heidegger says that humans are so embedded in their world that their subjective experiences cannot be separated from their social, cultural and political context (Heidegger in Lopez & Willis, 2004).

Despite these arguments, the philosophical assumptions of phenomenology rest on some common ground: it is based on lived experiences and the experiences are conscious ones from which essences are described rather than through explanation and analyses (Creswell & Poth, 2016). The key difference between the hermeneutic (interpretive) and

transcendental (descriptive) tradition is that, for the latter, the findings are less focused on the interpretations of the researcher and more on the description of the phenomenon. According to the interpretive tradition, research involves these essential steps: (1) identification of the phenomenon, (2) reflection on essential themes, and (3) description of the phenomenon in which the researcher interprets the meaning of the lived experience (Van Manen, 1990). On the contrary, the steps involved in the descriptive tradition are: (1) identifying a phenomenon to study, (2) bracketing out one's own experiences, and (3) collecting data from individuals who have shared experience of the phenomenon. The data are then analyzed by reducing them to "significant statements" or quotes and then combining these into themes. The researcher writes a rich description of what participants experienced, along with a structural description; that is, a description of the conditions and context within which the phenomenon occurred. The combination of the two descriptions makes up the overall essence of the experience (Creswell & Poth, 2016).

The hermeneutic approach to phenomenology is well aligned with both an interpretive epistemological position and intersectionality theory. Drawing from an interpretive position, it is not possible to entirely bracket out the researcher's own experiences (Van Manen, 1990), which corresponds with Heidegger's emphasis on the importance of the life world. Similarly, intersectionality theory as conceptualized by Crenshaw emphasizes the need to understand a person's experiences within their historical, social, and political contexts of interlocking oppression (Crenshaw, 1989). Therefore, adopting a broadly interpretive position is well suited to the study of intersectional stigma, as women's lived experiences of stigma are interpreted and understood in light of their contextual and historical oppression, such as historic gender discrimination in India.

#### 3.2.3 The phenomenological approach compared with other approaches

A hermeneutic phenomenological approach helps to address my research question about the experience of intersectional stigma among women living with HIV better than relevant alternatives. It calls for understanding the shared experiences of a number of women and capturing their essence; the general aim being to develop future stigma reduction strategies and policies. Alternative methods such as a narrative approach, ethnography, or grounded theory would not be appropriate for answering my research questions (Table 6). Narrative approaches are used to explore the life of an individual rather than exploring a particular phenomenon in that person's life. I was not trying to develop new theory on intersectional stigma using data from the people who have experienced it (grounded theory) and neither was I trying to describe the patterns of behavior in a culture sharing group (ethnography). My aim was to use in-depth interviews to understand the shared experiences of intersectional stigma of a number of women living with HIV in a particular social, political and cultural context.

Table 6: Phenomenology compared with other qualitative approaches (adapted from Creswell 2016)

Characteristics	Phenomenology	Narrative approach	Grounded Theory	Ethnography
Focus	Understanding the "essence" of the experience.	Exploring life of an individual.	Developing a theory from the data.	Describing and interpreting a cultural group.
Type of problem best suited for	Description of a phenomenon.	Stories of individual experiences.	Developing a theory based on views of participants.	Shared patterns of culture of a group.
Unit of analysis	Studying the shared experience of a phenomenon of a number of individuals.	One or more individuals.	Studying a process or interaction among many individuals.	Studying a group with a shared culture.
Data collection methods	Primarily interviews.	Interviews and documents.	Interviews with 20-60 individuals.	Primarily observation and interviews; extensive time in the field.
Data analysis strategies	Analyzing data for textural and structural statements.	Analyzing data for stories, often chronologically.	Open coding, axial coding, selective coding.	Thick description of the cultural group, themes about group.

## 3.2.4 Limitations of the phenomenological method

Although phenomenology provides a deep understanding of a phenomenon, it has certain limitations. Firstly, phenomenology requires some level of understanding of broader philosophical assumptions, which can be challenging for novice researchers (Creswell &

Poth, 2016; Wilson, 2015). This issue was addressed by gaining an understanding of the philosophical traditions that underlie the research and choosing an interpretative approach suitable for my research questions. Secondly, participants need to be carefully chosen so that they have all experienced the phenomenon under study (Creswell & Poth, 2016). This was addressed by including in the study only women who were living with HIV so that their experiences and perceptions of stigma could be understood. Similarly, key informants who had worked with people living with HIV were chosen so that they could share their experiences of working with this stigmatized group. Finally, since the phenomenon under study involved different stigmatized identities, there was the issue of respondents minimizing their experiences. Stigmatized people often deny or minimize their experiences as a way of coping with the stigma (Shih, 2004). It was therefore important to establish rapport and try to draw out women's experiences through the use of appropriate follow-up and probes, but this could be an issue in the quality of the results.

#### 3.3 Theoretical frameworks

## 3.3.1 Conceptualizations of stigma

Goffman's rich conceptualization of stigma as the process by which a person is devalued or discredited based on an undesirable trait has underpinned the field of stigma research for decades (Goffman, 1963). Link and Phelan expanded on this conceptualization with their seminal work that showed stigma could only operate when there was a power differential between the stigmatized group and those who did not belong to it. This type of social control was exercised through labeling, stereotyping, marginalizing, excluding, and causing a loss of status and discriminating against the stigmatized individual (Link & Phelan, 2001). In 2003, Parker and Aggleton refined this conceptualization further to show that stigma operated through social and structural inequalities and was "part of complex struggles for power that lie at the heart of social life" (Parker & Aggleton, 2003). I use these conceptualizations of stigma throughout my work as I examine how HIV and domestic violence stigma interact with women's other stigmatized identities to create systems of inequalities, oppression, and power. My thesis uses elements of all three conceptualizations of stigma, but with Link and Phelan's conceptualization at the core,

because of their incorporation of the concept of power differential as fundamental to the stigmatization process.

## 3.3.2 Domestic violence stigma framework

The Intimate Partner Violence Stigmatization Model (Figure 4) was developed by Overstreet and Quinn and provides a framework to conceptualize and measure the consequences of IPV stigma (Overstreet & Quinn, 2013). The model shows the individual, interpersonal, and sociocultural levels at which IPV stigma operates and also identifies three dimensions of IPV stigma that deter help seeking: internalized stigma, anticipated stigma, and cultural stigma. Internalized stigma works at the individual level by making victims believe the negative stereotypes are true to themselves, which prevents them from seeking help. Anticipated stigma works at both individual and interpersonal level. The survivor is concerned about the consequences of people knowing about the partner abuse (e.g. rejection, blame) and this hinders disclosure and help seeking. Finally, cultural stigma operates at the sociocultural level by promoting beliefs such as that IPV survivors are responsible for their abuse, and this de-legitimization of IPV becomes a barrier to seeking help. Centrality (the extent to which people consider an identity as important to their self-definition) and salience (the extent to which identity comes to mind) influence the stigmatization process and in turn help-seeking (Overstreet & Quinn, 2013). I used components of this framework, both during the development of my topic guide and during analysis, by trying to understand how the combined stigma of HIV and domestic violence affects help seeking for women living with HIV and adds to their overall burden.

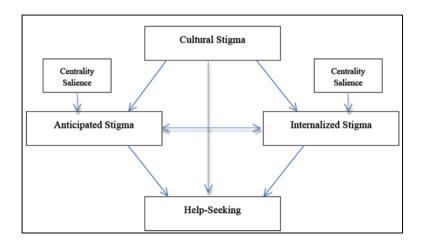


Figure 4 The Intimate Partner Violence Stigmatization Model (Overstreet & Quinn 2013).

Table 7 describes some of the key conceptualizations of stigma since Goffman's original definition, along with some key conceptualizations of HIV and IPV stigma.

Table 7 Description of key conceptualizations of stigma in general and in application to HIV and IPV stigma

Conceptualizations of (HIV/IPV) stigma	Key definitions/concepts	What it adds
Goffman 1963	Attribute that is deeply discrediting such as tribal stigmas (eg, race, religion), physical deformities (eg leprosy, blindness), and blemishes of character (eg homosexuality, mental illness).	First formal conceptualization of stigma.
Herek 1998	Concept of symbolic stigma (association with morally devalued characteristics) and instrumental stigma (fear of infection).	Concept of two aspects of HIV stigma introduced.
Link and Phelan 2001	A type of social control exercised through labeling, stereotyping, marginalizing, excluding, and causing a loss of status and discriminating against the stigmatized individual which operates through a power differential.	Introduced concept of power differential between stigmatized and stigmatizer.
Parker and Aggleton 2003	Stigma operates through social and structural inequalities and is "part of complex struggles for power that lie at the heart of social life."	Further refined concept of power in the context of HIV.
Earnshaw et al 2009	Framework introducing dimensions of stigma (enacted, anticipated, internalized).	Introduced dimensions of stigma.

Hatzenbeuhler et al 2013	The pervasiveness of stigma, its negative impact on a number of life domains and the health of populations. Stigma should be considered a social determinant of population health.	Conceptualized stigma as a fundamental cause of population health inequalities.
Overstreet & Quinn 2013	IPV stigmatization model showing the different dimensions of IPV stigma (anticipated, internalized, cultural) and how that impacts help seeking behaviors.	Improved on prior IPV stigmatization model to show the different dimensions of IPV stigma and that impacts help seeking.

## 3.3.3 Feminist Theory

My literature review showed how domestic violence related to HIV is essentially gendered. Feminist theories of gender and power highlight how men perpetrate violence as a means of keeping women under control. This power imbalance between men and women is further reinforced by the gendered nature of HIV stigma. I therefore chose to incorporate feminist theory to guide my understanding of how unequal gender relations and power imbalances shape experiences of HIV-related stigma.

Feminist scholars have theorized that the patriarchal system and its related power dynamics is a root cause of domestic violence (Dobash & Dobash, 1979). Connell's seminal work on gender and power shows the power imbalance within gender relations (Connell, 1987; Wingood & DiClemente, 2000). The Theory of Gender and Power posits three major axes on which the gendered relationship between men and women are based: (1) the sexual division of labour, (2) the sexual division of power, and (3) the structure of cathexis (Connell, 1987). The theory was adapted by Wingood and DiClemente to show how women's risk of HIV was a function of sexual division of labour (which restricts women to low paying jobs), sexual division of power (where men impose control in sexual relationships through violence and financial control), and cathexis (social norms that encourage traditional gender roles of motherhood, obedience, and faithfulness for women and promiscuity for men) (Wingood & DiClemente, 2000). Similarly, feminist political theory concerns notions of power relations based on gender, class, race, and culture, among others. One of the key points of this theory is that women have been

traditionally excluded from the 'public' sphere, and this is where men 'set the terms of their public and private power' (Tucker, 2011). One of the main goals of feminist political theory is the recognition of household work as labor and domestic violence as crime (Tucker, 2011). There are many other schools of feminist political thought, including postcolonial theorists, who critiqued Western feminist thought and emphasized the alternative expressions of power of the "Third World Woman" (Mohanty, 1984). Following such notions of global feminist thought, poststructuralists such as Gayatri Chakravorty Spivak have called for "strategic essentialism" so that women from the global North can engage in a shared struggle with those in the global South to achieve shared political goals (Spivak, 2012). However, arguments about Eastern versus Western feminism are not the focus of the thesis. I focus on theory that pertains to the gendered nature of power within relationships. This also shapes my understanding of how women can empower themselves so that they can overcome their experiences of intersectional stigma.

## 3.3.4 Intersectionality

My literature review identified a gap in our understandings of how different social identities play a role in the combined experience of HIV and domestic violence (Mukerji et al., 2022). Intersectionality theory was the guiding theory for this work as it provided the theoretical framework to understand how stigma associated with different social identities intersects with that of HIV and domestic violence. Ideas about intersectionality were developed by the African American critical theorist Kimberlé Crenshaw to show how overlapping and intersecting identities create systems and structures of oppression (Crenshaw, 1989). Intersectionality theory posits that these identities are not discrete and cannot be dissected out of the overall experience of oppression. Most importantly, the intersections of multiple disadvantages are not additive but synergistic. While intersectionality theory provides a conceptual framework for understanding people's experiences within "interlocking structures of oppression", the methods to do so are limited. Interpretation of the data by the researcher becomes the most important tool by making connections between what is said (interpersonal experiences) and the larger sociohistorical context of structural inequalities within which people are situated. There is no single reality of the

experience of one's multiple identities but rather multiple realities of each individual experience (Bowleg, 2008). The interpretive phenomenological approach helps with this understanding as it allows us to interpret how different social, political, and historical systems contribute to the phenomenon of interlocking oppression that people with multiple stigmatized identities experience.

# 3.3.5 Intersectional stigma framework

Several frameworks of intersectional stigma have been developed in recent years (Logie et al., 2011; Stangl et al., 2019; Turan et al., 2017). Table 8 broadly describes them.

Table 8 Comparison of intersectional stigma frameworks

Intersectional stigma	Key components	Reason for
frameworks	no, componente	inclusion/non-inclusion
		in my work
Logie et al 2011 (intersectional HIV stigma framework)	One of the first models for intersectional stigma for women living with HIV. The model examines women's experiences of HIV stigma due to overlapping identities such as race, gender, sexual orientation, and sex work, at different levels of the socio-ecological model. The model also examines coping mechanisms employed by women to resist stigma at multiple levels.	The model does not provide a framework for looking at how intersectional stigma may impact general health outcomes.
Turan et al 2017 (intersectional HIV stigma framework)	Examines how structural stigmas intersect with HIV stigma which impacts interpersonal factors (eg disclosure), psychological resources, mental health, and stress processes. These then have an impact on physical health either directly through (i) lowered CD4 counts/high viral loads or (ii) reduced engagement in care.	This framework fits very closely with my questions on the mental and physical health impact of stigma, but not the social impact of stigma.
Stangl et al 2019 (intersectional stigma framework)	This is a very broad model of stigma and is applicable to various other illnesses, not just HIV. It also shows how stigma of illness intersects with other stigmas (eg race, gender, class), which lead to manifestations of stigma (eg internalized stigma or discrimination) and stigma outcomes (access to healthcare, resilience) which ultimately has broad social and health outcomes.	This framework was chosen because it incorporates both health and social impact of stigma and has the closest fit with all of my research questions.

Although all the frameworks in Table 8 inform components of my research, I put forward reasons why I chose the Health Stigma and Discrimination Framework (Stangl et al., 2019) for the thesis (Figure 5). This framework can be applied to the stigmatized as well

as the stigmatizer, takes an intersectional approach to stigma, is applicable for populations in both high- and low-income settings, and is designed to be applied to a variety of health conditions, including HIV. One of the benefits of the model, the authors claim, is that it takes away the siloed approach to stigma that has been the case in stigma research until now. Such a framework should encourage dialogue among stigma researchers studying different health conditions, thereby allowing development of solutions that may be broadly applicable. The model looks at drivers and facilitators of stigma which lead to "stigma markings" (stigma due to a health condition and other intersecting stigmas eg race, gender, socioeconomic position). The stigma markings lead to the manifestations of stigma, categorized as stigma experiences (lived realities) and stigma practices (beliefs, attitudes and actions) which then lead to stigma outcomes that differ based on the target group (affected populations or organizations). I have used this framework to guide my work, not only because it uses an intersectional lens to examine stigma, but also because (1) the broad scope of the model means it can be applied across populations with a diverse range of stigma experiences, and (2) the model looks at both the social (experiences of violence, social isolation) and health impacts (reduced linkage to care, poor mental and physical health) of stigma. The framework fits with the interpretive approach by allowing the researcher to make connections between the larger social structures that fuel discrimination (race, gender, sexual orientation, and others) and individual experiences of HIV-related stigma and domestic violence.

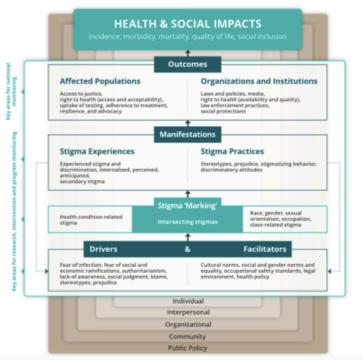


Figure 5 Health Stigma and Discrimination Framework (Stangl et al 2019)

# 3.3.6 Framework for coping with stigma

The empowerment model of coping developed by Shih (Shih, 2004) describes how people cope specifically with stigma as a stressor in positive ways. I have chosen this model because it shows a way forward for people with stigmatized identities by focusing on how they can live well *despite* stigma. The model suggests that people with stigmatized identities cope through (1) compensation (being more likeable, assertive, or making attempts to disconfirm negative stereotypes), (2) strategic interpretations of the social environment (comparing themselves to members of their own group rather than members of advantaged groups, attributing negative outcomes to group membership rather than individual factors, denying or minimizing their experiences of stigma), and (3) drawing on their alternate "positive" identities to protect themselves from stigma (Shih, 2004). People who take a "coping" approach which involves denial or avoidance (similar to avoidant coping strategies) are more likely to find the process draining, while those who take an "empowerment" approach, which involves living well despite stigma (similar to approach

coping strategies), are more likely to find the process energizing. The model was used to analyze my data on coping with negative experiences of intersectional stigma.

# 3.3.7 Modifications made along the way

Although my original research question focused on the intersectional stigma of HIV and domestic violence, the reality of lived experiences of women living with HIV is that they have multiple marginalized or stigmatized identities that shape their overall experiences of stigma. Intersectionality posits that it is impossible to treat these identities (e.g. gender, race, socioeconomic position, sexual orientation, sex work) as discrete and therefore to dissect some of them out of the overall stigma experience (Bowleg, 2008; Crenshaw, 1989; Logie et al., 2011; Stangl et al., 2019; Turan et al., 2017). Therefore, my research developed such that I examined the intersectional stigma of HIV, domestic violence, and other marginalized identities, and how it shapes experiences of stigma and violence for women living with HIV. Another modification that I made was to alter my exploration of the 2017 HIV Act. I started out wanting to understand how having anti-discriminatory legal structures or policies can impact individual experiences of HIV stigma related domestic violence. However, after the first few interviews and seeing the limited awareness of the Act, both among women living with HIV and key informants, I decided to modify my approach and instead try to understand the barriers to or utility of the Act in protecting women living with HIV from stigma related domestic violence.

## 3.4 Study setting

India is composed of 28 states and 8 union territories and the HIV epidemic varies by geographical region. The study was conducted with women living with HIV in Kolkata, the capital of the eastern state of West Bengal (Figure 1). West Bengal is a good setting for understanding experiences of intersectional stigma of HIV, domestic violence, and other marginalized identities and their impact on the health and wellbeing of women living with HIV because of high rates of reported domestic violence and HIV incidence. The state has always attracted migrants from neighboring states and its long porous border with

Bangladesh has made it one of the worst zones for human trafficking in the world (Guha Ray, 2018). Kolkata is also home to one of Asia's largest red-light areas, Sonagachi, where women are often sold into the sex trade, and was once the hub of the HIV epidemic in Bengal. An innovative community-based intervention implemented in the early 1990s led to sustained reductions in HIV incidence rates among this population of women (Jana et al., 2004).

Despite these improvements, HIV remains a public health problem in West Bengal, with the state ranking 4th for new infections in 2019 (NACO, 2019). Although prevalence is low, there are currently about 74,000 people living with HIV, which is 3% of the total number of people living with HIV in India. A more worrying trend is that West Bengal is one of the four states that did not report a decrease in annual new infections in the period 2010-2019 (NACO, 2019). It also reported the fourth highest incidence rates among MSM, which has implications for women, as MSM may not always identify as gay or bisexual (Bowleg, 2008), and in India are often married to women. There are currently no data on HIV rates among wives of homosexual men, an invisible pool of women who are mostly unaware of their husband's sexual orientation and their own HIV status. The prevalence of HIV among the general population of women in West Bengal may therefore be higher than is reflected in the current NACO estimations. Neither does West Bengal fare well on indicators of domestic violence, ranking fifth in India for cases of cruelty by husband and in-laws (NCRB, 2019). As West Bengal is considered one of the more liberal states in India, a reason for high domestic violence reporting rates might be that women are able to register more cases with the police than women in other states.



Figure 6 Map of India with location of West Bengal (Source: https://www.freeworldmaps.net/asia/india/westbengal/)

All of the interviews and photovoice activities were conducted on the premises of the NGO where the study was based. The NGO is affiliated with the Church of North India and, although located in Kolkata, caters to people living with HIV all over West Bengal. Outpatient and inpatient care is provided at nominal cost. The NGO has a residential home for children orphaned or abandoned because of HIV and several women who participated in the study worked and resided on site. A separate room or a gazebo in the garden (because of Covid-19 protocols at the time) were used for the interviews. Due to the relatively large space, it was not difficult to maintain privacy and most interviews were conducted without interruption. The photovoice exhibition was also held in the garden of the NGO.

#### 3.5 Data collection methods

#### 3.5.1 Semi-structured interviews

In-depth interviews with multiple respondents are a key data collection method for phenomenology (Creswell & Poth, 2016). Semi-structured interviews were conducted with women living with HIV; that is, participants who had common experiences of the phenomenon under study: intersectional stigma. Interviews with key informants who had worked with women living with HIV were used to triangulate the findings. Triangulation, as originally set forth by Denzin (Denzin, 2017) took four different forms: triangulation of

data (data drawn from different sources at different times, places, or people), investigator triangulation (use of different observers or interviewers to balance out subjective views of individuals), theoretical triangulation (approaching the data with multiple theories), and methodological triangulation (the use of multiple methods for conducting a study). However, Denzin's original conceptualization has been criticized for being too positivistic, by trying to arrive at a single "objective" truth. Such criticisms led to a change in how triangulation is viewed. Triangulation is now seen as more of a strategy to gain a deeper understanding of a phenomenon and a way to gain greater knowledge rather than as a validation technique (Flick, 2004). I have used data triangulation, where data were collected from different sources and analyzed together, to gain a deeper understanding of intersectional stigma and related health outcomes. This aligns with my interpretivist position.

Although there is no best method for conducting intersectionality research, semistructured interviews have been used extensively in the past (Logie et al., 2011; Rai et al., 2020; Rice et al., 2018). The advantage of using this method, unlike a biographical method, is that participants can be asked specifically about their experiences of different stigmas, which may either come out singularly or as co-occurring instances due to different stigmatized identities. These can then be interpreted within their broader social, cultural, historical, and political contexts (Bowleg, 2008). Women were asked questions about their experiences of HIV stigma, violence before and after diagnosis, issues in relation to identities such as widowhood, sex work, gender, and class, the mental health impact of intersectional stigma, the ways in which they coped, and their awareness and understanding of the 2017 HIV Act. Key informants were asked about their perceptions of intersectional stigma and violence in women's lives, the impact they have on their mental health, and the HIV Act (Topic Guides in Appendix 3). After the first two interviews, I went through the recordings and notes and amended the topic guide to include new probes and highlight topics of interest. Interviews lasted between 30 minutes and over two hours. All interviews were audio-recorded and all field notes prepared to note nonverbal cues and record impressions about respondents at the time of interview.

#### 3.5.2 Photovoice

Given my critical stance described earlier, I chose to use photovoice to supplement the findings from the semi-structured interviews with women living with HIV to understand how they coped with experiences of stigma. Photovoice is a research method rooted in the theoretical assumption of critical consciousness (Friere, 1970). It is a participatory action research method developed in the 1970s which allows people to reflect critically on their experiences through visual imagery (Wang & Burris, 1997). More recently, photovoice has been used within phenomenological enquiry to enhance understanding of lived experience (Donnelly et al., 2021; Plunkett et al., 2013). Here, women were asked to take pictures to show how they coped with negative experiences of intersectional stigma. The steps used for this process included explaining the activity, giving them a smartphone to take pictures, and asking them to choose the ones they would like to keep (although very few women took more than one photo). They were then asked why they took the photo and what it meant and how it showed their coping with negative experiences of stigma and violence. I was unable to conduct a group discussion due to the combination of Covid-19 restrictions and women's lack of enthusiasm and time (discussed in more detail in the section on recruitment challenges).

We were able to hold a small exhibition using the photographs that I managed to obtain, on International Women's Day, 2021. The exhibition was held in the garden of the NGO under Covid-19 precautions (Figure 7). The theme was based on a well-known Bengali poem, "Phul Phutuk na Phutuk Aaj Basanta" (which roughly translates as "Whether flowers bloom or not it is spring today"), signifying hope amidst adversity. The staff and young women at the NGO made handmade flowers and decorated the garden, songs of hope and resilience were played, and refreshments were provided. Women were asked to speak on the occasion if they liked. This seemed to be a big hit as they spoke about their strengths as women and how they wanted the future to be for the children.





Figure 7 Exhibition of photographs

# 3.6 Participants

The sample consisted of adult women living with HIV who were residing in West Bengal at the time of interview. All were receiving care or some other form of support from the gatekeeper NGO. Key informants included a diverse range of stakeholders who had experience working with people living with HIV or were familiar with the HIV Act. They included HIV physicians and nurses, public health officials, HIV and domestic violence NGO leaders, HIV activists, and members of the judiciary.

#### 3.7 Inclusion and exclusion criteria

I had broad inclusion criteria for both women living with HIV and key informants. Adult women living with HIV (18 years or over) who were beneficiaries of the gatekeeper NGO were included in the study. I purposely kept the criteria broad in order to recruit as diverse a sample of women as possible (1) so that we could uncover the different intersectional identities women might have (sex work, sexual orientation, migrant, widowhood, and so on), (2) because people with stigmatized identities often cope by minimizing or denying their experiences of stigma, we did not want to restrict our sample to women living with HIV who had also experienced violence by using a screening process that would exclude women who did not think the violence was significant. For key informants, our only criterion was that they had worked with people living with HIV so that we were able to

recruit a diverse range of key stakeholders who had knowledge about HIV stigma and the 2017 HIV Act.

# 3.8 Participant characteristics

I interviewed 31 women living with HIV, of whom eight agreed to participate in photovoice as well, and conducted 16 key informant interviews. Tables 9 and 10 describe characteristics of the participants. Detailed demographic characteristics of women living with HIV have been presented in Appendix 2.

Table 9 Key informant characteristics

Key informants	Number
HIV physician	3
HIV nurse	1
Counselor/social worker	3
Legal	2
Activist	2
HIV/sex work NGO	2
Domestic violence NGO	1
Public health official	1
Clinical psychologist	1
Total	16

Table 10 Characteristics of women living with HIV

Women living with HIV	Number
Туре	
General population	26
Sex worker	5
Total	31
Age range, years	25-60

# 3.9 Recruitment process

A mix of purposeful and snowball sampling was used. Purposive sampling involves selecting information-rich cases that allow one to gain an understanding of the phenomenon under study (Bloomberg & Volpe, 2008). A purposive sampling strategy was

used to recruit a diverse group of participants with a range of experiences or perceptions of intersectional stigma. Criterion sampling is usually used in phenomenological research to make sure all participants have experienced the criteria under study (Creswell & Poth, 2016). Because the main criterion was experience of intersectional stigma among women living with HIV, the main criterion for recruitment was women living with HIV. They were recruited if they visited the NGO for treatment and support services. Women working for the NGO were also recruited by the counselor in a similar process as the other women. Women were approached by the NGO counselor or outreach worker for participation and then I provided additional details and took them through the informed consent process. Recruitment continued until saturation was reached. Data saturation is an important concept in qualitative research wherein enough data has been collected to replicate the study, when it is thought that no new information can be obtained through additional data collection, and when additional coding is no longer feasible (Fusch & Ness, 2015). Additional recruitment is usually stopped when saturation is attained.

For key informants, I used my existing social and professional networks and snowball sampling to find people who would have knowledge about women's experiences of stigma, violence, and the newly enacted HIV Act. This allowed for a wide range of key informants to be identified and interviewed, with different perspectives on the area of research. They were initially contacted by phone and the study, the nature of the interview, and consent process was explained. This was followed by an email containing the participant information sheet and consent form. Once the signed consent form was returned a date and time for interview was agreed on and the online link for the interview sent out.

None of the participants dropped out once they were recruited. Women who showed signs of some distress, such as crying, were offered the option to stop the interview and return later if they wished, but they insisted on completing the interview. Among key informants, two interviewees initially agreed to interview, but later refused to sign the consent forms

and therefore could not be interviewed. This did not happen with the interviews with women.

## 3.10 Covid-19 and challenges in recruitment

Covid-19 restrictions at the time of my fieldwork meant that it was severely restricted and there were several challenges to recruitment. I received ethical approval to only conduct online interviews with key informants and only face-to-face interviews with women living with HIV (because of the sensitive nature of the research). Both presented challenges for recruitment.

I encountered difficulties recruiting key informants for online interviews. Some would want to meet in person, some had difficulties with using technology, and most found it a burden to print, sign, and scan consent forms. Once the whole process was explained to them, two refused to go ahead with the interview. This challenge was addressed by explaining the UCL rules at the time of Covid-19 and the majority accepted and agreed to interview. However, the nature of telephone and online contact meant some participants would just not appear for interviews after having agreed on a date and time. There were also some challenges with online interviewing itself, as intermittent connectivity issues meant that words and sentences would be lost, verbal expressions could not be seen, and pauses could be misinterpreted, causing some awkwardness in conversation. The advantages were that interviews were long and detailed as participants chose times that were convenient for them and were not restricted to an hour within the workday.

There were many challenges in recruiting women living with HIV. The NGO had suspended all inpatient services and the clinic was restricted to one day a week and only to residents of the NGO. This meant that I only had access to the few women who were residing at the NGO for the first few weeks. The clinic was later opened to a restricted number of non-residents and allowed me to try to recruit from that pool. Finally, even though the clinic remained restricted, it opened up services for inpatients, which meant I had access to more participants. This was particularly helpful as there were women with

HIV whose husbands were admitted and they had time to talk to me while they spent time at the facility. Another pool I tapped into was the monthly meeting of the microfinance group and the monthly ration day for sex workers. These were days when there were more women on the premises than any other. On the whole, there were very few women present on site to recruit from.

Another challenge to conducting interviews was the limited time, as most women were there to either see a doctor or for their group meeting and I could only interview those who agreed to give the additional time just for the interview. This problem was again exacerbated by Covid-19 because I could not ask women to come back another day for interviews as it would mean additional exposure. India's vaccination program had not been rolled out to all age groups at the time and there was vaccine hesitancy among participants, all of which meant that neither I nor any of the women were vaccinated at the time and we had to be extra careful. I was lucky to have conducted most of my interviews before the Delta wave hit India because things got really bad after that, with several outbreaks within the NGO and even stronger restrictions for entry and interaction. It was not difficult to recruit women apart from the Covid-19-related challenges. There were several who were eager to speak to me, and those who were hesitant at the first meeting were more forthcoming later as they became familiar with me.

While it was easier to recruit for the semi-structured interviews, it was much harder to recruit women for photovoice. First of all, the activity could not be conducted in the way it was meant to be because the NGO was hesitant to allow group activities and because people could not find the time to come together as a group (they had duties at the NGO or were taking care of their husbands, for example). This meant that the photovoice ended up being an individual activity. Secondly, I did not have funds to buy cameras for all participants and most did not have smartphones. We had to make do with an old phone which I lent to each participant for a time. Third, my initial research plan was to ask women to take pictures of how they felt because of their negative experiences. However, in trying to explain this to them I sensed that they felt I was reinforcing stigma rather than providing

them with a safe space to speak. I asked them what they would like to take photos of and our discussions revealed that they were much more receptive to the idea of taking pictures showing how they coped with stigmatizing experiences. Here too our restrictions on the types of photographs they could take, which had to be non-identifiable (no pictures of faces, identifiable street signs, and so on), made it difficult for women. Most refused to participate, saying they did not have the time, and others generally showed a lack of enthusiasm. This is in contrast to what is generally described in the literature on photovoice as a method, which is supposed to be empowering and a way to give a voice to those who have been silenced by society (Wang & Burris, 1997). Some of the reasons for this observation in my sample might be the lack of a group component in the activity, the general oppression and fatigue that women felt, and the difficulty they associated with the task. None of the women had confidence in using a smartphone and the task of learning and then taking photos of abstract objects that represented their feelings might have felt too cognitively burdensome. The timing also made a difference. Women had been through lockdowns and the associated economic and mental health challenges and probably did not find the enthusiasm for activities which took up additional time and energy.

#### 3.11 Supports for qualitative research

Apart from taking a trauma-informed approach to minimize distress caused to participants, I was aware of my own exposure to trauma and violence as a result of listening to women's stories. I felt quite distressed, particularly after the first couple of interviews, not just because of listening to stories of violence, but because I felt helpless at not being able to give anything back or make their lives better. Discussions with my supervisors, who have a lot of experience in violence research and ways to alleviate researcher trauma (San Roman Pineda et al., 2022), helped me greatly in alleviating these feelings. As I progressed through the interviews and women thanked me for giving them a chance to talk about feelings and experiences that they had kept buried inside them for so long, I felt much better. Also, knowing that several of the women were no longer in violent situations was a source of mental support for me. I had access to UCL's

Mental Health and Wellbeing Services and also the counselor at the NGO, but I did not need to use either of those services.

# 3.12 Feedback to participants

Upon completion of transcription and an initial analysis, key findings were shared with women living with HIV. I went back to the NGO and shared key findings from each transcript with the particular respondent. However, this could not be done with all of the women interviewed as it was not possible to have everyone come to the NGO for just this one activity. This process was mainly completed with the women who were residing at the NGO and any of the women who agreed to come in.

### 3.13 Research governance

#### 3.13.1 Ethics

Ethical consent was obtained from the University College London Research Ethics Committee (18291/001) and an approval letter from the gatekeeper NGO. Because of the highly sensitive nature of the research, several ethical issues and the safety of the participants were kept in mind. To ensure privacy, I conducted all interviews in a private space and interviews were paused if someone walked in. I did not record names of participants as part of the data and each pseudonymised transcript was given a participant ID. All soft copies of files with personal information and audio recordings were stored in password protected files on my encrypted laptop. To ensure safety of the participants, the interviews were conducted on the premises of the NGO so that women did not have to worry about partners or in-laws overhearing. All women were followed up for a week after the interview to check how they were feeling. A list of resources and support services was prepared and offered to women. Recruitment was done through the counselor or outreach worker at the NGO and this was an added layer of protection as women felt comfortable talking to someone who was recommended by a person they trusted. During the informed consent process women were told that:

- Their participation was voluntary
- Their refusal to take part would not affect the care they received at the NGO

- They could refuse to answer a question if they wished to
- The information they shared was strictly confidential and would not be shared with anyone outside the research team.

In addition, I made sure I ended all interviews on a positive note with questions on hope and resilience. I also made sure I checked on participants throughout the interview and afterwards to make sure they were all right.

#### 3.13.2 Informed consent

Written informed consent was taken from all participants (see Appendices 4 and 5 for participant information sheets and consent forms for key informants and women living with HIV, respectively). For those who could not read or write, a thumb impression was taken. For key informants, the participant information sheet and the consent form were emailed to them ahead of the interviews. They were told that they could get back to me if they had any questions. For women living with HIV, the research process and risks and benefits were explained by the NGO staff and if they agreed they were once again taken through the informed consent process by me. It was at this time that they were asked to sign the consent form. I always signed the form in front of them in an attempt to neutralize the power differential that might arise during this process. Although researchers have argued that mutual trust and rapport can be eroded by the signing of consent forms (Horowitz & Gerson, 2002), I had to follow this process in order to comply with the 2017 HIV Act, which mandates written informed consent from all research participants who are living with HIV. The signed consent forms were scanned and stored in a password-protected file on my encrypted laptop and the paper forms shredded.

#### 3.14 Data collection phases

Data collection began in India in October 2020, once ethical approval was obtained. This continued on and off throughout 2021. The different phases of data collection are described briefly below (a detailed audit trail of data collection activities is presented in Appendix 6).

# Phase 1: Key informant interviews

The first phase of data collection was through online interviews with key informants as ethical approval for face-to-face interviews with women living with HIV had still not come through.

# Phase 2: Interviews with women living with HIV

Once approval was obtained for this part, I focused all my attention on going to the field site and recruiting and conducting interviews with women. The topic guide was piloted with NGO staff and refinements made so that questions were understandable for women. As interviews with women progressed, further tweaks were made (additional probes added, some questions marked as less important).

#### Phase 3: Photovoice and exhibition

After a number of interviews had been conducted, I began recruiting women for photovoice. I wanted to hold the photo exhibition on International Women's Day to highlight the importance of the research for women and to have as many photos as possible before then. As described previously, I had a very challenging time recruiting women for this part of the study, but the exhibition on Women's Day was quite successful.

# **Phase 4: Key informant interviews**

As I interviewed each participant I made detailed field notes and summarized key findings. Going through these notes as I progressed through more interviews allowed me to identify when saturation had been reached and also where there were gaps and more interviews needed. This is how I decided to wrap up the interviews with women and do more key informant interviews. The last phase of data collection involved snowball sampling and networking to recruit more key informants.

# Phase 5: Analysis

Data management and analysis were carried out alongside the other phases.

## 3.15 Data analysis

#### 3.15.1 Data management

All of the interviews were recorded on a digital tape recorder and transferred to my encrypted laptop for transcription into a Microsoft Word document. Detailed field notes included notes on participants' non-verbal expressions, their tone of voice, any hesitation, as well as their clothes, description of the interview space, any interruptions, summary of the main findings, and my reflections about the interview were typed up at the end of each day and stored along with the recordings. This is an important step in qualitative research and also for my interpretative phenomenological approach as details of the interview context add depth to the data during interpretation and help with data immersion (Green et al., 2007). While typing up notes I listened to the recordings, which helped in data familiarization. As I was progressing with interviews I also started transcribing them. All of the transcripts and translations were done by myself, which was not only important for addressing ethical issues with confidentiality, but also helped me to become immersed in the data (Dearnley, 2005). The transcripts were imported into Nvivo qualitative software for analysis.

# 3.15.2 Translation dictionary

Since I have native proficiency in both Bengali and English and did the translations myself, I feel that it is important to share my impressions on how certain words were expressed by participants. This should help with understanding the quotes better. The actual Bengali word for stigma would be "kalanka" but none of the participants used this word. In fact, they used a much stronger word to denote stigma, which was "ghenna", which translates directly as repulsion or disgust. Therefore, I felt the need to keep the Bengali word rather than translate, in order to stay as close to how participants interpreted or experienced "stigma". Other commonly used words with their direct translations and what they actually mean have been described in Table 11.

Table 11 Translation and meanings of selected Bengali words

Bengali	Direct translation	Actual meaning
Kharap, baje	Bad	Indicates sexual link (bad disease (sexually transmitted disease), bad woman (sex worker or promiscuous), does bad work (sex work)
Bhalo	Good	Context dependent (when used in the context of HIV it means healthy; when used in the context of women it indicates morality or respectability, but could also just mean nice or good)
Baje jayga	Bad place	Red light district
Attyachar	Torture	Used commonly for abuse
Sharirik attyachar	Physical torture	Usually indicates sexual violence
Jhamela, oshanti	Problems, trouble	Indicates regular domestic violence (shouting, beating)
Jhogra	Quarrel	Indicates verbal or emotional abuse
Mela mesha	Hanging out, mixing	Sexual relationship, sexual intercourse
Ghenna	Disgust, repulsion	Stigma
Moner jor	Mental strength	Resilience, mental strength
Shahajyo	Help	Women use it to mean financial support

# 3.15.3 Data analysis

For an interpretative phenomenological study, there was the option of analyzing the data using either an interpretative phenomenological analysis (IPA) or thematic analysis, which is more versatile and can be applied across a range of epistemologies, including phenomenology. In fact, the end result of IPA and thematic analysis has often been described as similar when research questions involve asking participants about their experiences and perceptions of a certain phenomenon. A key difference, however, lies in the dual focus of IPA, which goes into a detail on the experiences of each individual participant (idiographic focus) as well as into patterns in the data across participants. Thematic analysis only focusses on the patterns of meanings across interviews (thematicanalysis.net). Thematic analysis was a better suited analytical method for my work because, rather than focusing on the meaning of individual experience, I was more interested in understanding the broader social and health impacts of intersectional stigma for women living with HIV. As described earlier, intersectional experiences are different

for different people, and interpreting them within the broader social and cultural context is an important step of intersectionality research (Bowleg, 2008). Thematic analysis allowed me to do this well because I could look at patterns in the experiences of intersectional stigma among women within the broader social and cultural context in which they lived.

# Thematic Analysis

Qualitative data must be analysed and interpreted in a rigorous and methodical manner in order to obtain meaningful results (Attride-Stirling, 2001). Thematic analysis is one widely used method to analyze qualitative data (Braun & Clarke, 2006). There has been an ongoing debate as to whether thematic analysis should be considered a method in its own right or as an analytical tool to aid a variety of qualitative methods (Nowell et al., 2017). Regardless, thematic analysis is a versatile technique that can be used across a range of epistemologies for answering a variety of research questions, thereby allowing researchers using different methods to communicate with each other (Boyatzis, 1998; Nowell et al., 2017). Although the advantage of using thematic analysis lies in its versatility or "theoretical freedom", therein lies its disadvantage (Nowell et al., 2017). The flexibility of thematic analysis can lead to inconsistency and incoherence when developing themes; a shortcoming that can be addressed by making clear the epistemological position underpinning the empirical data (Holloway & Todres, 2003). My interpretivist epistemological position with a focus on understanding experiences of intersectional stigma among a diverse group of women living with HIV meant that thematic analysis was a suitable method, as has been described in greater detail at the beginning of this section.

I used a form of thematic analysis called thematic network analysis as an analytical tool for my dataset. The flexibility of thematic analysis is that themes can be developed in different ways, including using tables, templates, codebooks, and mind maps (Braun & Clarke, 2006). In thematic network analysis, themes are developed using a web-like network (Figure 8) to organize codes and themes, which makes the process of going from text to interpretation clear (Attride-Stirling, 2001). While there is debate about coding

qualitative data (Coffey et al., 1996), there is a general consensus about the need for reducing large swathes of qualitative data into manageable chunks (Lee & Fielding, 1996). Thematic network analysis involves (i) coding data from which basic themes are extracted, (ii) clustering of basic themes with shared meaning into middle-order themes known as "organizing themes", and (iii) conducting an overarching level of analysis to develop "global themes" which "encompass the principal metaphors in the data as a whole" (Attride-Stirling, 2001).

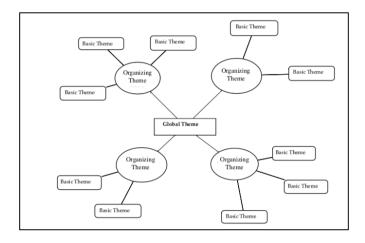


Figure 8 Structure of a thematic network (Attride-Stirling, 2001).

I coded my data using a mix of deductive and inductive coding: deductive analysis was guided by concepts in intersectional stigma theory (HIV stigma, sex work stigma, sexual orientation stigma) while inductive codes emerged from the data. Generally, a thematic map contains one global theme (the core of the map), but a dataset may contain a number of thematic maps. The web-like nature of the map is meant to demonstrate the non-hierarchical nature of the themes at each level (Attride-Stirling, 2001). The main reason for choosing thematic network analysis over thematic analysis, as described by Braun and Clarke (Braun & Clarke, 2006), was that building thematic networks helped me visualize how the various themes were connected. Specifically, it allowed me to (1) break up my large and complex dataset into thematic maps using my research questions as starting points, (2) see how the different orders of themes (basic, organizing, and global) were linked (explicit link between text to higher order interpretation, and (3) interpret how

the different global themes were linked, finally bringing all of the dataset and analysis together.

A description of the different analytical stages of a thematic network analysis is provided below to illustrate the stepwise fashion in which I moved from data collection and interpretation to the development of conceptual frameworks.

# **Analytical stages**

- Preliminary analysis of interviews during data collection.
- Initial reflections on interviews and participant observation noted.
- Listening to interview audio files.
- Transcription and translation with removal of all identifiers.
- Transcripts imported into Nvivo.
- Re-reading of transcripts with memos and annotations.
- Application of codes to transcripts using existing theory (deductive) and as information emerged from the data (inductive).
- Patterns from the codes aggregated into emergent themes (iterative process involving multiple discussions with supervisors).
- Overarching themes developed through a thematic network map.
- Development of conceptual framework from each thematic map.

Developing each map separately helped me organize the basic themes into a cluster of organizing themes, which was then abstracted into an overarching global theme that captured the essence of the key findings for a particular theme. For example, basic themes such as "most women are unaware of the HIV Act" and "stigma and ambivalence about using the HIV Act among women" led to the organizing theme, which was "Lack of awareness of the Act among women living with HIV". Similarly, basic themes such as "Non-disclosure clause for women in conflict with existing laws", "failure to guarantee right to residence" led to the development of the higher order organizing theme "Weaknesses in certain clauses of the Act". Such organizing themes finally led to the development of the overarching global theme, "The HIV Act was not designed to protect women against

HIV stigma-related domestic violence". This analytical step was done iteratively with multiple discussions with supervisors to refine the final global themes. Once the thematic maps were developed, I conducted an additional analytical step to make sense of how the non-hierarchal themes came together on a higher level. This led to the development of a conceptual framework for each of the main findings. I then went on to the final step: the exploration and description of each theme. This led to additional interpretation and further refinement in the themes and their naming.

#### 3.16 Evaluation of the research

## 3.16.1 Timing of interview

Since the study examined the intersectional stigma of HIV with other marginalized identities, including that of domestic violence, HIV diagnosis was a key point in women's lives after which to examine their experiences of stigma and violence. Although there were reports of domestic violence before diagnosis, I was interested in how this violence changed after diagnosis because it helped bridge the knowledge gap about how domestic violence was related to stigma for women living with HIV (Mukerji et al., 2022). The broad recruitment criteria allowed me to examine women's experiences of stigma (including internalized stigma) and violence over different periods. For example, women who had been diagnosed recently were likely to have had different experiences or fears than those of who had been living with HIV for a number of years. There might also be a difference in how women recalled their experiences based on the length of time that had elapsed, which could potentially have an impact on the findings.

#### 3.16.2 Criteria for trustworthiness

Addressing issues of trustworthiness of the data throughout the research process is important to ensure that the qualitative research is of high quality. I used the following trustworthiness criteria (Bloomberg & Volpe, 2008):

1. Credibility: making sure the participants' experiences and perceptions are represented accurately.

- 2. Dependability: making sure others can track the methods of data collection and analysis.
- Transferability: qualitative researchers do not expect findings to be generalizable, but transferability allows readers to judge whether findings can be applied to their own settings.

The steps taken to ensure the trustworthiness of the research process are outlined in Table 12.

Table 12 Steps taken to ensure trustworthiness (Based on criteria developed by Bloomberg & Volpe 2008)

Criteria for trustworthiness	r Steps taken	Details
Credibility	Reflexivity Thick quotes	-Maintaining a reflexive journal throughout the research process to document my position in relation to the research eg., gender, socioeconomic status and class, ethnicitySetting aside my assumptions to ensure objectivityFindings supported by thick verbatim quotes.
	Member validation	-Checking findings with respondents
	Triangulation	-Collecting data from a variety of sources eg women living with HIV and key informants. -Analyzing the data together as one dataset.
	Presenting variation in results and negative findings Developing relationships with participants	<ul><li>-Including data that are not in agreement with the findings.</li><li>-Rapport building with participants to ensure comfort and open discussions on sensitive topics</li></ul>
Dependability	Presenting an audit trail	-Detailed description of how data were collected and analyzed.
	Consulting others during analysis	-Regular meetings with supervisors during the coding process and development of themes.
Transferability	Including thick description	-Rich descriptions of the cultural, social, and historical context of the research.
	Diverse interview sample	-Purposive sampling to include respondents with diverse experiences, eg different intersectional identities.
	Field notes, annotations, and memos	<ul> <li>-Maintaining detailed field notes and reflections after each interview.</li> <li>-Detailed annotations and memos during the coding process.</li> </ul>

# 3.16.3 Reflexivity and the researcher's position

Reflexivity is a key component of the qualitative research process, in which the researcher acknowledges their contextual relationship, such as race, age, gender, socioeconomic status, with the participants, and how it might influence the data and interpretation of the results (Dodgson, 2019). It is an established way of maintaining the quality and rigor of qualitative work and has been considered a gold standard for determining the trustworthiness of research (Teh & Lek, 2018). Reflexivity and awareness of the researcher's position means that they are aware of their role in the creation of knowledge, and therefore the impact of their personal biases, beliefs, and experiences on the research (Berger, 2015). Next, I present my position as a researcher in terms of my gender, ethnicity, marital, socioeconomic, and HIV status and describe how this may have affected the data collected and its interpretation.

I am an Indian woman who grew up in Kolkata, sharing the same culture and ethnicity with most of my participants. Since I did not face a language barrier and I looked similar to the participants, I felt that they were quite comfortable in talking to me in that respect. It also meant that I identified with some of the cultural aspects of stigma and violence that my participants shared with me. Yet, there was a lot that I did not have in common with them. It was likely that my participants perceived me as coming from a position of relative privilege and education, putting me in a position of power which may have affected their responses. Given the sensitive nature of the interviews, and that domestic violence and HIV are both stigmatized or considered low class, it could be that some participants tried to minimize their experiences of both. Stigmatized persons have been known to deny or minimize their negative experiences to protect their sense of self-worth (Shih, 2004). This meant that the reverse was probably also true: what I may have believed to be a participant's experience of stigma or domestic violence may have been quite different from how they thought of it or how they would have liked me to think of it. I tried to overcome this second limitation by keeping my interpretation of the data as close as possible to what was said by the participants rather than trying to make meaning out of it.

I think being a woman influenced the research process in a positive way, given that the study was about women and all respondents with HIV were women. Given the sensitive nature of the subject, it was especially important for women to feel comfortable discussing matters of a very personal nature. Discussing them with a woman made it easier. Other studies from India have shown the importance of having gender matched interviewers for work with women in traditional settings, as a means of obtaining more accurate data on sensitive topics (Vollmer et al., 2021). However, being an unmarried Indian woman meant that I did not have any obvious signs of marriage (sindoor or bangles), which I felt made women a little uncomfortable about sharing details about anything of a sexual nature. This was especially true for some sex workers who may have found it difficult to open up completely. But the most important difference between the women and me was that I was not "positive". I wanted to know about them and their experiences, but I could never be one of them. I tried to mitigate some of this "us" versus "them" feeling by spending extensive time in the field and building rapport. For example, I would chat with participants before and after interviews to make them feel comfortable, have lunch with those who resided at the NGO, and spend time talking with them. Covid-19 restrictions made matters worse as I had to wear a mask at all times, gloves and a head cover, and keep my distance. I could not spend as much time with them as I wanted to in order to minimize exposure. Masks hide smiles and make it difficult to make immediate connections with a person. A stigmatized group who have associated gloves and social distance with HIV stigma in healthcare settings over their positive lifetimes might have interpreted my Covid-19 precautions as HIV stigma. I would make sure to reassure them of the reasons for wearing protective gear.

Despite these challenges, I think I connected with the participants and most said that they felt better after talking to me. It might even be that my perceived position of power meant that women felt good that I was willing to listen to their stories in a non-judgmental way.

## 3.17 Conclusions

I used a phenomenological approach to understand how HIV and domestic violence stigma overlap with other marginalized identities for women living with HIV in India. Semi-structured interviews were conducted with 31 women living with HIV and 16 key informants to understand lived experiences and perceptions of multiple intersecting stigmas. In addition, Photovoice was conducted with 8 women living with HIV to add depth to the understanding of their coping mechanisms against stigma. The data were analyzed using thematic network analysis and organizing and global themes identified. In the following chapters I present the findings from this empirical work.

# **Chapter 4: Intersectional stigma**

In the introductory chapter I have described the social context for gender discrimination against women in India and how it can result in domestic violence. I have also described the pervasiveness of HIV stigma in Indian society, with women often disproportionately bearing the brunt of it. Previous studies from India have examined the dual stigma associated with identities such as widowhood or sex work or transgender stigma (Azhar & Gunn, 2021; Azhar et al., 2022; Bharat et al., 2001), but not how they shape stigma-related violence experienced by women.

Although the interpersonal drivers and manifestations of both HIV and domestic violence stigmas may differ, certain key structural drivers of stigma, such as gender inequality or imbalances in societal positions of power, are common to both (Overstreet & Quinn, 2013; Seeley et al., 2012; Turan et al., 2017). Since women with HIV often experience HIV stigma and discrimination, one manifestation of which may be domestic violence, and both HIV and domestic violence stigma make women reluctant to seek help, the two may put a greater burden on women's lives. This has not been well studied to date (Hatcher et al., 2016; Marais et al., 2019) as shown in the findings of the literature review presented in the Chapter 2.

My first research question examines the intersection of multiple stigmas and how it impacts domestic violence in the lives of women living with HIV. Previous studies have shown that there is a bi-directional link between HIV and domestic violence (Maman et al., 2000). Women with HIV report an increased prevalence of domestic violence, which is both a risk factor for acquiring HIV and a consequence of it (Kouyoumdjian et al., 2013; Silverman et al., 2008). My systematic mixed studies review, however, showed that only a third of studies that have reported such findings attribute the violence to HIV stigma. Despite both HIV and domestic violence being stigmatized, there is a lack of studies that explore their intersectional stigma. In order to fill these research gaps, I present my findings on intersectional stigma. Specifically, I discuss how violence experienced by

women after an HIV diagnosis is a result of HIV-related stigma and how HIV stigma compounds domestic violence stigma to worsen stigma as a whole. In addition, I explore how this violence is worsened when HIV stigma intersects with the stigma of women's other marginalized identities, and causes women to hide the violence. Finally, I discuss the temporal nature of this violence in order to examine the reasons for the reduction in HIV stigma-related domestic violence over time. Although I have presented my findings on the intersectional stigma of HIV, domestic violence and other stigmatized identities in distinct categories, the interpretation is such that the stigmas from multiple identities are taken to be occurring together when the results are considered as a whole.

The findings presented below shed light on how the stigma of HIV and domestic violence intersect and overlap with other marginalized social identities, to shape women's overall experiences of stigma and related violence. Data from semi-structured interviews with women living with HIV in India and key informants were analyzed using thematic network analysis to develop themes (Table 13). The global theme for this chapter illustrates how violence is linked to stigma and will be described in more detail in the discussion.

Table 13 Examples of themes on intersectional stigma

Global theme	Organizing themes	Examples of basic themes
Stigma and domestic violence Intersectional	Intersectional stigma of HIV and domestic violence amplifies stigma as a whole	HIV stigma results in domestic violence against women living with HIV. Perpetrators reinforce HIV stigma through abuse. HIV stigma worsens domestic violence stigma.
	Intersections of multiple stigmas worsen domestic violence	The intersection of HIV and gender discrimination. The intersection of HIV and widowhood stigma. The intersection of HIV, widowhood, and girl child stigma. The intersection of HIV and sex work stigma. The intersection of HIV and transgender stigma. The intersection of HIV and poverty stigma.
	Stigma of HIV hides domestic violence	Women unable to share experience of violence with others. HIV stigma a barrier to help seeking from informal sources.

Women perceive reduced support from formal sources.

Temporal domestic violence triggered by HIV stigma

is Reduction in enacted stigma over time.

Reduction in internalized stigma over time.

# 4.1 Intersectional stigma of HIV and domestic violence amplifies stigma as a whole

HIV stigma-related violence was pervasive in this setting. Over three-quarters of women interviewed for the study had experienced domestic violence. Violence worsened after diagnosis for all who had previously experienced it, unless they were no longer living with their husbands or their families. For some, violence erupted for the first time after diagnosis. HIV stigma was a trigger for this domestic violence, with women reporting blame, isolation, physical abuse and rejection from partners and in-laws, due to fear of infection (instrumental stigma) or poor moral character (symbolic stigma). The different forms of HIV stigma related violence reported by participants have been described in Table 14.

Table 14 Descriptions of different forms of HIV related violence as reported by participants

	Types of HIV related violence
Denial of medical care	Forceful interruption or suspicions around clinic visits
	Actively stopping ART intake (using physical violence)
	Tearing up medical reports and denying having HIV
	Forced unsafe sex
	Not disclosing status to woman, depriving her of treatment
	Preventing hospitalization even when very sick (woman needs to continue to do housework)
	No support with medical costs
	Emotional manipulation to stop ART intake
Neglect	No help with housework when sick
	Emotional neglect
	Woman having to care for herself when sick
Forced migration	Forceful eviction from shared household
	Woman decides to leave on her own (fearing violence if family gets to know)
	Abandonment at hospital or women's shelters (upon diagnosis)  Forced to move out of village
Isolation	Forced to stay in one room of shared house
	No one speaks to woman and her children
	Specifically told not to attend social gatherings
	Utensils separated or not allowed to cook or touch family food
	Not allowed to use village pond

Nutritional	Denied nutritious food	
deprivation/economic	Denied financial support (woman has to start working for first time in her	
violence	life)	
	Denial of husband's property	
Publicizing status	Telling neighbours or extended family about woman's status	
	Gossiping about woman's status (behind her back)	
	Utensils separated by in-laws at large gatherings	
Intense psychological	Verbal abuse about poor moral character	
abuse	Notions of untouchability reinforced through isolation or threats of denial of	
	last rights	
	Husband and in-laws gang up to blame woman for "bringing HIV"	
	Widow blamed for "killing husband"	
	Woman made to feel dirty ("smells bad", "body riddled with worms")	

Key informants shared similar perceptions from their work with women living with HIV. Women living with HIV are at greater risk of domestic violence and the interaction of the stigma attached to both HIV and domestic violence amplifies the stigma they experience as a whole.

# 4.1.1 HIV stigma results in domestic violence against women living with HIV

Women living with HIV and key service providers reported increased violence against women after an HIV diagnosis. A few women reported violence for the first time after their diagnosis, most reported a worsening of violence, and some did not report violence despite having HIV. Violence was mostly verbal abuse and emotional violence, in the form of social isolation and rejection in the marital home. A physician from a large ART center discussed how women were blamed and isolated after being diagnosed with HIV, and this finding was supported by interviews with other key informants and women living with HIV.

"First of all, it is the ostracism, I will not take care of you, will neglect you, that is what happens most of the time. If there is a dispute between the husband and the wife, then there is an issue within the family, in some cases there is physical assault" (Physician, ART center).

An official from an HIV NGO described how this sort of "indirect violence" in the form of "abusive language, non-cooperation, isolation" was more common than reports of physical violence and had a worse impact on women than physical violence. Pre-existing domestic violence was worsened by the presence of HIV because of the stigma attached to the disease:

"This space of domestic violence is not just due to HIV, maybe domestic violence was already there, but it is now seen through the lens of HIV. And because, it is our absolute belief, when we get to know that someone is HIV+, then thinking of where they got it or how they got it, we have a habit of blaming them, through this process of blaming mental pressure is created for them" (Public health official).

Therefore, women who normally experienced physical violence from husbands and inlaws feared additional violence after testing positive for HIV, as reported by a counselor from a women's shelter:

"So, the women who come to us, I have heard that they are tortured in their marital homes. That the husband beats them, the mother-in-law or father-in-law beats them. So, then the women who are HIV+ they obviously have a fear in them that 'they beat me anyway, if they hear I'm HIV+ they will beat me even more'... For that reason, they have a lot more fear within them" (Counselor, women's shelter).

Violence also took the form of abandonment by the husband and marital family. A woman living with HIV who had been abandoned by her husband spoke about how her in-laws knew about her husband's status, but "they suppressed all of it because they wanted to show that our son is good, our daughter-in-law is the one with the disease" (CL001, 46 years). The counselor from the women's shelter described how women who had HIV were never taken back by their husbands or in-laws even if they were willing to do so prior to the women's HIV diagnosis. In her time working at the shelter she had "not seen a single married woman leave" to go back to her marital home.

"Yes, there has been a lot of cases where women from good families have also come and they have been found to be HIV+ later. Their family members came to collect them, now when a family comes to collect someone we have to tell the family that she is HIV+, but once they got to know this, even if they have come to collect the woman, they turned around and left. Didn't take them back... She is HIV positive so they will not take her back home. We explained to them that there is nothing to fear, she has a treatment card, you can get her treated at a hospital normally. But they refused to budge... Her husband immediately declared that she was characterless" (Counselor, women's shelter).

Although serodiscordance was rare, the problem was worse for couples when only the wife was positive, because in those cases women had little defense against the blame that came their way from in-laws; neither did they have support from their husbands. The only serodiscordant woman in the study, who was still living with her husband, reported that since her diagnosis "everyday there is a quarrel, when I sit down to eat they [husband and in-laws] quarrel, when I go to sleep they quarrel with me, they quarrel with me all the time" (CL002, 30 years). This did not seem to get better, unlike for some others:

"If both are positive then I don't think there is much stigma there, but if they say you had it first then I got it, but in a lot of cases it has been seen that wife is positive husband is negative, then this problem is more" (Physician, ART center).

This did not mean, however, that a woman was safe from domestic violence if both husband and wife tested positive. Eighty percent of women interviewed were seroconcordant, yet reports of violence were high. Apart from in-laws, husbands also blamed their wives and became physically abusive in some cases, either by denying that they themselves had HIV or by labeling women as 'bad' (euphemism for immoral or sexually corrupt in India). Some husbands blamed women for their HIV-induced job loss.

Neglect was another form of abuse reported by women, with no one helping them with housework or the care of their husbands, even if they themselves were sick.

There were very few reports of sexual violence among the women interviewed. One reason for this could be the taboo around talking openly about sex, especially with an interviewer who was not married. However, one woman did openly discuss how her husband repeatedly denied his HIV diagnosis (due to internalized stigma), blamed her for having HIV, and forced her to have sex with him without condoms:

"I explained that to him multiple times, 'see if you take it [medicines] then my health will be even better. I say that while taking medicine, let us have sex just with each other, he won't listen to that also, he will say 'you go away, I will marry again'... I am like 'you have this disease, where will you go by leaving me?', he is like 'all that is nonsense, all lies, all lies, all wrong, I don't believe it.' Saying that he won't use condoms, he will come back drunk and force himself on me and beat me and cause problems (CL027, 28 years).

Overall, it was clear that HIV diagnosis was a trigger for violence and this was primarily mediated by HIV stigma. This was either enacted stigma in the form of physical and verbal abuse from partners and in-laws or a function of internalized stigma among men who denied they could have such a "bad disease" and abused their wives instead, blaming them and beating them for having HIV. About half of the women in the study experienced a worsening of abuse following their diagnosis, with husbands or in-laws being the main sources of violence. The other half (15/31 women) technically did not experience HIV stigma-related abuse. However, a closer inspection of this statistic reveals the story behind the numbers as many of these women did not disclose their status for fear of anticipated violence and chose to move out of their marital homes quietly. Of the 15 women, four sex workers did not report stigma-related abuse as they either did not have partners or did not disclose to them, two widows left home without telling anyone in the family, two couples did not tell anyone in the family, two women were separated from their

husbands before diagnosis and either lived alone or with their children, and two women had been diagnosed recently and their partners or in-laws did not know. Only three women had accepting partners or families and did not experience any kind of HIV stigmarelated abuse despite partners, in-laws, or their natal families knowing about their diagnosis. Even those who did not experience any violence after HIV had heard of other women being abused because of HIV stigma, which caused them to have high levels of perceived and anticipated stigma. Most lived in fear of discrimination once people found out:

"I believe in this, that the truth can never be suppressed. No matter how big the incident, no matter how big or how small, maybe it will take some time but it will come out. That is my belief... If it is better not telling then let that be. Let it be good as long as it can be. It doesn't matter to me, I didn't tell anyone, so it didn't matter to me, now if I told them, then I would have to sacrifice a little bit, so if it is good let it be, I have no need to tell anyone. But this is not a matter to hide, so one day they will find out. When they find out we will see what the situation will be then" (CL004, 35 years).

Non-disclosure or strategic disclosure was therefore the most significant means by which women avoided stigmatization, with most not disclosing to family or neighbors unless they "found out". Women talked about discussing HIV generally with family or friends so they could judge their reaction. As described earlier, a common reason for women not reporting stigma experiences was that "no one knows". When both husband and wife were positive, most did not disclose to the extended family. In-laws usually came to know because diagnosis only happened when the man became very sick and family members usually accompanied the wife during the medical process. Sometimes when men were diagnosed first or his family was not told, violence was relatively rare or less severe. In such cases too, women felt like they would have experienced violence had they had been diagnosed first or been serodiscordant:

"Then absolutely there would be. 100% there would be. Now both of us have it and on top of that he got diagnosed first and then me, that's why nothing happened, so nothing happened regarding that but if I alone had it then there would definitely be problems... from everyone" (CL021, 32 years)

## 4.1.2 Perpetrators reinforce HIV stigma through abuse.

The previous section described how HIV stigma drives the domestic violence experienced by women living with HIV. In this section, I examine how domestic violence itself plays a role in reinforcing HIV stigma through verbal and emotional abuse. As discussed earlier, the most common form of domestic violence for women living with HIV is blame and ostracism. Blame for bringing the disease into the relationship can often reinforce stereotypes associated with HIV—poor moral character and association with sex work—while ostracism reinforces stereotypes around untouchability due to fear of infection. Reinforcing such stereotypes can in turn cause women to internalize the stigma. This has its own set of consequences, including poor help seeking, withdrawal and ultimately poor health.

Interviews with women and key informants revealed that as soon as people heard about her HIV they thought a woman was "bad". The verbal abuse that followed almost always reinforced this stereotype of sexual promiscuity associated with HIV:

"Yes, we stay together, mother-in-law, father-in-law, no one looks after us, so I take care of us, so I have to take care because no one takes care of us. I have four older brothers-in-laws, only in name, everyone earns, everyone is well, no one has illness, but they won't take care of us. For all of them I am bad, only I have become bad in everyone's opinion, after getting this disease, HIV. They think I have been sleeping around with people, I have done all that, no one is understanding" (CL002, 30 years).

Reinforcing HIV stigma through verbal abuse was not restricted to blame and the label of "bad woman". People living with HIV often face difficulties with cremation and conducting the last rites because of fear of infection. In-laws reinforced this stigma by reiterating how people would not touch the woman once she died:

"Sometimes, I mean nowadays there are doing a little, *didi*, the brothers-in-laws' wives, if there are quarrels they say sometimes, 'you have such a disease you have no one to turn to except us, when you die then we only have to do everything, they will not touch you, other people will not touch you', they say such things. Even now they say such things, if there are the slightest quarrels" (CL030, 39 years)

Women who had acquired HIV as a result of being trafficked into the sex industry were often abandoned by families after being rescued. They often had to reside in shelter homes, where they faced abuse from staff and fellow residents. Although this is not a case of domestic violence, since the shelter homes were now these women's permanent homes, the abuse meted out to them in such spaces is still relevant for this discussion. It reinforced several stereotypes around HIV: stigma of sex work or immorality, stigma of death and disease, stigma of contagion, and stigma of being abandoned by family:

"...'you have this [HIV], now all the other women will get it from you.' She does not use *tumi* anymore, it goes into *tui* [insulting way of addressing a person in Bengali], 'you will cause this, you will cause that, what do you think yourself, you have gone around doing this and this, that's why your parents will not accept you anymore, your husband will not accept you, you will have to die here' and many other things like this are said" (Counselor, women's shelter home).

This kind of behavior, reinforcing stereotypes associated with HIV, invoked feelings of internalized stigma in women. They often asked God, "what sin did [they] commit that such a thing happened?" A woman talked about how she started questioning herself after her mother-in-law repeatedly blamed her for contracting HIV and giving it to her son:

"This is their suspicion, 'she has ruined my son,' but I am saying by all means 'no, it is not like that, why? I didn't even know my way around then, that I would have a thing with someone else'... That's what gave me pain, why did it happen, where did it come from? Did her son really not have it? I used to think to myself." (CL008, 45 years).

A clinical psychologist said that, because women stay in the marital home with many inlaws, they often face a situation where the in-laws gang up on them and blame them for having HIV. They support the husband in his denial of behaviors that led to HIV. One woman's voice is drowned out by others and she starts feeling guilt for something she has not done:

"In this situation, women have less of an opportunity to project. Rather the introjection is more, 'maybe somehow it is my fault, maybe it is a fruit of my sins, if only I knew before, maybe I wasn't able to control my husband, maybe I wasn't able to help my husband, maybe I was not able to fulfill my husband's needs that's why he had to go somewhere else, had to do it with someone else'. Women have guilt like this... And if she doesn't feel guilty, this blame will be induced in her. The guilt will be induced in them. I mean the more the projection is on them, that it is their fault, see that I can throw off this projection, for that I need a lot more mental strength. As such she is weak because she has an illness, then on top of that if this projection keeps coming then there is less space to push it off, rather it becomes, if everyone comes together, stand there and say bad things, then if ten people repeat one lie then it starts feeling like the truth" (Clinical psychologist).

These feelings of internalized stigma as a result of verbal abuse reinforce HIV stigma and cause women to take unnecessary precautions like not sharing their food with others or keeping their children away from themselves. Even worse, they cause women to perceive that no one will help someone with HIV. A woman who was severely beaten by her husband on a regular basis felt that "no one helps an HIV in the neighborhood... everyone

has *ghenna* towards it. They won't? The disease is such..." (CL028, Age 35 years). This is a vicious circle of abuse and guilt.

# 4.1.3 HIV stigma worsens domestic violence stigma

Domestic violence also has its own stigma, with people often asking, "what did you do to provoke the violence" (Official, domestic violence NGO). "She has HIV" is a perfect answer to this question due to its association with morally devalued characteristics, particularly in settings such as India where a woman's reputation is paramount to the family's honor. When a woman has HIV and faces domestic violence, the stigma is greater "because the stigma is not just on the domestic violence front, but it's also HIV stigma added on to it" (Official, domestic violence NGO). An HIV activist who had been involved in activism for several decades shared how women living with HIV were reluctant to share their experiences of domestic violence:

"Yeah... if they have already been there, ..., been experiencing, ..., domestic violence, and, yeah, there is no safe space, ..., for them to talk. And similarly, ... if they are diagnosed with HIV also, like it's a kind of a ... double stigma, ... for women. And they don't talk about that openly. But it's very important for creating space... even among women living with HIV, they don't talk about domestic violence, you know. They only talk about HIV, that status, but often they don't talk about the domestic violence part" (HIV Activist).

Women also shared their thoughts on how HIV stigma made the stigma of domestic violence worse. They thought that, even for incidents of non-HIV-related domestic violence, people gossip, particularly the extended in-laws' family, but if HIV comes in the middle of that, "this will be even more" and therefore it is better to stay quiet rather than "tell others as the dirt will be splashed on me only" (CL004, 35 years). Gossip about HIV-related domestic violence was evidenced by women's accounts that described how in-laws would say, "she has AIDS, she has this disease, she has that disease" (CL002, 30 years), or "that woman brought it so my son is sick" (CL012, 32 years), behind their backs.

Gossip was more pervasive in rural areas because of how villages are set up and rural people's inquisitiveness, particularly about women. Women talked about how people gossip when there they hear about HIV but no one tries to help if there is violence related to it.

"We stay in the village, we have lived there since little, people have *ghenna* for [HIV] people. If this was the city one could lock the doors and there wouldn't be any problems. Who dies, who lives, no one looks to see, but there if something happens, they come, but not one extends a helping hand. Very few, very few" (CL023, 35 years).

The stigma of HIV worsened the stigma of domestic violence and caused women to withdraw socially:

"I don't talk to anyone now, before I used to talk to everyone in the rented house, now I don't talk to anyone, I don't like talking, people gossip you see and I don't like that. I know I am sick and will have to take medicines my whole life in order to live, but will people talking about me cure me of my illness? No, it won't, if they discuss, so I don't talk to anyone now" (CL002, 30 years).

The intersectional stigma of HIV and domestic violence manifested in other ways. Women felt that domestic violence "happen(s) but then it gets resolved by itself", but with HIV it becomes a problem. A woman described how she had reported domestic violence from in-laws after her diagnosis to the local administration, but did not mention HIV because she felt that the stigma would be greater and people would be unsympathetic:

"Rather than help I think they would have more *ghenna* towards me. More people would get to know than the few people who knew, I mean if some [people] call [other] people then a lot of people would get to know, then from a lot of people a lot of other people would know, if I called them then it would become a big deal.

That's why I didn't say these things. I just told them about the trouble but I didn't tell them very much more" (CL019, 25 years).

This evidence demonstrates how the intersection of HIV and domestic violence stigma manifests as worsened abuse, gossip, reduced help seeking and social withdrawal. The quality of women's lives is impacted by this intersectional stigma, which becomes worse when combined with other marginalized identities.

# 4.2 Intersections of multiple stigmas worsen domestic violence

The last section described how the stigmas of HIV and domestic violence intersect to amplify the stigma experienced by women in general. In this section, I discuss how the stigma of HIV interacts with other marginalized identities, which are often also stigmatized, such that it worsens the domestic violence experienced by women. Over 80% of women interviewed were from the general Indian population and were either currently married or had been before. Even within this group, women had different identities that contributed to their marginalization and therefore how they experienced HIV stigma and domestic violence. Some of the additional stigmatized identities were not always obvious when I started conducting the interviews, but came out in the course of conversation and gained prominence as I progressed through subsequent interviews.

4.2.1 "He is a man after all. Can a man's character be blemished?"- the intersection of HIV stigma and gender discrimination

The interviews centered on the lived experiences of stigma for women living with HIV, and both women living with HIV and key informants were specifically asked whether they thought women's experiences of HIV stigma were different from men's. It was evident from most responses that HIV stigma was gendered, with women experiencing more violence from marital families than men as a result of HIV stigma. A counselor from a women's shelter said, "Even if he has HIV there is no problem, he is a man after all. Can a man's character be blemished?" Several participants talked about how when a woman

has HIV she is asked how she got it or is labeled as promiscuous or a sex worker, but this does not happen for men.

"When women have [HIV] it is worse, they say the woman is bad. They will say this to women, they will not say this to men, if a man has a thousand faults it will be covered up, but a single fault in a woman is a big deal. It's not just for this [HIV], for everything, a little thing becomes a big issue for women" (CL012, 32 years).

Women who tested positive first were blamed for bringing the virus into the relationship, and most were diagnosed only after their husbands became very sick or died soon after diagnosis. Yet women were the ones who were blamed by their in-laws for bringing the virus and passing it on to their husbands. A young woman described how trouble erupted for the first time in her marital home only after she tested positive, even though she was asymptomatic and her husband had tested positive first. The violence only stopped after counselors at the HIV NGO convinced the in-laws that the son was the one who had HIV first and the couple left the man's house and went to live with the woman's natal family. In this case the husband was supportive of his wife, but in most other cases there was an increase in both partner and family violence against women.

"There was a lot of trouble, lot of trouble, if one person quarrels and moves away, then another comes to quarrel, then after that one moves away, another one comes to quarrel. I had to run away to my mother's house at night... there was trouble and quarrels, this and that, 'where did you get it from, tell us who you had a relationship with', this that, a lot of things" (CL019, 25 years).

It is often the expectation that a woman must keep the family together no matter what men do. When men had HIV, some in-laws accused women of being unable to satisfy their husbands' needs so that they had to seek the company of other women.

"Ah it's [stigma] for both, but always wife is accused. Because you know, because family, they expect that the wife should maintain the family and her husband. So that he should not have any perversion or deviation in his life. So always it is accused that 'you are not been able to keep your husband in the house' (Official, HIV NGO).

Although migrant workers are a high-risk group for HIV in India, their wives were blamed for having relationships with other men while the men were away, instead of the other way around. A woman whose husband worked as a goldsmith in another state reported how people would say, 'he would go away for goldsmith work and the woman would stay alone, that's why she got into trouble' (CL030, 30 years). These examples illustrate how the blame of poor moral character (symbolic stigma) fell on the wife no matter what her husband did.

Most women found this kind of emotional violence difficult to manage. For those who tried to maintain their innocence, it was difficult to convince people that they did nothing wrong and that they might have acquired the HIV from their husband or from blood products:

"But it is a matter of believing her. Now listen, will she be able to make each and every person believe her, that how she got, what happened. What proof will she carry with her? That is the thing. Before that she will be finished off mentally, socially, these two ways, mentally, socially, physically, will be finished in both ways. By the time she can turn around and stand up, most people will finish her off" (Counselor, HIV NGO).

One woman who had suffered a lot of abuse at the time of diagnosis felt that women had to endure greater stigma-related violence as they lived in the man's house and in-laws always tended to blame the daughter-in-law:

"That happens more [discrimination against women]. You know why? Because [women] stay at the in-laws' place. The son is theirs, they will never try to put the blame, 'that it is my son's fault'. I mean 100% of in-laws believe that 'my son is good, daughter-in-law is bad'. They talk about that. They never question that the daughter-in-law stays at home, son stays abroad [migrant], they can never accept that it can come from the son. They cannot accept, they will put the blame on the other person's daughter. But our fathers, I mean every daughter's fathers are afraid to put the blame on [them], that she needs to live there, but the in-laws are not afraid of that. They think my son is good, the other person's daughter is bad' (CL019, 25 years).

Gender discrimination combined with HIV stigma also affected women indirectly. If both husband and wife had HIV, a woman's traditional gender role as caregiver meant that her husband was allowed to rest and recover while she must take care of the housework as well as her sick husband:

"Men do not suffer as much because, women suffer more, *didi*... If you ask why, women have to do everything, she has to do this for her husband, that for her husband while the husband eats on time, lies down, goes to sleep, and we do not get any rest the whole day maybe. We have to keep working, then ART at night" (CL017, 35 years).

Similarly, women suffer more due to lack of nutrition because Indian women are brought up to think that "it is more important to give the food to my husband," even when they are sick and "need the same amount of nutrition" (public health official). In addition, as men are the earning members they can buy healthy food for themselves while women, who are mostly financially dependent on men, are deprived:

"Men are happily eating well, eating from outside, and what do women eat? They don't get anything, they only can eat what is cooked at home. Men are working

outside and happily eating fruits and everything, we don't get anything" (CL022, 51 years).

Women from minority religious groups, including Muslim women, talked about the kinds of stereotype people attached to women living with HIV, including acquiring HIV by having sex with men of a different religion:

"They say that woman was a used woman, that's why she has this. They say she probably didn't choose between religions, that is why she has this. The say things like this, they say a lot of things... I mean maybe she had [sex] with a Hindu man [lowered voice], they say a lot of things like that" (CL019, 25 years).

There were wider gender disparities in rural areas where women were expected to follow traditional gender roles. Women living in rural areas reported experiencing greater marginalization because of their HIV status and for being women. They lived in fear of violence from their communities. Their families were also likely to hold more stigmatizing beliefs about HIV, such as spread of infection through touch. A public health official said, "even today, rural women who are HIV+ have to face a lot more problems." Women talked about how the mindset was different in rural areas:

"Sometimes, I mean in our village people will say *chhi chhi* [expression for shameful] about this disease, where did this disease come from, she does not want to do hard work that is why she brought this disease, they will say these things in our village side" (CL031, 34 years).

However, not everyone thought that gender discrimination and HIV stigma intersected to magnify the women's suffering. Some women thought that there was no difference in how women and men were treated, in that "they say the woman had a bad nature and maybe they tell the men too, even if they didn't do anything, maybe they will say that he went

somewhere else, he did something" (CL015, 50 years), although this was less likely to happen within the family.

4.2.2 "Husband is the roof, husband is our shield"-the intersection of HIV and widowhood stigma

Another way in which gender discrimination plays out in Indian society is through the stigmatization of widows. Widows, especially if they are young, are often blamed for their husband's death, are considered a bad omen, and have traditionally been denied their basic rights including the right to their husband's property. Almost one third of the women interviewed were widows, as men were often diagnosed with end-stage AIDS and did not survive long after diagnosis. This particularly vulnerable group suffered from the intersectional stigma of widowhood and HIV. Widows suffered some of the worst violence immediately upon diagnosis, when they were battling grief, the shock of discovering they had a "bad disease", and were economically most vulnerable. There were numerous examples, both from widowed women and from key informants, of how domestic violence worsened as soon as the husband died, with in-laws immediately blaming the woman for her husband's disease and death:

"Those whose husbands die or those without husbands, they are tortured much more. People do not want to accept, I mean the family does not want to accept that their son is positive and so the woman also became positive, they will not accept since the man has died, the torture starts on the woman immediately. They do not want to accept at all, they turn around and claim that our son got infected from you" (Counselor, HIV NGO).

A woman who lost her husband to HIV soon after diagnosis and faced severe abuse from her in-laws, who accused her of being a sex worker and tried to take away the land she owned, felt that if her husband was around no one could question her morality: "The pain, if my husband was there then they would not be able to do this. These nasty things that they are saying, if today my husband was around, even if he was bedridden he would say my wife, even if I did bad work, he would say my wife didn't. And not doing it [now] I have been blamed. That was my pain. And because of the two children I can't do anything also. That I will be able to do something [suicide] I am not able to [voice choking], my mind is changing" (CL014, 36 years).

Widows are often denied their right to their husbands' property and this was evident in the interviews. The stigma of HIV was used as an additional weapon by in-laws to deny women their husband's property by framing them as either immoral or infectious, such that they could not be allowed to stay on in the marital home. Almost eighty percent of widowed women had either moved out of their marital homes or had to move into a single room within the home. A 33-year-old woman whose husband died within a month of being diagnosed described her ordeal as her in-laws threatened her with police action soon after her husband's last rites were completed, so that she would leave the house:

"When my sister called and told them your brother has HIV, she told my older brother-in-law, we have to tell his family once, they will ask how is he doing in hospital, what did the test reports say? So, at that time my sister like a fool said your son has HIV, my sister has to get her blood tested too and you have to bring in the children too. They were shocked upon hearing this, 'my goodness he has HIV we cannot believe it'. Then after my husband's last rites were performed my younger brother-in-law, in order to stop me from staying, started disturbing me, I mean so that I cannot stay, 'I need the reports, you cannot stay in this house', he thought that maybe we would fall on his shoulders [Bengali euphemism for financial burden], me and my two children would fall on his shoulders... Then my sister-in-law said, 'she has this disease, if she doesn't get tested then I will take the police to her house,' I mean to my natal home" (CL013, 33 years).

She ended up leaving with her two daughters and staying in her natal home, where she faced HIV-related abuse from her natal family. The "mental torture" from in-laws continued whenever she visited her marital home, where she was fighting for her property rights. Another woman who left her marital home as soon as her husband died, thereby relinquishing her claim on the property, felt like the abuse would be greater: "if there is an issue about property they will [create problems] for sure" (CL029, 34 years).

The remarriage of widows has also been stigmatized in India. Among those interviewed only one widow had remarried, for which she had to face violence from her ex-in-laws, especially as her second husband was from a different caste (itself stigmatized in India):

"Yes, my in-laws created some trouble that 'he is from a different caste, why did you marry him? We would have taken care of you.' They would never have taken care of us, their brother died and no one helped me with one rupee even. That I can say that they helped me with one rupee, no one even did that. What could I do?" (CL014, 36 years).

4.2.3 "You don't have boys, go, get lost"- the intersection of HIV, widowhood, and girl child stigma.

In a patriarchal society, birthing daughters is an additional source of stigma. Combined with the lack of male children, widowhood increased women's vulnerability to violence and eviction from the home. Women who had given birth to daughters often spoke about the abuse they faced from husbands and in-laws even when they did not have HIV. A woman living with HIV described how HIV stigma coupled with having a daughter led to some of the abuse she faced from her sister-in-law:

"Oh, she says, she has brought this disease, she has a daughter and now has had an operation [tubal ligation]. She only has one daughter, I have three sons, she says about that too. I mean she is always trying to bring me down. She makes allegations to my husband behind my back" (CL006, 26 years).

This abuse worsened significantly when the woman was widowed: widows who had only daughters were more likely to be evicted from their marital homes. One woman described the verbal abuse she received from her mother-in-law when she tried to go back to live in her marital home after her husband died of HIV:

I had gone back there once with the daughters, when my husband had died. I was like, 'I have HIV, your son has died, so what will I do? You let me stay with you, I will work and take care of my daughters and will give you money as well.'... So she was like, 'go prostitute them and feed them, you also prostitute yourself, and when the girls grow up then get them into it as well. Go, go, go. Females, I will not keep females, it they were boys then at least they would have a place here, you don't have boys, go, get lost.' So, what could I do. She would absolutely not keep them (CL008, 45 years).

A woman who lost her husband to HIV described how her in-laws planned to "create trouble and throw them out, will throw the two daughters out on the streets and get the land in our own hands" (CL014, 36 years). Another woman discussed how she and her daughter were made to "stay by the entrance [of the house] for six months" (CL030, Age 39 years) by her father-in-law when her husband died. She subsequently moved out of the house and built a small place for herself and her daughter.

Just as daughters are an additional reason for stigmatization and abuse, sons are often a source of protection. An older woman who faced abuse from her in-laws following the simultaneous trauma of her own diagnosis and death of her husband reported how she was protected from eviction from her marital home by her adult son. Now that the son had left with another woman, abandoning both her and the daughter-in-law, their troubles had increased:

"Husband is the roof, husband is our shield, once the husband is gone no one understands anything about the wife. When my son was there people were afraid of my son, no one could show their eyes, now my son is not there even, now they all take advantage of that. That's why we no longer talk to anyone in the family. They will quarrel about the smallest things, so we don't say anything. Before we had some strength, now after my son left us, we have lost our strength even more, we don't have the power. Didn't have my husband but had my son. Now we don't have my son, we don't have anyone. I don't have anyone by my side, I am alone" (CL022, 51 years).

4.2.4 "If we take her back our honor will be lost"-the intersection of HIV and sex work stigma.

Female sex workers are a high-risk group among whom the Indian HIV epidemic has been largely concentrated. The dual stigma of HIV and sex work can trigger violence against them. My interviews included four women who had previously engaged in sex work and one woman who had been trafficked into sex work and subsequently rescued. Most of them seemed to have so much internalized stigma about their sex work that they were extremely reluctant to speak about it. It was, therefore, virtually impossible to get answers on intersectional stigma of sex work and HIV. However, answers from key informants helped to bridge some of this gap by detailing the HIV stigma-induced violence experienced by sex workers. A consultant with a prominent sex worker NGO in Kolkata discussed how sex workers with HIV experienced significant concerns with HIV stigma as it impacted both their professional and personal relationships:

"So, I would think that internally the biggest concern they would have would be the HIV-related stigma. Because if it was disclosed, if they disclosed or it was found out that they were HIV positive, then they're going to have problems with you know their... social networks and personal relationships around... the HIV status. They

are going to have people extorting them. A lot of problems with extortion because sex workers make money and they make more money than a lot of other women. So, if they are positive and only some people know it could easily turn into a case of extortion" (Consultant, Sex Worker NGO).

Sex workers themselves agreed that stigma would be greater if others found out about their HIV status, and that there could be violence from clients if they found out. A sex worker who had a *babu* (partner) said she had not disclosed to him because "he comes once in a blue moon, he does not come regularly" (CL026, 45 years) and she felt there was no need for him to know. All of them reported, "we don't tell them [clients], [instead] we use condoms while working" (CL024, 50 years). This highlights the importance of concealability of HIV for sex workers as it protected them from further stigmatization and resulting violence. According to key informants, the intersection of HIV and sex work stigma mainly manifested in economic loss for sex workers since they would lose clients or be forced out of their jobs if other sex workers got to know:

"What happens with sex workers is that they live in adjacent rooms, so 'if the other sex worker knows I have HIV, she will use it to shoo away my clients, won't let them come to me. She is HIV+, don't go to her room, if you go then you will get it too'. So in this case, maybe it's not the woman's fault, she was infected through this work, so they got this disease from one customer or the other in most cases, so here the other woman tries to put the blame on her or put this mark on her, and in that way wants to steal her clients for herself. These things happen among them a lot of times. So for that reason she wants to conceal [her status]. So, there is this stigma within them, because this is their job and they may lose their job, and if they lose their income then other things will be a problem" (Counselor, ART center).

However, sex workers themselves were not a homogenous group. All the sex workers I interviewed were brothel-based and were already "out" in terms of their sex work status. Not all sex workers are brothel-based and commuted to red light areas for work, but

otherwise led "normal" lives. The consultant from the sex worker NGO reported that these women were likely to be very discreet about their HIV status because if it became known their sex work status would also come out, which would then result in violence from partners and in-laws. Similarly, women who had been trafficked into the sex trade, acquired HIV as a result of it, and then rescued and brought to shelter homes faced abandonment from families once their HIV status was disclosed.

"To tell the truth in the case of women, women are really neglected. Very neglected. Because these are mostly trafficked women... maybe because of that the family rejects them more. A lot of families don't want to take them back because she has been rescued in that way [from the sex trade], if we take her back our honor will be lost. If they hear HIV+ then even more honor will be lost (Counselor, Women's shelter).

This was also true of a woman who had been rescued from sex work, brought back to her natal home and had lived there until she tested positive for HIV, when her natal family abandoned her at the hospital. This highlights how HIV stigma worsened the stigma associated with sex work: HIV meant that she no longer had a home or family, and now worked and resided at the NGO where the study was conducted.

4.2.5 "Neither is she getting any sympathy from trans people nor from people with HIV"the intersection of HIV and transgender stigma

Although transgender women were part of the inclusion criteria, I was not able to recruit any as none were attending the NGO clinic. The evidence on transgender stigma was limited to key informants familiar with the stigma they faced. It was clear from the interviews that violence due to stigma was pervasive for transgender women. Unlike female sex workers whose sex work status may not be known, the transgender identity is usually not concealed and they face "a constant question mark on their lifestyles, and for that they have to face a stigma, and with that when she is infected with HIV then a

multi stigma is created" (Public health official). The intersection of HIV and transgender stigma compounds the stigma experienced by transgender women, because once they have HIV they are neither accepted by the HIV- transgender community nor by the HIV community:

"If am an individual belonging to "Other Sexuality" then I am stigmatized by society in different ways, and this is causing me to become isolated, but when I am within my peer group then when I am diagnosed with HIV, then I am stigmatized within my peer group, then where will I go now? A circle is being created within a circle, a box is being created within a box. So, in the case of transgender women, the problem is much greater, I mean trans women, when a man is trying to be trans then there is every effort made to ostracize him. And the same thing, when she is in that peer group she is being stigmatized and when she is going to the HIV+ group then she is being stigmatized for being trans, she is facing another round of stigma for being trans positive. So, her place is much more vulnerable... neither is she getting any sympathy from trans people nor from people with HIV, there the number from the general population is greater, there she is being asked to get lost for being trans" (Public health official).

Transgender women are often also involved in sex work, and if they have HIV as well they face multiple layers of stigma which make them more vulnerable to violence, both in their sex work and non-sex work relationships. When the consultant for the sex work NGO was asked to rank the different stigmas, he felt HIV stigma would rank highest and that transgender sex workers were most likely to want to conceal their HIV status:

"Your stigmatized statuses make you more vulnerable to violence is an extreme manifestation of discrimination or power dynamics ... So, you know the transgender women sex workers experience more violence and that's universal all over the world... So, they're going to experience more violence within their sex work relationships, within their non-sex work relationships, within their families, on

the street from random strangers, you know .... So, they're going to experience more violence. That exposure and experience of violence will make them more sensitive and concerned about other stigmatizing statuses. Sex work potentially, but HIV status I think in particular. So, intersection of transgender stigma, HIV stigma, sex work, stigma. Where would sex work fall on that list? I would think it would be third. Where would HIV stigma fall in that list? Well, you know probably first in terms of being wanting to manage that status and the disclosure of that" (Consultant, Sex worker NGO).

# 4.2.6 "People are afraid of the rich"-the intersection of HIV and poverty stigma.

All of the women interviewed came from lower socioeconomic strata and were likely to experience the stigma of poverty along with the stigma of HIV. They were specifically asked if poverty added to the stigma of HIV and almost all felt that poor women suffered more. An HIV activist described how, in the early days of the epidemic, upper-class women used their money to protect them from unwanted disclosure and therefore violence by going to private healthcare facilities for their treatment:

"See the upper class, money... protected them because they can afford to going to the specialized doctors where their status was not disclosed... the women of lower socioeconomic status, they didn't have any place because the private sector healthcare system started closing their doors and so they were all sent to public health systems, so there you get exposed... Their rights were violated... everywhere they went, you know, wherever they went for their treatment, their status was constantly disclosed by others" (HIV activist).

The practice continues today. The HIV physician at the NGO said that "some very high society people who don't at all want to disclose their status to anybody, they are only taking medicines privately." ART centers at government hospitals are open spaces where

all people on ART have to line up for treatment, thereby making them visible and open to possible discrimination from others.

When asked whether poverty stigma compounded the stigma of HIV, most women felt that stigma was worse for poor women. One said, "people speak more abusively to the poor. They don't, I mean, accept the poor, they are more abusive to the poor" (CL027, 28 years). Another participant thought that the rich experienced less abuse because people were generally afraid of them. The poor often need help and this opens them to further discrimination. For instance, a woman living in poverty will not be able to afford additional paid help for housework when she is sick and will have to continue to do everything on her own. If she is not able to do the work properly, she will be asked why and if she discloses her illness it will open her to further abuse and discrimination.

"Yes, it [discrimination] is more, see people talk about poor people more, no one can talk about rich people. People are afraid of them [the rich]. [People] are not scared of poor people. They think at some point [the poor] have to come to us, but the rich think they don't have to go to anyone. Because the rich do not need help." (CL019, 25 years)

A key informant felt the same way: poor people would likely need more instrumental or financial support, which meant that they would need to disclose their status to more people, which then could increase their risk of stigma and stigma-related violence:

"...Women with low income and access to less other sort of resources will ... rely on their social support networks for instrumental support more, for helping with things of daily lives and daily activity where women with higher income don't need to rely on that instrumental support as much. Yeah, and then you know, extrapolating out into disclosure issues there might be some kind of relationship there as well, because you can imagine that if you're asking for support, instrumental support ... if you have, to reach out for help, people might ask why

you need and then you have the decision, strategic decision to make... you know if you do disclose your HIV status ... you have to try to trade off the decision between getting the initial instrumental support you need with the risk of stigma and discrimination" (Consultant, sex worker NGO).

A quote from another woman illustrated how she felt the stigma of poverty intersected with that of HIV: she expressed how poor people are thought of as dirty and bringing disease:

"They have money, no one will have *ghenna* towards them. They won't? We don't have money, they will say, 'dhur who knows what she has, she can give it to us, let us stay away from her.' That's how it is" (CL014, 36 years).

However, a small proportion of women felt that there was no difference in discrimination experienced by the poor and the rich and all suffered the same stigma once they had HIV.

#### 4.3 Stigma of HIV hides domestic violence.

The stigma of domestic violence is often a cause for non-disclosure and HIV stigma only makes this worse; that is, HIV stigma hides domestic violence. Shame associated with self-stigma and fear associated with anticipated stigma of HIV mean that woman withdraw socially and are unable to talk to others about the HIV-induced violence they experience. Most women felt that they would not get help from friends and neighbors in instances of violence because of the stigma of HIV, and preferred to bear it in silence. There was a mixed response when asked about seeking help from the police: there were some who felt that they would be stigmatized further, while others were confident of help.

### 4.3.1 Women unable to share experience of violence with others

The first step to help-seeking is being able to tell others about the problem: domestic violence due to HIV. However, women talked about how they were unable to share their

experiences of violence if it was related to HIV, because of the stigma of HIV. Most were fearful of how others might react and some also felt ashamed of having HIV. HIV stigma-enforced silence on domestic violence caused women to suppress the pain within themselves:

"Want to say but it gets stuck. Lots of thoughts, what will they say or not say, if someone hears what will she do, will show *ghenna* or love" (CL023, 35 years).

Despite domestic violence being stigmatized, women felt that they were able to talk to others about regular violence from partners or in-laws, but felt compelled to exclude HIV from the conversation. For example, one woman who was being severely abused by her in-laws after her husband died would talk to her friends and neighbors about her suffering, but could not tell them about the role of HIV in it:

"Yes, I would feel like telling someone but I could not talk about this suffering, but I could not utter this, this [HIV]. I used to talk about my suffering, that I am suffering, that people are saying this and that, they are doing this and that, everyone would say 'no don't do anything, you might do something in anger, you live alone, you might do something, no need, you have two children, you look to them" (CL014, 36 years).

Another woman spoke about how she explained to neighbors about the violence at home, usually because they could overhear the shouting. She also talked to her friends, "but I tell them about the drinking but not about the disease" (CL006, 26 years). A woman who experienced worsened violence from her husband after her diagnosis, and would often leave for her natal home when unable to bear it any longer, said that she would never speak about the HIV because she felt ashamed. This inability to speak about the real cause of the violence caused women to withdraw completely.

"I had problems with him, I would have problems and leave for my natal home and stay there for months. Everyone would tell me 'why do you leave like this', I would be like 'my husband gets drunk and verbally abuses me', can I tell the neighbors that my husband has this disease, this would be buried within me" (CL027, 28 years).

It was not just HIV stigma that silenced women. Domestic violence stigma also played out in complex ways. A woman who resided in the HIV NGO did not feel she could talk to others about the violence from her husband when she visited him, because of the stigma of domestic violence. Here, all the other residents shared the stigma of HIV, so domestic violence became a matter of gossip and blame for women. She described the feeling of being "crushed from within" when experiencing violence from her husband but not being able to speak about it:

"If he causes problems then I feel like the problems are crushing me from within. Is crushing me. I sit alone quietly by that window... I stay quiet, don't tell anyone. When there are problems within, I stay quiet at times and at times I [want to] let them know that I have such problems. Then I think, what's the point in telling?" (CL007, 40 years).

### 4.3.2 HIV stigma is a barrier to help seeking from informal sources

HIV stigma was a barrier to help-seeking from friends and neighbors in matters of domestic violence for women living with HIV. There were many ways in which this barrier worked: fear of revealing status when asking for help, perceptions that no one would help a woman with HIV, and self-stigma (shame) in asking for help when she had HIV. Firstly, women were afraid to ask for help due to fears of making their status public and thought it was better to bear the violence quietly:

"Yes, because of that fear [of revealing HIV status] I don't want to tell [anyone], that what will they think. The ones that want to help will help and those that don't want to will not help. They will say a few words, what else will they do. I will have to listen to those taunts... people will say why does she have it, how did it happen, that's why I don't tell anyone" (CL006, 26 years).

Secondly, women believed that no one would help them in matters of domestic violence because "she has HIV, the neighbors know, the fault will lie with the woman, it will be the woman's fault. And everyone has *ghenna* towards this disease" (CL013, 33 years). One woman with HIV even said that "they [women with HIV] are not supposed to get [help]... if the family members cannot accept this disease then the neighbors won't have a problem at all, they will not accept it even more. Because they are neighbors. They will definitely not accept" (CL005, 38 years). Thirdly, women assumed they could not ask for help because of their own shame (self-stigma) for having HIV:

"How will I ask from them? [laughs] How will I be able to tell them? I will be ashamed to even try to say anything" (CL012, 32 years).

The domestic violence stigma experienced by women living with HIV was not all about perception. Women who had sought help after incidents of domestic violence described how neighbors refused to help them because their HIV status was known. One woman who experienced HIV-related physical violence from her husband until he died said, "if there were beatings and all, they would close the door, the people there wouldn't come out" (CL008, 45 years). Another woman who had been continually abused by her husband and in-laws since her diagnosis reported that no one helped her as they thought it was "all her fault," and she had learned to accept this behavior:

"No, they won't say anything, to them husband is good, husband is good according to everyone. To everyone husband is good. So, I'm like let it be then... It is all my fault (CL002, 30 years).

A counselor from an HIV NGO who had seen many cases of domestic violence against women due to HIV stigma talked about how she had almost never seen a woman with HIV be helped by neighbors in cases of HIV-related family violence:

"Yes, she can say that, but how many people will come to save her is the question. Obviously, she will want to be saved, but how many people will come to her aid. I doubt if I can count the number on my fingers. I doubt anyone will come to her aid if they know she is positive. In that case does anyone come to help? I don't think anyone has ever come to help" (Counselor, HIV NGO).

However, some women and key informants thought of the problem differently. The real reason for people not helping a woman, they felt, was that they had some sort of anger towards her and this was their opportunity to take it out on her. If the woman was liked by the community in general she would definitely get help even if she had HIV. Some women were also of the opinion that, despite their biases, people were inherently good and there would be at least some who would help a woman with HIV during episodes of violence.

"See all people do not have the qualities, if [people] see some qualities in the woman, this woman's behavior and traditions, she is good in all ways, she will definitely get support. And if at that moment they find some other negative traits, like she was like this, she did that, she talks badly, she tells people off, then in that moment that anger will work against her. I mean at that moment they will get the chance to take that anger out on her. If they find something negative in her. In that moment, they will not give her support" (CL004, 35 years).

### 4.3.3 Women perceive reduced support from formal sources.

Despite half the women in the study experiencing violence after an HIV diagnosis, reporting to the police was rare. Only one reported violence from ex-in-laws to the police

after her remarriage, but it was done with the help of her second husband. Two women had reported extreme violence from partners and in-laws to the police, but this was before their diagnosis. Reporting domestic violence to the police is considered an extreme step in India as it is considered a family matter; the preservation of marriage is important and reporting compromises the family's honor. A woman who bears violence quietly is appreciated, while a woman who walks out is condemned by society. Therefore, women were mainly of the opinion that domestic violence should not be reported to the police if it could be avoided.

"Some people think that why should I go to the police. I still have to remain as a family; if anyone is belittled it will be my husband, and if my husband is belittled then I will be belittled. Now if I go, if I don't want to I will not live with you, so then I can go to the police, but if I want to live with you. I want us to be together, then going to the police is like spitting on your own self." (CL004, 35 years).

Another problem with reporting to the police is that such a step can draw a crowd, particularly in rural areas. If a woman calls the police for a domestic violence incident, the whole village will gather around her house and her status will be made public and can spur community violence. This was another reason for women living with HIV to be hesitant about reporting domestic violence to the police:

"Maybe they [police] will go and tell them [family] but then she will have to return to the same place, isn't it? Maybe the police will go for 5 or 10 minutes or half an hour and tell them but the woman will never have happiness since now it has been made public. After going back home she will not have happiness. She will not have happiness from the village folk, from the family. Now that it [HIV status] has been made public everyone will tell her to get lost, will have *ghenna* towards her. Every single person" (CL010, 45 years).

There were also women who were of the opinion that structural discrimination within the law enforcement system meant that people living with HIV would not get help from the police. A sex worker who had reported violence to the police and received help from them felt that "once they know [about HIV] will they [help]? They won't" (CL024, 50 years). Two women who had reported domestic violence to the police before their HIV diagnosis felt they would not have been able to do so had they known their status. One of them, who was now separated from her husband and lived with her grown children, suspected that, rather than helping, the police would have blamed her if they knew she had HIV when she went to register her domestic violence report:

"I think they would have blamed me. 'That the woman is a bitch her husband is good. This woman goes out of the house, works, brings sawdust, sells wood to eat, she must have messed around with a man.' That is what they would say. That is what I think. But I have never gone down the wrong path" (CL011, 60 years).

Key informants also agreed with women's hesitation to report HIV-related domestic violence to the police for fear of additional stigmatization. A public health official pointed out, "whether the person is HIV+ or HIV-, how easy is it for women to report a domestic violence case," but this become more difficult for a woman with HIV as "women are not confident to tell police that I am HIV infected person" (Official, HIV NGO). In fact, a counselor at a shelter for women who had worked closely with the police for several years reported witnessing an instant change in the police's attitude as soon as they heard a woman had HIV.

"Even if she goes to the police, when the police will get to know, they will do an inspection at her home, when they will get to know from her husband that she has HIV/AIDS, the husband will say she has sexual relations with many men and has HIV/AIDS, police will turn completely against them. Their view changes completely... This is how the police tells them, 'you will sleep around with all these

men and if anyone is not to your liking then you will file a case against him' (Counselor, women's shelter).

However, an HIV activist thought that this sort of behavior could be treated on a case-by-case basis and that it really depended on the policeman on duty on the day. If a policeman happened to be knowledgeable, the woman would be treated well. It was, however, important to be aware that once a woman's status entered the public space it could induce further violence against her from the police themselves:

"I cannot really generalize, I would think that mostly if the police force... if they are aware of these you know, then probably they'll be very sympathetic... so they wouldn't really take HIV status as an additional [factor] ... But that's not the case unfortunately [laughs] you know because if they are not being educated then the moral angle will take over and [they will] say... "this woman deserves domestic violence because she is already HIV+," you know because they will start questioning her morality, that is a possibility, I wouldn't deny that... that's why the police force and the [law] enforcement... they need to be really aware of how it triggers violence, further violence you know, in the hands of the enforcement... once it goes to that public space and then the police start using that ... status as a reason to stigmatize, further stigmatize and discriminate the women" (HIV activist).

There were others who felt that HIV status would make no difference to how women were treated by the police if they tried to report violence. A public health official felt it was more the woman's self-stigma which made her sensitive to the behavior she experienced than actual enacted stigma from the police:

"...per se that a person does not verbally express anything, but body language is also a language, so these people, I will not say just for trans people, it is for trans woman for sure, but also for HIV+ woman, the matter is about self-stigma, they cannot get over this self-stigma. Because I cannot get rid of the self-stigma, I am

not able to be empowered, so when I go there and see the man's body language, and we are very sensitive, for that reason the man's body language, maybe he doesn't say anything to me verbally, but from the body language I can say that he is not giving me any importance, and because of that lack of importance I am not going to go report" (Public health official).

Similarly, several participants felt that the police would treat women regardless of their HIV status as they "protect women, rescue them. It is their job, their duty" (CL031, 34 years). Often women did not report because they did not want to break up their marriage. They knew they had nowhere else to go because the natal family would not be supportive and they were economically disempowered to take action. HIV stigma could also work to protect abusive men who had HIV. A key informant from a domestic violence NGO reported how police refused to arrest a man because he had HIV because they didn't "want to be anywhere near a positive person." The other problem was that "there is also this understanding if you're, you know, if you're sick, how can you be abusive" (official, domestic violence NGO). This key informant went on further to say that courts refused to hold cancer patients accountable for wife-beating. Although there were no similar examples for HIV, one might assume that men with HIV could avoid criminal prosecution for similar reasons.

### 4.4 Temporal domestic violence is triggered by HIV stigma

For a number of women, domestic violence triggered by HIV was temporal in nature, with violence being at its worst during the initial period after diagnosis and slowly diminishing over time. This could happen either because enacted stigma (violence from perpetrators) reduced over time or because internalized stigma reduced over time (which enabled women to resist the violence). The different time points and severity of violence at each stage of the HIV trajectory are illustrated in Table 15. Although the complexity and nuances of each individual experience cannot be captured in such a table, it provides a representative picture of the temporal nature of violence experienced by most women.

Table 15 Table showing severity and time point of violence at each stage of HIV trajectory

Participa							
nt number	Participant background	Intensity of domestic violence at each stage of HIV trajectory					
number	ranicipant background	Disclosure /initial period after	Husband's (partner's) illness/death	Own illness (if	Clinic	Taking	Everyday life after initial period of diagnosis (if
		diagnosis	applicable)	applicable)	visits	medications	applicable)
CL001	Abandoned upon diagnosis		,				
CL002	Married (serodiscordant)						
CL003	Sex worker (no partner)						
CL004	Widow/Left home						
CL005	Married/Left home						
CL006	Married						
CL007	Separated/Left home						
CL008	Widow/Left home						
CL009	Widow/Left home						
CL010	Married						
CL011	Separated before diagnosis						
CL012	Married/Left home						
CL013	Widow/Left home						
CL014	Remarried						
CL015	Separated before diagnosis						
CL016	Married (recent diagnosis/partner unaware)						
CL017	Widow						
CL018	Married						
CL019	Married/Left home						
CL020	Married						
CL021	Married						
CL022	Widow						
CL023	Married (recent diagnosis)						
CL024	Sex worker (no partner)						
CL025	Sex worker (no partner)						
CL026	Sex worker (partner unaware)						
CL027	Married						
CL028	Married						
CL029	Widow/Left home						
CL030	Widow/Left home						
CL031	Abandoned upon diagnosis Severe (abandonment, isolation, publ						

Severe (abandonment, isolation, publicizing status, severe verbal and emotional abuse, physical or sexual abuse, severe neglect, stopping clinic visits or medication)

Medium (regular verbal abuse, some physical abuse, neglect, gossip)

Low (infrequent verbal/physical abuse, stigmatizing behaviours from families)

Little or no violence

Not applicable

# 4.4.1 Reduction in enacted stigma over time

Women reported that violence was usually at its highest during the initial period after diagnosis and reduced over the years. One key informant described this process as the stages of grief, as initially there was anger and denial as the family came to terms with the diagnosis:

"So a woman is HIV positive, my take is oftentimes the husbands will become aware of it because they'll need to be tested. So, and if there's children, the family, they all need to be tested, and so you at least have that level... and then you could imagine there would be domestic violence potentially about the process, through the process of the family in different members of the family coming to terms with the status. Potential you know like if you think about the process of grief, so violence amidst the anger, and denial and anger phases of that process" (Consultant, sex worker NGO).

Multiple factors often influenced the reduction in violence. While leaving the marital home was the biggest single factor behind reduction in violence, it was often accompanied by other factors that worked together for an overall reduction in violence from perpetrators.

One reason for the reduction in violence was that families thought that women had been cured, which reduced the stigma they felt towards them. Women who had moved out of their marital homes often did not experience violence when they went back to visit because "everyone knows that [I have] stopped taking medicines, I have been cured and I have stopped taking medicines" (CL007, 40 years). A woman who had also moved out of her marital home with her husband saw a reduction in violence due to a combination of factors: moving out of the marital home, counseling support from the NGOs convincing the in-laws that the son was the one to get HIV first, and thinking the woman had been cured:

"The trouble lasted for about 3 or 4 months, then when they got to know for sure that I got it from my husband then there was no longer any trouble. Since then we are on our own... so my father took us with him, then there was no more trouble" (CL019, 25 years).

Another reason for reduction of violence was seeing a woman in good health. An official from an HIV NGO, who had been working with people living with HIV over the past 15 years, said that in "about 70% of cases we saw the improvement [in stigmatizing behaviors]" as women started leading healthy lives. When women are first diagnosed, their families think they are contagious and that they will become a burden on them due to treatment costs and their inability to do housework. When they start to see women as productive, healthy individuals who will not spread disease, the violence reduces due to a reduction in HIV stigma.

"No, no they don't say anything. At the beginning, they used to say things, but now I am healthy, I can walk around. I can walk around, I mean they are amazed. At times, they wonder 'wow how is she so healthy?" (CL013, 33 years).

For one woman, the reduction in violence may have been primarily due to moving out of the marital home, but other factors including filing a domestic violence complaint with the police before diagnosis and her husband having a more fatalistic attitude since their diagnosis also influenced this outcome. In this case the stigma towards HIV may have persisted within the family, but they were unable to project it onto the woman.

"I have my own home, before we used to live in the same house. Now, my mother gave something, took out a loan together, I have made a house next door. I don't live with them... I have built a new house. I live in that house. I don't even enter this [in-law's] house, and there are no quarrels" (CL012, 32 years).

Similarly, support from children and neighbors helped in reducing the violence against women. A widow who had faced a lot of abuse after her husband died soon after her diagnosis slowly saw a reduction in the violence with the support of her son and neighbors:

"...the Bengali wives who live next door said, 'why are you telling her, it was your son's fault, she got this disease from your son. Did she ever go for trips outside? Then how would she get it?' [In-laws would say] 'Who knows where she got it? She is blaming my son', so they said. 'No, don't say all this', the neighbors and all said this, the Bengalis who live around us, they said, 'no you will not say this, she has no fault'. By repeatedly saying this, things have got a bit better. Now no one says anything, I work, I eat, I stay to myself. There are no problems anymore (CL022, 51 years).

A non-stigma-related reason for reduction in violence from perpetrators was the reduction of physical strength of the partner due to illness as men often became symptomatic before women:

"It was a little less than before, he used to beat me a little. My strength was more and his strength had decreased. Understand? I mean I had just been diagnosed then. I was stronger, he was not able to put up with me" (CL008, 45 years)

## 4.4.2 Reduction in internalized stigma over time

Other than a reduction in violence from perpetrators over time, women also learned to resist the violence as their own internalized stigma of HIV lessened. They initially reported being very concerned about what people might say or feeling ashamed for having HIV, but these feelings eased over time.

"I thought so but I am not afraid anymore. I don't pay attention to anyone anymore. If they have to know let them know. I mean I used to be afraid before" (CL004, 35 years).

Women generally did not report guilt about their HIV diagnosis. The guilt that had been induced by perpetrators had started to wear off over time, particularly once they left the site of abuse—the marital home—and counselors repeatedly asserted that their HIV was not their fault. Sex workers were aware that they acquired HIV through their work, but they too challenged their internalized stigma by voicing their reason for entering sex work, which was mainly due to husbands not providing for them and their children:

"Why am I here, I have come down this path that's why I caught this disease. Now if today he gave a thick saree and a bit of good food to eat, thick saree and a little coarse rice, would I be staying abroad? He gave me a child and left me. Who will raise the child? The mother has to do it isn't it? So, what will that mother do? She will steal, will mug, will beg on the street, that's how she will raise the child... Why does a mother become bad? Because of her child" (CL003, 60 years).

Women learned to ignore the abuse as it did not affect them as much over time and it also led to a reduction in verbal abuse from perpetrators:

"It goes in through this ear and goes out this ear [laughs]. What else to say. If I talk back then the whole thing will escalate. What is the point in that. So, I don't want to talk back" (CL006, 26 years).

Some women chose to actively resist abuse from in-laws and others by blaming them for their condition:

"Yes, if my mother says something, then I tell her directly, 'it is because of you all that my life has been ruined. If I had wanted I could have remarried, it is because of this disease that I cannot remarry today" (CL029, 34 years).

Women who had worked to establish a new life after their diagnosis also became stronger in resisting violence. Some felt so empowered after working and living on their own that they said, "I don't know if anyone will show *ghenna*, but even if they do who cares" (CL015, 50 years). Moving away from the marital home, the site of stigma, allowed women to escape from constant blame and reframe their status in a more positive way. A clinical psychologist said that women who felt supported were better able to resist violence from in-laws. A woman who fought off the abuse meted out to her by her in-laws after her husband's death talked about how she learned to resist the violence over time by focusing on rebuilding her life:

"Initially I was very much worried, then I let go of the worries, I will work and eat, will eat what I can afford, work for a living, will keep my health well by taking medicines, I will listen to the doctor, all of that was in my mind, then I was doing well" (CL030, 39 years).

#### 4.5 Discussion

It is well established that HIV increases the risk of domestic violence against women, but few studies have linked this violence specifically to HIV stigma (Abuogi et al., 2019; Colombini et al., 2016; Derose et al., 2017; Fiorentino et al., 2019; Hatcher et al., 2016; Jiwatram-Negron et al., 2018; Ramlagan et al., 2019). My findings suggest that, for most women, domestic violence not only increases after an HIV diagnosis, but that perpetrators use abuse to reinforce HIV stigma and that HIV stigma worsens domestic violence stigma. This abuse is worse for women with other marginalized identities. I conceptualize the intersectional stigma of HIV and domestic violence as an amplification cascade (Figure 9) in which multiple stigmas intersect to amplify stigma, which manifests as abuse in

general. My model provides scope for recognizing that women are not a homogenous group and that other marginalized identities intersect with HIV stigma to shape each individual's overall experience of HIV stigma-related violence.

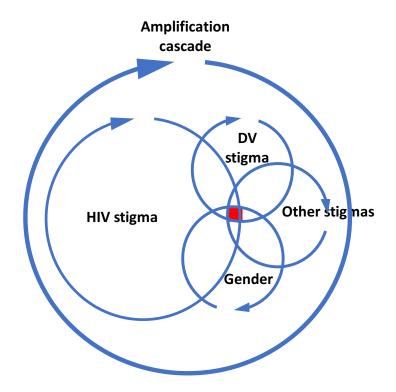


Figure 9 Conceptual framework of stigma amplification cascade

The recognition of multiple intersecting identities draws on intersectionality theory (Crenshaw, 1989), which has been brought into the stigma literature to develop understandings of intersectional stigma; that is, the intersection of multiple marginalized or stigmatized identities shapes a person's overall experience of stigma and goes on to impact their health and quality of life (Logie et al., 2011; Stangl et al., 2019; Turan et al., 2019). Although relatively new in its application to the field of HIV stigma, this theoretical framework has been used to study how HIV stigma intersects with other marginalized identities such as gender, race, sexual orientation, sex work, poverty, incarceration, and weight (Azhar & Gunn, 2021; Doyal, 2009; Earnshaw et al., 2015; Goodin et al., 2018; Logie et al., 2011; Monteiro et al., 2013; Rai et al., 2020; Rice et al., 2018). Some of these

identities—gender, poverty, sex work, and transgender stigma—were also uncovered in my study, but identities such as widowhood and remarriage and having daughters also emerged as prominent stigmatized identities, highlighting the importance of situating theories of intersectional stigma in particular social contexts. Although stigma related to caste and religion were mentioned, they were not prominent. Identities that have salience in some settings may not be the same in others (Turan et al., 2019). In India, racism cannot be viewed as a stigmatized identity in the same way as it can be in the United States, while caste is a unique stigmatized identity in the Indian context. Intersectional stigma experiences of inter-caste or inter-faith couples with HIV is a promising area for future research in this setting.

While women's experiences of HIV stigma-related violence may be viewed as a result of the confluence of various stigmatized identities, my findings point to the potential role of gender as an underlying identity with which every other identity intersects. Almost one third of women interviewees were widows. In India, the majority of women living with HIV from the general population are married (Gangakhedkar et al., 1997) and men are often diagnosed with later-stage AIDS and die soon after diagnosis. Gender norms that position women within the private sphere and as reliant on men for participation in public life contribute to the stigmatization of widowhood in India, with social restrictions being imposed and widows denied adequate nutrition and the right to their husbands' property (Chen, 1997; Mohindra et al., 2012). This discrimination was amplified when the stigma of HIV intersected with that of widowhood because of the ways in which gender norms blame women more than men for contracting a sexually transmitted disease. Gender norms that maintain men as more important and valued are used to stigmatize women who give birth to girl children. The stigma of HIV, widowhood, and having girl children combines to worsen violence experienced by women, and may be understood as manifesting gender norms that view women as inferior to men and subordinate women's position by exploiting their additional vulnerabilities.

While other studies have also highlighted the intersections of poverty and HIV stigma, none have related them specifically to HIV-related domestic violence (Rai et al., 2020; Rice et al., 2018). All the women who contributed to my study were of lower socioeconomic position and felt that their experiences of stigma were amplified by being poor and ultimately led to them experiencing more violence. Applying an intersectional stigma framework allowed me to see how these identities interacted in complex ways to shape women's overall experiences of violence in "interlocking structures of oppression" (Bowleg, 2008). The interaction of stigma from multiple identities is complex and unpredictable, but our findings largely point to a synergy of multiple stigmas. Applying an intersectional stigma lens to the overall stigma experiences of women has allowed me to view patterns of interlocking oppression that would not have been evident otherwise. Identifying additional vulnerabilities that result in increased violence against women living with HIV also underscores the need for additional stigma reduction interventions and services for them. Multiple identities can, in fact, be used to overcome stigma as people often have positive identities, such as having a job or being a skilled cook, that they can focus on to avoid the negative identities associated with stigma (Shih, 2004). Multilevel approaches that enhance community mobilization and advance social justice may be an additional resource to improve women's resilience to stigma-related violence (Logie et al., 2021).

The intersection of multiple stigmas not only worsens domestic violence against women living with HIV, but the presence of HIV stigma hides this violence. Women surviving domestic violence due to HIV stigma were not able share their experiences with friends or neighbors and were reluctant to report to formal sources. Unlike studies from other settings, which found that internalised stigma or the fear of not finding a new partner trapped women in abusive relationships (Derose et al., 2017; Logie et al., 2011; Marais et al., 2019; Moreno, 2007), Indian women found it hard to leave abusive relationships because of the social stigma of divorce magnified by HIV stigma. Stigma reduction interventions at both the interpersonal and the structural level would be needed to

improve women's ability to seek help for HIV-related domestic violence, so that they are not exposed to further violence at the hands of the police or the community.

Lastly, domestic violence as a result of HIV stigma was seen to be temporal in nature, with violence slowly reducing over time for some women. This validated my findings that the violence was not happening due to existing gender norms, but rather due to HIV stigma, and that a reduction in stigma over time led to a reduction in violence over time. Reduction in stigma was attributed to two reasons: a reduction of enacted stigma from perpetrators and a reduction in internalized stigma among women which allowed them to resist the violence. Women feel the most internalized stigma in the initial period after diagnosis, and this stigma reduces over time as they get more information about HIV, interact with others with HIV, and learn to cope with it better (Kumar et al., 2015; Rael et al., 2017; Steward et al., 2011). My findings add to these understandings of reductions in internalized stigma over time by showing that as women understood more about their diagnosis they did not feel guilt. Individuals who perceive that stigma has been forced onto them unjustly often react to it with anger rather than guilt, and are more likely to take action to remove the stigma (Shih et al 2004). This is probably why little guilt was observed in this group of women, because they were confident that they acquired HIV from their husbands. This confidence increased as time passed and was particularly seen among women who had moved out of their homes and rebuilt their lives with support from NGOs or their natal families in the years since their diagnosis. However, several women also reported a decrease in enacted stigma over time as families understood that HIV was not contagious or thought women had been cured when they saw them leading healthy, productive lives. These findings add to previous understandings of stigma, which have generally conceptualized it as invariant in its impact on lives and health. The identification of this temporal trend has important implications for practice and policy. Firstly, it means that it would be most useful to target violence reduction interventions with HIV stigma reduction components during the initial period after diagnosis. Secondly, this is also the time when women should be given maximum support, including a place to stay

and job training so that they can re-establish themselves, often in a new way of life, after the trauma of HIV diagnosis.

The findings presented in this chapter have some limitations, including the tendency by women to normalize experiences of violence. Some women were hesitant to admit that they had been stigmatized and the experiences only came out as the interviews progressed. The Covid-19 pandemic meant wearing masks and minimizing exposure times, which made it difficult to establish rapport with participants despite the subject of the research being sensitive. This may have had some impact on the information provided, although efforts were made to minimize this limitation by having a general conversation with each participant before the start of the actual interviews so that they felt more relaxed. Finally, it was not always easy to capture the experiences of multiple stigmatized identities. Although intersectionality as a theory is an important framework with which to examine people's experiences, there has been much debate about how to measure the impact of multiple marginalized identities in a truly intersectional way (Bowleg, 2008; Caiola et al., 2014; Hancock, 2007; McCall, 2005). There is no real consensus to date on the best method of measurement, be it qualitative, quantitative, or mixed methods (Bowleg, 2008; Goodin et al., 2018; Turan et al., 2019). I have used semistructured interviews followed by thematic analysis, as have others in their qualitative research on intersectional stigma experienced by women living with HIV (Azhar & Gunn, 2021; Logie et al., 2011; Rai et al., 2020; Rice et al., 2018). Women were asked openended questions about their multiple stigmatized statuses, but they did not always understand the question and probing questions had to be added. This may have led them to think of their identities additively rather than synergistically: a common problem with qualitative intersectionality research. As Bowleg mentions, it is virtually impossible to avoid asking additive questions, in both qualitative and quantitative intersectionality research, and even if the questions are not additive, participants often perceive their different identities additively (Bowleg, 2008). Considering that the methodological tools to conduct intersectionality research are "severely limited", the most important tool available to intersectional researchers is the interpretation of data; that is, it becomes the

researcher's job to make the connections between multiple marginalized identities and interpret the findings as a whole (Bowleg, 2008). This is what I have attempted to do: even though the intersections of HIV stigma and other stigmas have been presented in distinct categories, the findings should be interpreted as occurring together when the results are considered as a whole.

The strengths of the study included a diverse sample of women with multiple marginalized identities. Although it was conducted with an NGO in the city, women visited from remote rural areas and I believe that I captured the perspectives of both rural and urban women. Key informant interviews with a diverse group of service providers were a valuable addition. It was not possible for me to ask participants about every marginalized identity (Bowleg, 2008), but several identities emerged over the course of the interviews and added richness to the data. Finally, the study is the first to my knowledge to examine how multiple stigmas intersect to shape domestic violence experienced by women living with HIV.

### 4.6 Conclusions

The application of an intersectional lens to women's experiences of stigma-related domestic violence highlights how multiple marginalized identities shape the life experiences of women living with HIV. The findings presented in this chapter help shape new understandings of intersectional stigma and how it relates to domestic violence: intersectional stigma worsens domestic violence, it differs by social context, and the violence as a result of this stigma is often temporal in nature. These findings point to several novel targets for domestic violence reduction strategies: (1) any domestic violence reduction intervention for women living with HIV must be accompanied by HIV stigma reduction interventions, (2) women's additional marginalized identities such as widowhood and having girl children must be prioritized for such interventions, and (3) in order for such interventions to be most effective, they should be delivered in the initial period after diagnosis and supplemented with empowerment programs for women.

The findings from this chapter indicate that women living with HIV with multiple marginalized identities often suffer worsened domestic violence for which they are unable to seek or get help. Such experiences worsen their quality of life and could negatively affect their mental and physical health. The next chapter presents my findings on lived experience of mental health and how it leads to poor physical health because of experiences of intersectional stigma and violence.

# Chapter 5: Lived experiences of mental health due to intersectional stigma

My second research question examines the lived experiences and perceptions of women's mental health in light of experiences of intersectional stigma and resultant violence. In the previous chapter, I have shown that HIV stigma often intersects with the stigma of other marginalized identities to worsen the violence experienced by women living with HIV. In this chapter I present my findings on the implications this has for women's mental health. HIV stigma and intimate partner violence, separately, are known to negatively affect women's mental health. I start this chapter with an overview of this literature, and then present my findings. As a chapter on lived experience of mental health, it lends itself well to phenomenological enquiry, which has been described in detail in the methodology chapter (Chapter 3). The mental health experiences of women living with HIV may be seen as an accumulation of multiple negative experiences with a number of different people that shape their overall experience. The analysis in this chapter adds to the literature on the mental health consequences of intersectional stigma by providing an understanding of the lived experience of mental health due to experiences of stigma at the interface of HIV, domestic violence or other marginalized identities, and related violence.

## 5.1 Lived experiences of mental health as a result of HIV stigma in India

Current narratives of mental health as a result of experiences of HIV stigma and discrimination center on common mental health disorders such as anxiety, depression, and others (Rueda et al., 2016). This is also true for the HIV-related mental health literature from India, which focusses on such diagnostic categories (Charles et al., 2012; Das & Leibowitz, 2011; Steward et al., 2013; Steward et al., 2008). However, we know that stress presents differently in different cultural and social contexts, which do not necessarily fit with current established diagnostic categories of mental illness (Desai & Chaturvedi, 2017). People may present with body ache or general weakness which are interpreted by healthcare providers as "vague" and not related to mental distress, when in reality such symptoms are a different mode of expressing distress (Desai & Chaturvedi,

2017). Such "idioms of distress" are considered alternative modes of expression where circumstances do not allow for any other form of expression of distress (Nichter, 1981, 2010). As people's expressions of mental distress cannot always be captured in terms of clinical diagnostic categories, it is important to listen to them in their own language—their lived experiences—in order to understand and best support them. However, hardly any studies from India report on the lived experiences of mental health of women as a result of HIV stigma (Dhaor, 2021; Krishna et al., 2005; Subramoney, 2015). These studies have highlighted a range of feelings from anger to hopelessness, thoughts of death, and guilt and fear as a result of HIV stigma. These descriptions of mental health experiences help us understand what women actually feel, and the support that they need after experiencing HIV-related stigma and discrimination.

# 5.2 Experiences of domestic violence and its impact on mental health among Indian women

Lived experiences of mental health as a result of domestic violence have been described to some degree in the literature from India. Women's lived experiences of mental health and illness have been described as the presence of stressors, of which conflict with husband and mother-in-law and resulting domestic violence are prominent (Kermode et al., 2007). In other studies, women describe how experiencing domestic violence makes them feel extremely stressed, gives them sleepless nights, and makes them hope to die in order to escape the violence. As leaving your husband is considered shameful, with the social consequences of such an action perceived to be worse than the abuse, women describe feeling helpless and trapped and often attribute the abuse to past sins (Dhar, 2014). The Indian cultural context, in which women are expected to endure abuse in order to avoid bringing shame on the family (Bhandari & Hughes, 2017), can add to their distress. Although the existing studies touch on the idea of the stigma of leaving violent relationships in the Indian context, there is a dearth of studies on how the stigma of domestic violence affects women mentally.

If there is little evidence from India and elsewhere of the lived experiences of mental health as a result of either HIV or domestic violence stigma, even less is known about the mental health effect of these stigmas combined with those of other social identities. Yet an understanding of lived experience of mental health is important because (1) it helps us understand women's mental health experiences in their own language, which (2) allows us to acknowledge alternative modes of expression of distress, and (3) see how women's experiences might differ (or align) from interpretations of healthcare providers.

My semi-structured interviews with women living with HIV and key informants were analyzed using thematic network analysis. Table 16 summarizes the themes that were developed. I have attempted to show key informants' interpretation of women's mental health in contrast (or in agreement) with how women expressed them, throughout the discussion of the themes presented in the next sections.

Table 16 Examples of themes on lived experiences of mental health

Global theme	Organizing themes	Examples of basic themes
Vicious circle of stigma and violence pulls women into spiral of poor health.	Violence compounds the mental health effects of stigma, and vice versa.	Mental torture of stigma and violence.
pulle werner into opirar or poor meatur.	choole of slighter, and vice versa.	Profound sadness due to stigma and violence. Hopelessness and wanting to die. Mental disturbance of constant fear of people finding out. Intersectional stigma manifests as worries about children. Distress of intersectional stigma of HIV and poverty.
	Stress of stigma and violence on mental health contributes to poor physical health.	Poor mental health causes poor adherence to ART and non-linkage to care. Effect of chronic stress on CD4 counts. The physicality of stress. Stigma leads to poor health and vice versa.

# 5.3 Violence compounds the mental health effects of stigma, and vice versa

The intersectional stigma of HIV, domestic violence, and other marginalized identities worsens the overall violence experienced by women living with HIV. Such adverse experiences of intersectional stigma and related violence act as stressors that take a toll on their mental health. In their own words, women reported feeling emotionally distressed by the experiences of stigma and violence, profound sadness, hopelessness, and constant worry. Since non-disclosure or strategic disclosure was a common strategy women used to avoid stigmatizing experiences, including violence, fear of anticipated stigma if people found out was a real concern and caused them considerable stress.

## 5.3.1 Mental torture of stigma and violence

Interviewees reported numerous examples of enacted stigma. Stigma came mainly from in-laws and sometimes from partners, natal family, the community, and healthcare providers. Reports of community stigma were limited, possibly due to low levels of disclosure to people outside the family. Since the focus of the thesis is on domestic violence related to HIV stigma, the negative experiences discussed are all related to stigma from the family. A clinical psychologist discussed her observations, which she termed psychopathologies, including depression, anxiety, and even post-traumatic stress-like symptoms among women who had faced HIV stigma-related violence from families:

"The mental health issues that I have found among females, I mean I have found two, one is depression which is common for both cases, but for female is more. Even though it is there in both genders, it is more among females. The other one is, where they have faced violence, not everyone, I mean they have faced active, I mean prominent violence, in those cases some ... post-traumatic stress disorder-like symptoms were seen. I have seen that. Anxiety was another thing where I have seen, I mean anxiety is also common, but if I say intense, then it can be seen in those with kids" (Clinical psychologist).

A counselor at an ART center explained that violence due to HIV stigma was bound to "leave a mark on the person's physical and mental health" as any violence at home disturbs mental peace, but violence due to HIV stigma makes things worse due to the intersectional stigma of the two. In response to a question on the impact of intersectional stigma of HIV and domestic violence on women's mental health, the clinical psychologist said emphatically that it was "more, more, more!" and went on to describe how depression and other psychopathologies worsened with the addition of more stressors, in this case stigma of HIV and stigma of domestic violence:

"... Like I said at the start, when only, diagnosis itself works as a stressor, ok, but when along with the diagnosis other negative situations come through, then the intensity of the stressor increases a lot. In that case the coping is disturbed more, therefore depression or other psychopathologies that are being formed, that is a lot, a lot more" (Clinical psychologist).

Similar to these accounts, a counselor from an HIV NGO said that it was natural for women to break down mentally due to the emotional violence or "mental torture" that follows an HIV diagnosis. This sort of emotional violence takes multiple forms including verbal abuse, blame, ostracism, and isolation - all of which combine to worsen HIV stigma and cause women to "break down mentally":

"Mental torture is there, they are tortured mentally, so they obviously break down, not having anyone by their side they will obviously break down mentally. Now with this disease, different types of physical ailments also appear. Mental illness means what, if she is mentally tortured by society at all times, if she is always facing problems throughout the day, then what will she do?" (Counsellor, HIV NGO).

Women used different language to express similar narratives of distress due to intersectional stigma. They used terms such as *chinta* (worried or troubled) or *mon* 

bhenge giyeche (mentally or emotionally broken) due to HIV stigma and related violence. A woman who had recently started experiencing severe violence from her husband described how she felt mentally broken: "As it is I am sick, if he beats me on top of that, doesn't the mind become weaker?" (CL028, 35 years). A serodiscordant woman described the worsened abuse and gossip after her diagnosis, along with the belief that "to everyone husband is good... it is all my fault". Her experience of intersectional stigma made her stress unbearable:

"You know then my heart just broke. That I would live, what would I fight to live for? I used to be quite plump before, I used to work, but I didn't have to worry, but now as the days go by it's like so much worry has entered my mind. What will happen? It's like my mind is not working. The way they treat me. They even beat me. The middle brother-in-law's wife beats me, my mother-in-law beats me, everyone is used to beating me" (CL002, 30 years).

For widows, the stress of stigma-related violence was greatest in the initial period after diagnosis, as they were facing grief, knowledge of their own illness, and the abuse that came with the stigma of being a widow with HIV. They were often unable to process all of the emotions involved with the stigma of an HIV diagnosis, widowhood, and abuse:

"Now just think, there are a lot of people, I mean women who, according to our society's norms, have so much love for their husband that they cannot imagine and when they find out, at that time they are not able to believe. And when the husband dies, her beloved person is dying, then that is painful for her and HIV is another pain" (Public health official).

Some widows chose to leave the marital home after their husband's death to avoid stigma-related violence. A widow who had left her home with her children (without letting anyone know of her HIV status) talked about the stress of living in a strange place (at an

HIV NGO) and dealing with people's insults. It was the intersectional stigma of HIV and widowhood that forced her to leave home:

"Yes, there is a little mental impact. Maybe at that moment she is not able to tell anyone, she keeps it [to herself], becomes weak... worries, feels stressed, that happens. It happens to me too. At times I think that if I didn't have this disease, like when I have an argument with someone here, feel angry, then I think if I didn't have this disease, I mean this is a thought, a stressful thought, I wouldn't have come here with these strangers, what relation do I have with these people? I would never have met them ... I would not have to talk to them, would not have arguments and problems. At times, I suffer when I think about it. Then I think about it, I mean really what place is this? All of it is strange. What relation do I have with this place? If I didn't have this disease, I would not have a relationship with any of these people, I wouldn't have to listen to insults" (CL004, 35 years).

The intersectional stigma of HIV and domestic violence meant that women often felt that people would be unsympathetic towards the violence they were experiencing. This meant that women could not talk to anyone about the violence at home and kept the negative experiences within themselves. One woman who regularly experienced physical violence described her situation: "I feel everything, anger, hurt, sadness, my eyes tear up, I tolerate and stay on" (CL028, 35 years). Suffering in silence added to the mental stress of violence, stigma, and dealing with a life-threatening diagnosis. An ART counselor described how women were being "tortured" and yet "suffering in silence":

"They are accepting all of it in silence, not saying a word, this also happens in some cases, in the case of some women. Because she knows that she has nowhere else to go, that happens a lot of times in a lot of cases" (Counselor, ART center).

# 5.3.2 Profound sadness due to stigma and violence

Key informants expressed women's suffering in terms of mental health problems. An HIV nurse said that women without family support after diagnosis "have a huge amount of mental health problems." On the contrary, women did not see this sadness and suffering as mental health problems, but expressed their profound sadness using language such as *dukkho* (sadness) or *koshto* (pain) and hopelessness amidst the stigma and violence they experienced.

Sadness was worse among those with other marginalized identities such as widows, sex workers, or those experiencing greater poverty. While some described moments of hopelessness, others felt that they had lost the fight and were merely waiting out the days left for them to live. A widow who had experienced violence from her in-laws and was forced to continue working in order to feed her family, despite age and ill health, said she had no hope to go on living:

"I hope I die. That is what I hope for. When will God take me, when will I go, that is what I hope for... I don't feel like living at all. I have no wish to live... I have no hope to live for" (CL022, 51 years).

A woman who had been diagnosed when she was pregnant, only to find out later that her husband had been on ART for years, but instead was blamed, abused, and stopped her treatment, described how her husband's violence broke down all the hopes that she had. Once her husband died, the intersectional stigma of HIV and widowhood meant that she was blamed and thrown out by her husband's family. The mental health effect of this intersectional stigma caused her to question herself, which added to her distress:

"That's what gave me pain, why did it happen, where did it come from? Did her son really not have it? I used to think to myself" (CL008, 45 years).

Remarriage of widows is often stigmatized in Indian society, and having HIV makes this worse. Young widows were often taunted by in-laws: "They tell me to get married, I mean they say it as a taunt" (CL013, 33 years). In addition, the constraints that Indian society puts on widows meant that they were not able to dress up or wear certain colors, which often became a symbol of their stigmatization as widows. These intersectional stigma experiences contributed to young widows describing how sad they were:

"But because I don't have my husband, I can't dress up like married women do, so I am not able to do that. So when I see others like that it makes me sad, I used to wear *Benarasee* sarees (heavy brocade), I used to dress up, used to wear different coloured blouses [laughs] and heavy jewelry, some heavy makeup, I think about that. I think that even if husband is a drunk or whatever [you can do these if he is alive]" (CL013, 33 years).

Women who had been mentally broken by stigma and abuse were resigned to the idea of an early death, even if they were young and healthy. Many widows described how they were particularly affected by thoughts that no one would care for them once they became sick because of the intersectional stigma of HIV and widowhood:

"How much longer will I live? This is what has entered into my mind... Everyone wants to live, but if God wants to take them away, if He makes the person fall sick then it is done, there is no one who will take care." (CL030, 39 years)

Sex workers in particular described their feelings of hopelessness at not only aging, but having to leave their professions because of HIV. They felt that this made them particularly vulnerable to abuse from others in the community due to poverty. When asked about her hopes for the future, one said, "What hope will I see? I don't have any hope. All my hopes are gone." (CL026, 45 years). Another just answered, "I don't find mental strength, *didi*" (CL024, 50 years) when asked about hope and resilience.

### 5.3.3 Hopelessness and wanting to die

Although less common, some women discussed wanting to die in the initial period after diagnosis. The reasons for this ranged from fears of contracting a life-threatening illness, often termed a "big disease", to fears of anticipated stigma, to the inability to cope with actual experiences of stigma and related violence from partners and in-laws. Two women threw away their medications in the early days of diagnosis in order to end their lives. Similar thoughts were expressed by other women, although they did not take direct action to end their life. The burden of their adverse experiences of multiple stigmas and related violence was such that they did not want to go on living.

"This ART that the patient has to take, I mean regularity, the medicine that she must take to stay alive, maybe she is forgetting to take it, not taking it sometimes, expressing apathy 'that I don't need this anymore, I am having to tolerate so much torture, there is no need for me to live' something like that, she has a disgust towards herself" (Counselor, HIV NGO).

A woman who lost her husband soon after diagnosis talked about a night when she wanted to kill herself because of the HIV stigma-related abuse and the stress of living with HIV. She discussed how the stigma of HIV and domestic violence meant that she could not even talk to others about the real cause of the violence she was experiencing, which added to her stress:

"One time my condition was such that I was so disturbed that I was just not able to sleep at night. My husband had died and my aunt was living next door. She used to verbally abuse me so much [in collusion with the in-laws] ... use such abusive language, that I was just not able to fall asleep at night. I left the house at three in the morning, locking the door behind me. I had left the house. Then I thought let me do something [suicide]. Then I had this wish, let me do something, what the heck I don't feel like living anymore. The whole this and that [problems], then I

have all this disease in my body, on top of that can I stand listening to so much abuse? I don't know what came over me..." (CL014, 36 years).

An elderly widow who had been enduring abuse for a long time had "no desire to live". She said she felt this ever since her marriage to an abusive husband and in-laws; violence which worsened after her husband's death and her diagnosis. Years of abuse were worsened by the stigma of HIV and widowhood, which she said had made her lose the will to live:

"I am alive like I am, after this I have no desire to live [voice breaking]. Sometimes I feel like, let me take something and go to sleep. Let me take something and fall asleep. Then I think no, if I die what will happen to my [grand] children. Small children are there, they come running to me, I think of that" (CL022, 51 years).

# 5.3.4 Mental disturbance of constant fear of people finding out

Since non-disclosure was the most important strategy to avoid stigma, including domestic violence, women discussed how they suffered from a constant fear of people finding out their status, which they described as *chinta* (worry) and *bhoy* (fear). This affected them mentally as they could never have peace of mind and were always worried. One woman described how she could not stop worrying about "someone saying something" if they knew about her HIV, despite it being almost nine years since her diagnosis:

"Yes, the fear stays, 'what if someone says something'. Most likely no one will say anything but what if they say something to my face. That fear stays with me. What if they say to my face 'you don't come to my house' and all. That is what. I really don't think anyone will, but still I live with that fear within me. If they say, 'don't come to my house'" (CL007, 40 years).

This worry was worse for widows, especially if they had not disclosed their husband's HIV and had left the family home. One described her fear of people making assumptions about her if they got to know her status now, because she had lived away from home for almost six years. The intersectional stigma of HIV and widowhood plays out significantly here: a single woman living away from home and having HIV is bound to raise questions about her morality. It was not surprising when she described her constant internal conflict between wanting to disclose and being afraid to do so:

I am also thinking, my thinking is different, so I think that I should tell everyone. Because there is no way to raise a finger at me, that I could do this, do that, I got it through this, therefore now they may have suspicions, because they don't know from before or they don't know that my husband had it, so now that I am in Kolkata, they may misunderstand me. That maybe she went somewhere and so she got it or she had a sexual relationship with someone so she got it. Maybe these thoughts can enter their mind. There is no reason for it not to come, it is people's minds, it can come. That's why I have a bit of doubt about this part. If I had told some people before they would probably have believed me that I had this from before. But because I am here for a long time they will be curious now. Maybe she came here and did something, that's why she got it. So I do give this a little bit of importance at times but at other times I think, oh what the hell, whatever happens will happen, will see then" (CL004, 35 years).

Both these examples show that, although the violence associated with stigma is temporal (it decreases over time), the mental health effect of it is not. Women continue to suffer mentally even if they have been living with an HIV diagnosis for many years. Such fears of stigmatizing experiences, such as insults, labeling, or social isolation which women described simply as "worries" and "fear" were categorized as trauma by a clinical psychologist. She thought this "trauma" was greater among women than men:

"The other thing that is there that I have seen as trauma, that is very significant, that is the fear of social isolation. That trauma was found to be pretty intense. It can definitely be categorized as trauma, that social isolation, and they have experienced something. Both males and females, in both cases, but female are more affected" (Clinical psychologist).

# 5.3.5 Intersectional stigma manifests as worries about children

The biggest worry for mothers with HIV was getting their children married, even if the children were themselves uninfected. This was more so for those with daughters because of entrenched gender discrimination: HIV stigma combined with gender discrimination diminished the marital prospects of girls. Women often talked about their worries about unmarried daughters as a source of great mental "tension" as single women often faced multiple forms of violence. A widow who had fought against a lot of abuse from in-laws after her husband's death and her own remarriage said, "If I can get the two daughters (who do not have HIV) married off then I will have peace, I don't have any other worry" (CL014, 36 years). A young woman who had been recently diagnosed along with her husband spoke about her worries about her daughters' marital prospects if people knew both parents had HIV:

"I have two daughters, have to get them married, both parents have this disease, girls from such a house will get married? Different people will say different things. Understand?" (CL023, 35 years).

Apart from marriage, women also described their worries about how children would be treated within the community if people came to know they or their parents had HIV. Several participants worried about this problem and refrained from disclosing their children's status in schools. Women talked about feeling stressed and worried about possible stigma and violence from the community towards their children:

"Yes! Isn't that a matter of stress, what if something happens to the sons in the future, what if no one allows them to live in the neighborhood, this is of course a matter of stress." (CL020, 32 years)

### 5.3.6 Distress of intersectional stigma of HIV and poverty

Women who had lost their husbands also lost their main source of income. Sex workers would often lose their jobs once their HIV status was known. Women therefore talked about being extremely worried about finances. Sex workers described their worry about losing their income as the greatest stress after being diagnosed with HIV. One talked about constantly being worried about money since she had stopped working after her diagnosis. She felt that, if having HIV did not translate into job loss, "The worry would probably be a little less. It happens but it would be a bit less" (CL024, 50 years). Increased poverty led to sex workers having to take up menial jobs and the resulting stigma of poverty (feelings of shame or being demeaned) and the enacted stigma of HIV (verbal abuse) from other sex workers led to some women having thoughts of dying because of experiences of these combined stigmas:

"Maybe some say the body is riddled with worms, some say there is a bad odor...
'You don't stand next to me' someone will say, 'don't stand next to me and talk',
but they need me only. They need me only, 'go get two buckets of water for me' or
'get me these things from the shop' or 'bring me some tea'... They will make you
do the work and then [say] all that. Then I feel like if only God took me away right
now then I would go right away." (CL025, 50 years).

Worry about finances was not restricted to sex workers. Widows also worried because the main breadwinner of the family was dead. The stigma of poverty, widowhood, and HIV combined to worsen violence and contributed to the mental stress on widows. A widow who was evicted from the marital home with her two daughters described her desperate worry about finances after her husband's death:

"...then I was income less, my husband's income was not there, so who will feed me? I am a young wife with two children, husband did not leave us with anything" (CL013, 33 years).

Women from the general population who worked in professions such as childcare had to stop working because the nature of the work required them to be in different places at short notice. In addition, they were sure they would be fired if employers got to know they had HIV. Here too, women described their fears of abuse because of poverty and HIV stigma, which added to their mental stress:

"I feel sad, I think what will happen to us, what if we are not able to work, this illness has happened, what if we are not able to work, then who will feed us? When the wives of the sons come will they give us then? I think of that. See now the sons are alone so they are giving us. Here they are giving us rations every month ... If the ration is increased a little bit then you know what happens, *didi*, then it becomes a bit easier for us, we don't have as much stress. Especially the sons' moods are good sometimes and sometimes not. They are not my own sons so I can't pressurize them either. I find it very difficult" (CL010, 45 years).

# 5.4 The stress of stigma and violence on mental health contributes to poor physical health.

As seen in the last section, experiences of worsened violence due to intersectional stigma leads to poor mental health of women living with HIV. What is less known is how this negative impact on mental health affects women's physical health. This happened principally through four pathways.

### 5.4.1 Poor mental health causes poor adherence to ART and non-linkage to care

Women often reported throwing away their medication in the period after diagnosis, when stigma and resulting violence against them were at a peak. Many women said that their mental state was such that they felt it was better to die than to live such a life with a lifelong disease, stigma, and violence. Not adhering to medication was their way of taking control of a seemingly uncontrollable situation:

"As soon as I heard that I was diagnosed, I thought in my mind, I have such a big disease, I will not be able to socialize with anyone, I will not be able to eat with anyone, I will not be able to go anywhere, then why should I keep this life? I will die" (CL015, 50 years).

Women also reported forgetting to take medications when there was violence at home. One described how the stress of HIV-related abuse caused her to neglect her health and medicines even though she actually had every intention to adhere and survive:

"When I would fall asleep after a whole day of fights, I would feel upset and feel down, at that time I was supposed to take it at 9:00... then it was exactly on time... I mean, sometimes he would come back from the truck early in the morning, or at midnight, or at 3:00 or 4:00 in the morning. Maybe he would cause problems and leave or cause problems and stay at home, then there were several times I had gaps in taking medicines" (CL027, 28 years).

However, many key informants perceived such actions as mental health issues, although they did understand that the issues were related to stigma and violence. An HIV nurse described how she had seen many women refusing medications during her long career because they did not want to go on living.

"Yes, they definitely have mental health issues, like a lot of times there may be violence at home, and that is manifesting in the medicines, she is not taking the medicines properly." (HIV Nurse)

Apart from poor medication adherence, HIV-related abuse caused women to drop out of care. A counselor from an HIV NGO seemed to understand how intersectional stigma of HIV and domestic violence made women feel like they were "not able to go on" and was the reason why so many were lost to follow-up:

"Maybe she is not able to work properly, her health does not permit. I mean if she is always having to bear mental torture or societal torture then that will of course impact other parts of her, the bad effects of it will appear. When health wise she is not able to go on... Maybe at times you will see she is not willing to be linked to care, there are a lot who are becoming LFU (lost to follow-up) cases, not coming for treatment, 'didi I am just not able to take this [torture]." (Counselor, HIV NGO)

Another intersection described in the previous chapter is that of sexual identity and HIV. Transgender women with HIV often face additional violence due to the combined stigma of their sexual identity and HIV. A public health official felt that such intersectional experiences often cause trans women to suffer from such poor mental health that they choose to forego treatment:

"The self-esteem is so low that they feel that going on living every day is miserable, so getting treatment means I will go on living, a person who wants to live will come within the treatment regime, someone who does not want to live will not come within the treatment regime" (Public health official).

### 5.4.2 Effect of chronic stress on CD4 counts

Chronic stress is known to have a negative effect on the immune system and for people living with HIV this is thought to directly affect CD4 counts. Although measuring CD4 counts was beyond the scope of this work, low CD4 counts due to stress were often an explanation given by some women for why they thought their illness was worse than others.

A woman who had suffered severe violence from her husband and was diagnosed with HIV much before him discussed how the stress of experiencing violence lowered her CD4 counts and was the reason she experienced symptoms much before her husband did. She felt that even now her CD4 fluctuated with her stress levels:

"Now I only have one question ... I did not do anything wrong, then how did I get such a big disease. But as soon as my husband had it I understood... his CD4 was good that's why maybe he got diagnosed later, he didn't have much mental stress, I had a lot more stress, I could not stand the blow, that's why I got diagnosed first" (CL015, 50 years).

Women were also of the opinion that stress due to stigma-related violence caused their CD4 counts to fall, which then caused them to become physically weak. They talked about how a person living with HIV who might be doing well could become sick from the stress associated with negative experiences of multiple stigma and violence:

"If people think about it [stigma and abuse] they may fall ill, if I am doing well I might fall ill. Because that thing called CD4, then from worrying, if the CD4 is high, then from worrying the CD4 falls, once the CD4 falls, slowly you become weak" (CL005, 38 years).

An HIV physician, however, attributed the impact on CD4 counts and viral load to his observation that fights between couples caused them to "throw the medicines out".

Although a clinical psychologist acknowledged the role of stress in CD4 counts, much like the women did, she also acknowledged the role of ART in improving CD4 counts. She reported seeing a patient whose CD4 count worsened when she was experiencing severe violence from in-laws' due to HIV, widowhood stigma, and girl child stigma, and subsequently improved as she started getting support from an NGO.

"Yes, stressor, yes this I have definitely seen, the typical CD4 count or T cell, that is measured, there is a lot of difference in that. Like just now the example I gave of a woman, that she was forced to stay in a small room, later when she got linked to an NGO, and according to their medical report, I mean from the repeated assessments that they have, there the CD4 count is measured continuously... So in her case we saw that it was at quite a good level, it had improved, it had gone down then gradually it had improved. Now the impact of ART is of course there, the impact of ART is undoubtedly there" (Clinical psychologist).

# 5.4.3 The physicality of stress

Women were asked how their mental health (as a result of all the negative experiences) made them feel physically. Responses included descriptions of several different physical symptoms when they felt worried, stressed, or sad. They described physical symptoms such as loss of appetite and sleep, but also included headaches and other physical symptoms. One woman described severe headaches after HIV-related verbal abuse from her husband:

"If I get stressed, for like half an hour or one hour, my head will hurt so much that I will not be able to tolerate it, but still he will not listen, sometimes he doesn't listen at all. If he drinks then he will not listen at all" (CL006, 26 years).

A woman described how she had lost so much weight due to stress and worry after her husband's death and subsequent abuse from in-laws that she weighed 30 kg (CL030, 39

years). Another described losing her appetite and sleep after episodes of verbal and physical abuse from her husband. Overall, she felt that her health was not improving due to the continued stress of HIV-related violence and having to hide it all because of stigma:

"Yes, then I feel stressed, I am not able to eat properly, I worry, that he is behaving like this with me, I could not sleep, night after night I would also worry. Because I would worry all the time, I mean the disease would always poke at me... I would explain to him but he would not understand" (CL027, 28 years).

A woman who had been forced to stop taking ART by her abusive husband in the initial years of her diagnosis still complained of health problems, including breathlessness and hallucinations as a result of the long-term nature of HIV-related stress:

"The breathing difficulty worsens, I start to gasp... My head doesn't ache so much, it just hurts a little, am not able to sleep, stay awake all night and worry. I hallucinate" (CL008, 45 years).

Another woman attributed her poor physical appearance to the stress of having HIV and all that it entails:

"No, I mean now due to excessive stress my appearance has become like this. You will see my picture [from before] I am completely different. Before I was totally different, no one could tell that I had this thing in my body" (CL020, 32 years).

The overall impact of stigma-related violence at home following an HIV diagnosis is illustrated by the following quote, which shows how the different pathways converge to worsen mental and physical health for a woman living with HIV:

"I mean if there is tension at home that has an effect. HIV patients are always told to be happy, not worry, so if that space is disrupted, then there is definitely a physical and mental health impact of that... maybe they skip meals, they don't eat properly, they don't take their medicines properly, they don't feel like it" (Counselor, ART center).

### 5.4.4 Stigma leads to poor health and vice versa

Just as stigma can lead to poor health, poor health can increase stigmatization. Women felt that good health was a means of avoiding stigmatization. A sex worker said, "Because of my mental strength no one can say that she has this disease in her body. And I keep myself in shape." (CL003, 60 years). Similarly, another woman said she took medicines and food on time to maintain her health: "No, even if I feel sad, I take my medicines on time, my food on time, eat my rice on time, do everything on time" (CL017, 35 years). On the contrary, being in poor health meant greater stigma as it reinforced stereotypes of contagion, death and debilitation associated with HIV.

### 5.5 Discussion

I hoped to provide an understanding of the lived experiences of mental health due to intersectional stigma and related violence for women living with HIV. While previous studies have shown how intersectional stigma leads to poor mental health (Logie et al., 2013), none have shown how women who experience worsened violence due to intersectional stigma experience mental health. Since mental health or mental ill health is often a balance between stressors and coping with them, I cannot say that the adverse experiences of stigma and violence definitely worsened women's mental health. Neither can I claim that any of the women interviewed suffered from mental illness as I was not in a position to label women with diagnostic categories. It was, however, clear from the interviews that women were suffering from poor mental health because of their adverse experiences related to multiple stigmas and resulting violence. Lived experience becomes a powerful tool for presenting women's mental health, as this perspective allows us to present their collective experiences due to marginalization and loss of status, breakdown of relationships and violence due to intersectional stigma, rather than presenting them as

ill, with a particular diagnostic label of a mental illness (Byrne & Wykes, 2020). It also allows us to re-conceptualize mental health experiences through the eyes of those experiencing them, rather than placing them in artificial categories which they may not have any understanding of.

Although women living with HIV described their experiences a little differently from key informants, a few of whom saw them as suffering from mental health issues, almost all thought that women's expressions of mental health were due to their adverse experiences of stigma-related violence. Participants conceptualized women's mental health as experiences of profound sadness or pain or constant worries and fears after episodes of violence. They experienced pain as a result of hiding the violence or thinking they were undeserving of help. There was no instance in which any of the participants, including key informants, described women as pagal (mad), which is a common way of addressing severe mental illness in India. Although women were perceived as sad, mentally broken, worried, or troubled, they were not thought of as mentally ill. Similar findings have been reported from studies on community mental health in the Sunderban Delta of West Bengal (Chowdhury et al., 2001). This underscores the importance of Summerfeld's original critique of diagnostic categories for mental illness and the need to revisit and revise them to fit local understandings of mental health and illness (Summerfield, 2001). This brings me to my first main point. All of the women had access to counseling through the NGO or ART centers, but not being labeled as mentally ill helped them experience their mental health as a "normal" outcome of negative experiences rather than as an additional illness to worry about. It also helped them avoid the additional intersectional stigmatization that often comes with diagnostic categories of mental illness. However, healthcare providers need to be cautious about the 'normalization' of mental health experiences as it may mean missing out on those requiring additional help, such as with medication or specific therapies.

Women's lived experiences of mental health showed how they conceptualized stress responses as affecting physical health. Low or fluctuations in CD4 counts were attributed

to the stress of stigma and violence on their bodies and often a reason for why their health was worse than others. Similarly, symptoms such as lack of appetite or sleep and headaches were described as mental health effects of stigma-related violence. Studies on local understandings of mental health in India have shown that women often conceptualize poor mental health as a consequence of outside stressors such as poverty, poor marital relationships, and violence (Kermode et al., 2007; Pereira et al., 2007). In addition, such women with clinical depression tend to present with somatic symptoms rather than emotional problems (Patel et al., 2005; Pereira et al., 2007). One reason for this may be that, given the stigmatization of mental illness, having physical ailments allowed women to legitimize their experiences and give them the break they needed from their regular duties (Pereira et al., 2007). However, here women directly attributed their poor physical health to their poor mental health, which was a direct consequence of their stigmatization and violence. Although stigma and violence were often seen as temporal: despite a reduction in stigma-related violence over time, the mental health impact was not necessarily attenuated. Women continued to feel the fear of anticipated stigma and some even attributed their poor health to the impact of long-term stress on their bodies. These findings bring me to my second main point. Lived experiences of mental health allow us to not only see how women perceive their illness experiences as a consequence of poor mental health, but also that they see their present state of poor physical health as a result of past wrongs inflicted on them. Such conceptualizations allowed them to shift the blame for their poor health onto the perpetrators of violence. While this could potentially allow them to take control of their mental health by letting go of negative thoughts and worries in order to feel better physically, it could also make them feel powerless to improve their health because of their past experiences. Counselors need to be aware of the pitfalls of overly emphasizing the role of chronic stress on women's physical health, and work in ways that make women feel they can take action to feel better mentally and physically. It also means that women's mental health concerns can be addressed in a way that is useful for them, such as violence or stigma reduction interventions rather than prescribing medications for depression or anxiety.

Despite the widespread availability of free ART and care, women rejected medication because of poor mental health related to intersectional stigma and violence. In 2005, Farmer and Castro made the argument that in resource-poor settings the real driver of HIV stigma was lack of proper healthcare services and treatment because the sick and dying were often stigmatized as they were a drain on scarce resources (Castro & Farmer, 2005). They went on to say that the widespread rollout of ART would ultimately lead to the disappearance of stigma. Even though the role of economic factors in driving stigma cannot be denied, stigma continued to exist despite the widespread availability of ART. My findings not only add to the body of literature showing that stigma continues to be driven by psychosocial factors—that is, fear of infection and moral blame (Campbell et al., 2011)—but that the mental health effect of HIV and other stigmas makes women reject the ART that is freely available to them. Women would either intentionally throw away medications because they wanted to die or forget to take them because of the stress of intersectional stigma and violence. Similar findings have been reported from South Africa, where women reported deliberate non-adherence to ART due to HIV stigma-related violence (Hatcher et al., 2016). This brings me to my third main point. The advent of ART meant that HIV was no longer the death sentence it used to be, yet the mental health impact of intersectional stigma means that women continue to be lost to follow-up, suffer additional stigmatization due to sickness and loss of productivity, and ultimately die from a chronic, manageable disease. These findings highlight the need for integrated stigma reduction and mental health care services, which incorporate local understandings and presentations of mental health, for women living with HIV.

I conceptualize my findings to show how the stigma amplification loop (which has been described previously) now feeds into a health cascade, as shown in Figure 10. Experiences of intersectional stigma and related violence lead to poor mental health, which in turn leads to poor physical health. When women start showing symptoms of poor physical health, this feeds into the stigma cascade as sick and unproductive individuals are stigmatized further. It is therefore important to address intersectional stigma through resources such as counseling and awareness, so that myths and misconceptions around

HIV are dispelled. De-stigmatizing mental illness is also critical so that women who present with symptoms of sadness or tendencies to self-harm due to the stresses associated with HIV and other stigmas, are able to seek treatment and care. In addition, as Indian women often present with somatic symptoms, it is important for HIV clinicians to be attentive to such symptoms so that the underlying mental health issues are treated appropriately. For women living with HIV, where stigma is an additional stressor that worsens violence in familial relationships and leads to income insecurity, support groups for women that include income generation activities might be particularly helpful in improving mental health and wellbeing.

Very few people in India have their mental health needs met and the mental health component of HIV is often neglected in HIV intervention programs (Das & Leibowitz, 2011). Considering that women living with HIV may be at increased risk of experiencing poor mental health, it is important that India's National AIDS Control program does more to increase capacity and deliver appropriate, gender sensitive mental healthcare for women living with HIV. Mental healthcare models that address cumulative trauma (Kira, 2010), by taking into account women's multiple marginalized identities, may be a promising approach for treatment and care.

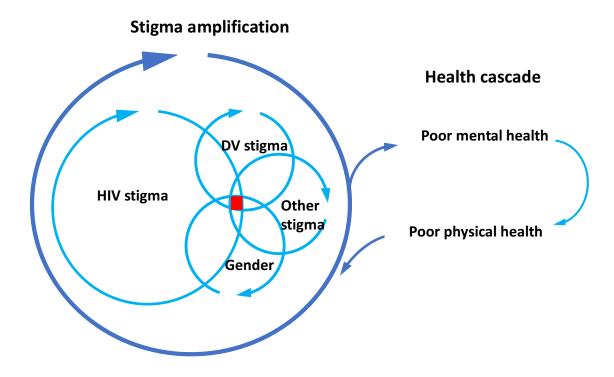


Figure 10 Conceptual framework of intersectional stigma and health cascade

### 5.6 Conclusions

The study presents the lived experiences of mental health of women living with HIV who experience worsened violence due to their multiple stigmatized identities. Women reported feeling sad, hopeless, and worried, all of which contributed to their poor mental health. Two key tensions were identified: (1) avoiding labels of mental illness allowed women to avoid stigmatization but could also mean they missed out on treatment; (2) conceptualizing poor health as a consequence of negative experiences of intersectional stigma allowed women to let go off negative thoughts, but could also make them feel powerless to take control of their health. Finally, poor mental health meant that the biomedical gains made by the widespread rollout of ARTs were lost as women declined treatment. Enhanced government and non-government programs that offer support through improved counselling, stigma reduction interventions, and empowerment opportunities are needed to address the poor mental health status of women living with HIV. Together they should improve health and wellbeing for women living with HIV who are survivors of intersectional stigma and resulting violence.

This chapter has shown how women are affected mentally and in turn physically due to the adverse experiences of intersectional stigma and related violence. The next chapter describes my findings about how women utilize a variety of resources to cope with such experiences.

# Chapter 6: Coping with negative experiences of intersectional stigma

In the first two chapters of findings, I showed that intersectional stigma worsens the violence experienced by women and that this often contributes to their lived experiences of poor mental health. My third research question aimed to explore how women cope with the mental health effects of intersectional stigma and violence. As stigma can be considered a stressor, people often cope with it in similar ways with which they cope with other stressors (Oyserman & Swim, 2001). I present my findings using an empowerment model, described in the methodology (chapter 3), which views stigmatized individuals as not just passive recipients of stigma, but as empowered individuals who actively create positive outcomes for themselves (Oyserman & Swim, 2001; Shih, 2004). People who cope in this way "develop a sense of mastery and self-efficacy at their accomplishments." People who cope by avoidance can ultimately feel depleted (Corrigan & Penn, 1999; Shih, 2004). I do not present findings on how women avoid stigma, such as through nondisclosure, but consider how women can stay well despite stigma: for example, by challenging stigma, focusing on their positive identities, praying, relaxing, and spending time with others living with HIV. Because social support from family, NGOs, support groups, and others is important for buffering the negative effect of stigma, I have also presented findings on the external or social resources that strengthen women's internal resolve to cope.

The literature on coping mechanisms is well established and much has been written on how people cope with stressors such as HIV (Makoae et al., 2008), domestic violence (Mitchell & Hodson, 1983), stigma (Miller & Kaiser, 2001), and various life adversities (Roth & Cohen, 1986). Some of the first coping frameworks came from the field of psychology, the most commonly described being an avoidant and approach coping model (Roth & Cohen, 1986). Briefly, this model describes the two ways in which people cope with life adversities by (1) avoiding or repressing negative thoughts or the stressor or (2)

approaching the stressor so that appropriate action can be taken to make it more controllable. Both strategies have advantages and disadvantages. Avoidant strategies are helpful in reducing stress and crippling anxiety, while approach strategies are useful for taking control of a stressful situation (Roth & Cohen, 1986). Although not identical, similar approaches to coping have been developed in the stigma literature (Corrigan & Penn, 1999; Oyserman & Swim, 2001), and a "coping" versus "empowerment" model of coping with stigma was developed (Shih, 2004) and has been described in detail in the methodology (Chapter 3). Several studies have described how people cope with HIV stigma using a combination of avoidant and approach coping, with the latter having better health outcomes (McIntosh & Rosselli, 2012; Swendeman et al., 2018) A study from India has shown how such positive coping strategies can help people living with HIV live with confidence (Kumar et al., 2015). Two studies from North America have described how women cope with intersectional stigma that they experience in various settings, such as in healthcare settings and from friends and family (Logie et al., 2021; Rice et al., 2018). The contribution of this chapter to the emergent literature on coping with intersectional stigma is that it shows how women living with HIV cope with intersectional stigma and the domestic violence that results from it.

Key informant interviews and semi-structured interviews with women living with HIV, and photovoice conducted with a subgroup, were thematically analyzed to generate the themes for this chapter (Table 17). The global theme recognizes the unique needs of women living with HIV who experience violence. This need is filled by a combination of psychological and social resources that women utilize to cope with negative experiences of stigma and violence.

Table 17 Examples of themes on coping with intersectional stigma

Global theme	Organizing themes	Examples of basic themes
Stigma of HIV and domestic violence create the need for specialized resources for women to cope.	Women draw on their psychological resources to cope.	"Moner jor" or resilience
		Prayer
		Positive reframing
		Challenging stigma
		Focusing on positive identities
		Engaging in activity
		Acceptance and moving on
	Social resources strengthen psychological resources to cope.	Feeling included
		Feeling loved
		Building financial independence
		Getting help with daily needs
		Seeking information

## 6.1 Women draw on their psychological resources to cope

Women were asked during the in-depth interviews how they coped with negative thoughts and feelings arising from experiences of intersectional stigma and violence. Questions included "what gives you 'mental strength" or "what do you do to feel better or relax your mind in times of distress". A subgroup of women also participated in the photovoice exercise (described in detail in chapter 3), in which they took pictures to show what gave them mental strength or what they did to feel better. They then discussed their coping strategies through the pictures. Responses from both in-depth interviews and photovoice were combined to determine themes as part of the analysis. Women described multiple different ways in which they used their psychological or internal resources to cope with experiences of intersectional stigma and violence, including their "moner jor" (mental strength or resilience), faith, and relaxation activities. Some women were able to reframe stigmatizing experiences in a positive way, several challenged stigma directly or focused on their positive identities, and others accepted these experiences but were ready to move on. All of these internal resources worked together to help women cope with experiences of intersectional stigma.

## 6.1.1 "Moner jor" or resilience

Women were asked where they found their "moner jor" to counter the negative impact of intersectional stigma and violence. This common phrase in Bengali encompasses determination, courage, and overall resilience and is colloquially used to praise people who have come out of negative experiences or ask them how they cope. Here women demonstrated many examples of mental strength and positive thinking. Most were pleased to be asked the question as it showed that they were not victims of stigma but courageous survivors. A newly diagnosed woman spoke about how "living is very painful," but "my mental strength is keeping me alive" (CL023, 35 years). Despite the associations of HIV stigma with poor moral character, women found mental strength knowing that "I have never gone down the wrong path" (CL011, 60 years). A woman who had rebuilt her life after struggling with violence related to intersectional stigma of HIV and widowhood spoke about her courage:

"And because I have summoned the courage that's why I am able to live in a place like Kolkata. I am able to go around everywhere. And if I had lost courage then I would not have been able to do anything. Slowly I have worked my way to more or less building a place to live. When [my children's] father passed, he had only bought the land, there was nothing there, there was not a place to stay. With my courage, I am able to stay well now" (CL014, 36 years).

For almost every woman interviewed, children were a source of mental strength and a reason to go on fighting to live. A woman who had initially given up taking her ART because she wanted to die said she started taking medicines again, thinking, "I will live for my daughters, it is true they don't have their father, who will care for them other than me... I am standing strongly for them" (CL008, 45 years). A woman who had entered sex work after becoming a widow and not having the means or family support to care for her son spoke of how she looked forward to living:

"Today I am alive because of this mental strength... Where will I find it, I find it within myself, I don't have any useless addictions, I just drink a bit of tea and eat two meals a day. This is how I make myself go on. I am the mother. I am the father. I am everything" (CL025, 50 years)

Another woman took a picture of herself with her daughters to show how being with her children made everything better (Figure 11 Photovoice image).



Figure 11 Photovoice image
"If I stay with the children I feel good...If I have my two
daughters I feel like I have everything" (CL005, 38 years).

Not every woman, however, talked about living for her children. One took a picture of a small plant breaking out of the concrete to show that she too wanted to come out of the challenges in her life and not just live, but thrive (Figure 12 Photovoice image).



Figure 12 Photovoice image

"This plant, I really like this plant... it is living, it wants to live. Wants to live life. It is small, it wants to become bigger... This plant, with water, sunshine, I mean with everything, with fertilizer and everything, if it gets it then the plant will have vigor. With my mental strength, I also want to live like that plant... If a plant is alive, then why can't I be alive?" (CL017, 35 years).

## 6.1.2 "He gave it, He will make us better": Prayer

Faith was an important coping strategy for most women regardless of religion. They found peace and strength in prayer and most actively prayed through good and bad times. Women were of the belief that "He gave it, He will make us better" (CL023, 35 years). A woman who had been trafficked into sex work and had endured severe violence from clients and traffickers spoke of how she coped with the negative experiences in her life, including having HIV, by putting all of her faith in God.

"Mental strength? *Jagannath* of the Puri temple gives me mental strength. I am a child of the promise made there. When my parents were trying to have children, none of them were surviving. When they donated a fruit there, I was born. I am a child of the promise made there... A blessing of *Jagannath*. Wherever I go, I never come back defeated... I don't let myself feel sad, I never worry. Even if there is no food at home, no money, I don't worry. I just let one person know when I go to bed and let one person know when I wake up" (CL003, 60 years).

Women also reported getting peace from prayer when things were particularly difficult. A widow spoke of how prayer helped her cope with intersectional stigma-related violence following her husband's death:

"When I felt a lot of pain I would pray, 'God you have given me so much pain, now you only deliver me from it'. I would pray and get peace, I would cry, pour water [religious ritual], then I would feel lighter" (CL014, 36 years).

Prayer was a source of hope and many believed that God always answered their prayers. It was also a way to resist stigma. A widow with two daughters, one with HIV, prayed that they would grow up as empowered women who would teach people not to stigmatize others. Her prayer was a way of recovering her lost value as she would "show" the perpetrators of stigma how well she had raised her daughters (Figure 13 Photovoice image).



Figure 13 Photovoice image.

"I hold Jesus in my hands and pray to him twice a day ... that my daughter can stand on her two feet, can earn for herself, by earning I mean not a job, I mean there is no shame in any job... Nurse training, teaching in a school, taking care of an ill patient, like that. That she can care for everyone, explaining to everyone that do not have *ghenna*, not shoo anyone away, let my daughter be like that, I want that, that is my dream. That is my hope. It's my lifelong hope, that is what I want... Please fulfill this hope. I don't have any other

hope. Let me able to show everyone that they grew up to be good human beings. I will show them with their eyes... those who have shown *ghenna* towards me... my sister, my mother-in-law. I want to point my finger and show them" (CL008, 45 years).

Apart from praying individually, group prayer at the temple was a coping strategy as it allowed for social participation, something that is generally denied to the stigmatized. It was also a means of distraction from negative thoughts. A sex worker spoke of sitting by the temple in her neighborhood and enjoying the festivities during *pujas*. A woman spoke about how she looked forward to devotional songs and prayers at the temple with all the other wives of the neighborhood, rather than being at home alone with intrusive thoughts:

"Every Monday, all the *Bihari* people take *prasad* (offerings) and eat. All the *Biharis* get together and sing. Everyone will sing devotional songs, dance and sing. When I go there, I feel better. Sitting at home I start feeling weird: what work is there? So I go to the temple to do *puja*. Everyone is singing there, so I go there" (CL018, 35 years).

A clinical psychologist also thought that religious coping worked well for women living with HIV:

"And another thing that was there with this was religious coping, 'I didn't do anything bad myself, so maybe God will not do anything bad with me. I am praying to God for this and following all the rules.' Religious coping worked. At least for the group that I worked with, what I found in them" (Clinical psychologist).

Not everyone found solace in prayer. An elderly widow said she felt let down by God when her husband died despite her prayers, which meant that she could not cope through prayer during the negative experiences that followed:

"If there was a God today would this have happened? Everyone said pray to Jesus, to the almighty. When my husband was sick, I prayed so much. I prayed so much to Jesus, but where did he make him better? What God do I pray to? Which God will help me?" (CL022, 51 years).

#### 6.1.3 "I feel like it is good I have this disease": Positive reframing

Positive reframing was another coping strategy used by women living with HIV. A woman who had left home with her husband, who was also living with HIV, spoke about the benefits of having HIV and working at an HIV NGO. She felt HIV was the reason she got to travel to many places with the NGO, something that would not have happened otherwise:

"Today we have disease, but I am very happy about one thing, that just because we have this disease, we think this way, that just because we have this disease, dada [NGO head] has taken us to so many places. This would never have happened if we stayed at home. Dada has taken us or sent us to many places. [Names of holiday spots] are nothing to us, Dada has taken us everywhere. Now I think that in one way it is good I got this disease [laughs]. This is what we think. That if we were at home we could not have gone anywhere, or no one would have taken us. We did not have the ability. So we think whatever has happened is good. Now, whoever asks ... I say 'I am happy, I am very well'. I don't know what others think but I feel like it is good I have this disease" (CL005, 38 years).

A widow whose natal family asked her to stop visiting them after they found out that she had HIV fought back against the stigma by saying:

"Yes didi, I will keep my children in my lap, I want to live, I want to go out, I want to travel. Maybe I can't go to my natal home, maybe I can't go to my sister's place, is

there no other place? There are so many temples, I can visit those with my children" (CL017, 35 years).

Another woman who experienced physical violence before diagnosis, and blame and ostracism from her in-laws in the initial period after diagnosis, felt that having HIV was a blessing of sorts because her husband had become kind and violence had reduced:

"I think, when I say that on the one hand it killed me means, say I am having to take so many medicines for this illness -- I used to not take one medicine before - now I have to take so many medicines. I used to be very afraid of medicines, but I am having to take medicines. So on the one hand it has killed me, but on the other hand there is peace in terms of the quarrels and stuff. The husband also thinks you never know what may happen, so he doesn't hit me and neither does he say anything. I also don't say anything because what if something happens to him" (CL012, 32 years).

A HIV activist who had been living with HIV for a long time spoke about how stigma actually brought women together, particularly in the early days of the epidemic.

"So that was the thing, stigma always has a negative connotation, but it has a positive spin as well, in terms of how stigma, you know, like stigma really brought many people under one platform, like HIV stigma was the one binding force, so ... it's a positive thing, because it helped really to reach out to others with ... similar experience or status. It's just status that brought everybody together, whether you are rich or poor... whether you are lower caste or higher caste, so whatever you are, low profile or high profile, highly educated or uneducated [laughs] ... it brought them all under the same platform, just the status, it was because of the stigma. Only for the stigma. No other disease could have had that kind of ... So I think that was the good thing that happened and helped people manage and cope with the epidemic and inspire other people" (HIV Activist)

#### 6.1.4 "HIV is not as bad as blood sugar": Challenging stigma

Many women also challenged the stigma associated with HIV and other marginalized identities. A woman who had been recently diagnosed responded angrily when asked if she had fears about people finding out about her HIV status:

"If they get to know, they know. I don't care. I am sick, do I have time to think about what people say? I have to live. I have to fight. I have to look after my children. I have to work. I have to eat. Will my life suddenly change based on whether people say I'm good or bad? Will I commit suicide for people? Will I give up my life? My whole life is ahead of me" (CL023, 35 years).

Sex workers challenged the intersectional stigma of HIV and sex work. Since people stereotyped them as "bad" because they were sex workers and had acquired HIV because of it, they questioned how women from "good" families could get HIV:

"Good people are getting HIV, today I am staying in a brothel in [name of place] that's why I have HIV, but I am seeing good people when I went to [name of hospital], that's why I watched them with my hands on my head, sitting down and thinking, these girls and wives come from good homes so how did they get it?" (CL026, 45 years).

Another sex worker challenged the intersectional stigma of HIV and sex work by saying that "women in tall buildings" would not be able to live if it was not for women like her. She described how she was the "chosen one" who gives the first fistful of soil needed to build the idol for *Durga Puja* (the biggest religious festival for Bengalis where it is customary to get the first handful of soil from a red light area):

"... if this 'line' was not there, then women in tall buildings would only be able to peep outside, at one time it was like this... Women would not be able to stay at home. But now see, be it women, men, children, everyone is able to go out on the streets. You remove this 'line'... from everywhere, girls and wives from good families will not be able to step outside, they will be torn apart, like the dogs tear up [a piece of meat] that is how they will be torn apart. And people feel *ghenna* towards us?! Those who don't understand feel *ghenna* but those who understand ... on the day of *Durga Puja*, if we don't give a handful of soil then there will be no *puja*. I give it myself. There are four or five women who live in our house, they will call everyone, will make them stand, will look from one to the other, won't take the soil from anyone, will take the soil from me. They understand from whose hands the soil is auspicious. They understand" (CL003, 60 years).

Women also challenged stigma by normalizing HIV and reframing it as a "better" disease than others. They spoke of how HIV was nothing and they would often forget they were sick until it was time to take their medication or when they went to collect their medicines at the hospital.

"Everyone has some disease: someone has this disease, someone has that disease. HIV is not as bad as blood sugar. The worst is cancer, sugar. HIV is better than that. Then why behave so badly? You go to the hospital and see how many people have it. I am not the only one" (CL006, 26 years).

The fact that they felt and looked healthy also helped them challenge their own internalized stigma:

"So what, it has happened, so what? Medicines have been started. See the person who doesn't have the disease, look at their appearance. We have this disease and look at our appearance" (CL003, 60 years).

When asked how they thought society could be made to be more accepting of women living with HIV, most women had a pessimistic outlook, but some felt that change was possible. One said, "If everyone stands up and resists why will it not change? There has to be change, otherwise how will we live? (CL015, 50 years). Several women felt that education and awareness were needed to change attitudes: "It will change, if they get to know everything then it will change. If they don't know then it will not change. They must be informed" (CL030, 39 years).

#### 6.1.5 "I have cured so many people": Focusing on positive identities

In Chapter 4, I outlined how a combination of negative identities, such as HIV and widowhood or HIV and sex work, worsened the overall experience of stigma and violence for women. In this analysis of coping, intersections of women's positive identities also seemed to help them resist the negative mental health effects of multiple stigmas and violence. The support that had been given to women, mainly by HIV NGOs and sometimes by family or friends, had helped them to rebuild their lives. Such support helped them create positive identities, which were now a strength they used to resist stigma, including their own internalized stigma. When asked if there was a gender difference in how people with HIV were treated by others, one woman's response showed how she coped: she knew HIV was not contagious and being a cook who had won a lot of prizes meant that she was right.

"I think that HIV means HIV, that's all. This disease is not good and neither is it bad. But, uhh, I have worked here in this place for a long time. When there were programs or meetings, I was the head cook. I got a lot of prizes also. I have heard that HIV is not a contagious disease..." (CL015, 50 years).

Another woman had been trafficked into sex work, rescued, and then abandoned by her family once they found out she had HIV. She worked as a cleaner at the HIV NGO where

she also lived. Focusing on her role of "serving others" helped her cope with her experiences of intersectional stigma:

"When a patient comes in well or unwell, I take care of them. I clean their shit and piss. I have cured so many people, they say 'what magic do you have in your hands?' The nurses say so. Sister [name of nurse] says that, 'you have magic in your hands, God in your hands.' I have cured a lot of people..." (CL031, 34 years)

Yet another woman living at the NGO after being abandoned by her husband expressed her pride at going "from a patient to the position of staff" (CL001, 46 years) at the organization. Whenever she talked about negative experiences, she followed up with how she was happy now.

"...from there doing odd jobs, now I am a staff here. Now I take care of the children, total care of the children. Who will take medicines when, who will go to school when, who will study what, with which teacher? From getting the teacher's signature to everything" (CL001, 46 years).

Most women were mothers and focusing on the positive identity of motherhood was a great source of mental strength that helped them cope. This was particularly true for sex workers who focused on their identity of being good mothers to help them cope with the internalized stigma of joining sex work and acquiring HIV as a result:

"I have a husband then why am I having to live in such places? ... Why am I here? I have come down this path, that's why I caught this disease. Now if today he gave a thick *saree* ... and a little coarse rice, would I be staying abroad? He gave me a child and left me. Who will raise the child? The mother has to do it, isn't it? So, what will that mother do? She will steal, will mug, will beg on the street, that's how she will raise the child. Then? What else. Why does a mother become bad? Because of her child" (CL003, 60 years).

An HIV physician described her experience of counseling a client who was severely depressed after being emotionally abused by her in-laws after her husband died of HIV. The woman used to draw very well and the physician focused on her positive identity as a good artist to help her cope:

"I had seen one patient, I counselled her personally, the lady is very educated and draws exceptionally well. I mean you cannot imagine how well she draws. So, her husband had become positive, in whatever way, husband later died, then the lady was mentally tortured a lot there... She was in tremendous depression, so we would ask her to visit every day. We used to joke with her, we used to chat with her, 'you paint pictures, why don't you give some to me?' She had locked up all her drawings in a box. I was like 'you cannot put them in a box, you must open the box and bring them to me, because I need paintings to decorate my house', like that and boosted her up in many other ways, for many days, in fact she was counseled for many months..." (HIV Physician, ART Center).

#### 6.1.6 "When I feel upset I go to plants": Engaging in activity

When women were asked what made them feel better after experiencing negative behaviors from people, different women had different answers. As social isolation was a big part of the intersectional stigma experience, they found ways to cope that involved engaging in relaxing activities which they could do on their own, such as watching TV, listening to music, resting or playing with their phones:

"I climb up to the terrace and sit there, let no one talk to me if they don't wish to. I put on nice songs on my mobile and lie down in the room" (CL010, 45 years).

Engaging in hobbies was another way in which women coped. A woman took a picture of her gardening, as this was her way to de-stress and relax when she encountered or remembered negative experiences (Figure 14 Photovoice image):



Figure 14 Photovoice image.

"Since my childhood I like planting trees, to see them grow big and fruit... Like one raises a child I will raise this plant, I mean a flowering plant will blossom, a fruit tree will bear fruit, then I feel very happy. I really love planting trees. When plants grow big, blossom and fruit, then I feel very happy... When I feel upset I go to plants, think about plants..." (CL004, 35 years).

Many women felt better after spending time with friends and family. One described how talking to others helped her feel good, both mentally and physically:

"I like talking to people, I feel more at ease then... When I feel physically unwell, I feel unwell during the afternoons, so then if I talk to someone I feel much better, much lighter... When I feel lighter, I feel better" (CL020, 32 years).

Another woman described how her neighbors always looked out for her during times of violence and now invited her to family gatherings, all of which helped her to cope:

"Like yesterday, no day before yesterday they called '[name of participant] have you come?' so I said, 'yes just came', 'come upstairs for a bit' so I went, they had cake...the daughter had got a job, since her father had done much for her, so the daughter was celebrating her father's birthday. So, she said share some cake with Mummy, that girl calls me Mummy, share some cake with Mummy. So, they called me to have some cake" (CL022, 51 years)

#### 6.1.7 "Whatever has happened has happened": Acceptance and moving on

Most women seemed to accept their diagnosis. It was common to hear the phrase "whatever has happened has happened" in different contexts, but a positive aspect was that women were ready to accept this and move on. A woman who did not experience stigma-related-violence, but had internalized stigma due to HIV being a bad disease, said she intended to move on with life:

"Again, sometimes when I travel by bus or walk on the streets, then I think to myself: these people are healthy and I have this disease inside of me. If only I was healthy like them -- this comes to mind. Then again, I think, whatever happened was in my destiny, there is nothing to do. Now if I bang my head then also nothing will happen and if I give up my life also I will not be able to do anything... thought that even if I give up my whole life... I will not get back my old life. So, no point [thinking] about it, I have to take this along with me and fight. As long as I live I will fight with this alongside" (CL005, 38 years).

Another married woman described how she felt shocked upon hearing her diagnosis. But then she realized she had to fight and move on as thinking about the illness and its consequences was not going to change anything:

"My mental strength is keeping me alive. Because I know I have to fight for my children. If I start worrying, will worrying bring anything back? It will not come back.

I have to stay well, I have to take my medicines... that is what I think" (CL023, 35 years).

### 6.2 Social resources strengthen psychological resources to cope

In the previous section I showed how women living with HIV experiencing violence coped. These coping strategies were strengthened by external support from a variety of sources, such as NGOs, healthcare providers, family, friends, and neighbors. External support that helped women build financial independence, fulfil daily or informational needs, or that made them feel included and loved, made it easier for them to use their internal resources to cope with their negative experiences.

### 6.2.1 "Our friends, they are positive. They are like us": Feeling included

For members of a stigmatized group, belonging to a group or feeling included can be crucial for their mental health. When women are diagnosed, their first thought is often that they are the only ones who have the illness. When they go to the ART centers and see that many other people have it and are leading healthy, normal lives, their fears subside and they start feeling better. This sense of belonging was even more important for women who experienced stigma-related domestic violence, which often worsened the stigma of HIV, and made women feel isolated. Feeling that they belonged to a group gave them the mental support they needed. A woman who was living in the NGO after being abandoned emphasized the importance of feeling included in order to cope:

"The people who are here, our friends, they are positive. We don't have any issues with them. They are like us" (CL001, 46 years).

This idea was illustrated through a photograph taken by a woman to show how having a friend made it easier to cope with experiences of stigma and violence as it allowed her to share her deepest feelings (Figure 15 Photovoice image):



Figure 15 Photovoice Image.

"You are my friend from today. I am with you. I am with you during your troubles and your good times. Whenever you call me, even if I'm asleep, you will be able to find me. This is what I want to tell her: that from today you are my friend. It makes me happy to share my deepest feelings with someone, like she is sick so she doesn't understand, but to be able to tell her, from today she is my friend" (CL008, 45 years).

A widow who had been forced to leave her marital home after her husband died said she found mental strength from seeing others with HIV:

"... when I go to [name of hospital], I see some people who are happy and healthy, then I think if these people can stay well then why can't I? You can't tell by looking at them that they have this disease. They are healthy. They come well put together, laughing and joking amongst themselves, chatting with each other, then I am amazed. If they can laugh and joke, then why can't I? You can't even tell by looking at them" (CL013, 33 years).

Several women were part of a microfinance group at the HIV NGO and group membership gave them an additional layer of support. Being part of a savings program meant that members had a sense of purpose for their future, as each planned what they would do with their loan. Some thought of it as a way of leaving abusive relationships, some wanted

to use it for their child's education, but for some it was just enjoyable to meet others every month and catch up.

"Yes, I like it. I like it a lot. I get to meet everyone here. See I am at home, I sit at home all day. I go out once in the morning and once in the evening. I do the cooking and everything at home. I feel so much better when I come here. I take the train, see a lot of people, then come here, meet everyone here, that is what I like" (CL019, 25 years).

The intersectional stigma of HIV and domestic violence meant that women could hardly talk about it and never mentioned the cause of the violence. When women visited the HIV NGO they were not only cared for, in terms of treatment, nutrition, and rest, but they could talk to others openly about the problems they were facing. This made them feel much better:

"Yes. If I felt sick, if someone said anything, if I am feeling sad, if I am not getting help from anywhere, then I would stay here a couple of days. I would stay here a couple of days, stay here a month, I would stay here, *dada* would not say 'go home', instead he would say 'stay here, you are not feeling good, you stay here and get checked by the doctor, eat well and feel better.' Then I would get a little bit of peace, that someone is standing beside me. All the suffering that was within me, I would come here and share" (CL014, 36 years).

A woman who had been diagnosed recently and felt lost with sadness and fear during the first interview, expressed the importance of feeling included in order to cope through her photograph (Figure 16 Photovoice image):



Figure 16 Photovoice image

"I am trying to explain through this picture that in a place where there are children, there you feel happy. Talking to children makes you feel happy, you feel free. Even though we have all kept our children and come here, but staying with children makes us feel happy... Talking to them [others in the ward], laughing with them, all of this makes me feel very good. We are all staying happily together. I don't worry so much about home anymore" (CL016, 35 years).

A widow living away from home since her diagnosis summed up the importance of being able to talk to everyone openly and feeling accepted. Support groups held by the PLHIV Network helped women feel included and cope with the violence they were facing at home. One had been going to these support groups which she felt contributed strongly to her ability to cope:

"It is not about food, talking to people also helps, that is the most important. Talking to people, chatting with them, that is the biggest help for the body. If you are able to speak to someone openly about the pain in your mind, then your body will feel lighter. The mind will feel lighter. You will feel better. That is what I think more. If I can openly share with someone the pain that I am feeling, then I feel that the pain will be lessened. That is what I think. I say that to everyone. The thing that you are harboring within yourself, if you tell other people about it, if you share with them, then your body will be well and your mind will be well. The biggest disease in people's bodies is stress. Stress. I mean hiding pain. Hiding pain. The more you

share with people, if they know something about it they will tell you, will help you" (CL004, 35 years).

#### 6.2.2 "When I come home, they come running to me": Feeling loved

Feeling that they were loved was important for women to cope with their experiences and fears of stigma-related violence. Although it was not easy to come by, women reported emotional support from different members of the family, particularly children. Women who felt they had lost all hope had found love and support from their children.

"My son is very innocent, and when he talks to you, you won't be able to hear him... He still cries hugging me. When I am discharged and go home, three children will carry me, 'Mum you are healthy now?' If I say yes then they will be very happy" (CL017, 35 years).

Feeling loved and supported was rare for sex workers as most had cut off all ties with family. Yet here too, children were often the source of support. An elderly sex worker described her experience of disclosing to her daughter and the support that followed. Such experiences of loving support are often what gave women the strength to cope with their negative experiences:

"...'I have the same disease as [name of woman] aunty', [daughter said] 'don't you worry, there are medicines now, you are taking medicines?' I am like 'yes', 'then what is there to worry, don't worry, I am there, what is there to worry about?' She is like me, she gives a lot of support" (CL003, 60 years).

Although this was less frequent, some women reported emotional support from husbands, especially if a husband was the first to be diagnosed. A woman who cared for her husband and nursed him back to good health described how she and her husband supported each other: "When I worry, I cry and my husband explains, and when my husband cries I

explain" (CL018, 35 years). Although support was more common from the natal family than the in-laws, some in-laws also showed support. This included encouraging women to carry on with treatment, visiting them at healthcare facilities or just making them feel part of the family. This kind of support gave women the mental strength to cope:

"My brothers-in-law used to come to see me here. Their wives would come to see me here. Everyone used to come to see me" (CL007, 40 years).

Emotional support from neighbors and from employers were also important. A woman said her neighbors told her "to take my medicines regularly, then you will be fine. Just take your medicines properly" (CL029, 34 years). Another woman who had been abandoned described the loving support she got from the children she cared for at the HIV NGO through a picture (Figure 17 Photovoice image).



Figure 17 Photovoice Image

"If I am sick myself, then I think, if I cannot get up then my children will not get proper care. If I can take care of them a little bit, if they have eaten on time, if they took their bath on time, if they took their medicines on time, if they are healthy then I know that I am healthy as well. That is what. If my children are healthy then I feel like I am healthy... If I get a little sick also then the children do a lot for me... [they love me] *very* much... I mean, what could be a bigger strength for me than this?" (CL001, 46 years)

#### 6.2.3 "I find my mental strength through work": Building financial independence

Hopes of rebuilding their lives through work were evident in women's narratives. A serodiscordant woman who had been experiencing worsening abuse after having HIV looked forward to starting her own flower business with a loan from a microfinance group. This helped her cope as she felt that financial independence would allow her to leave the abusive relationship and also care for her son. She was currently working as a home help, but with HIV she wanted a job that was less strenuous and a business would allow her to have an independent income without putting a strain on her health:

"I take courage in my mind, that I will borrow some money and start a flower business, or something else, then I won't have to work in people's houses. People's health may not be good forever that they are able to work" (CL002, 30 years).

Economic support through jobs also improved women's mental health by giving them confidence and improving self-esteem. A woman who had faced physical and verbal abuse from her husband decided to move away from her marital home after her HIV diagnosis and now lived and worked as a cook at an NGO. She described how work gave her the mental strength to move on with life (Figure 18 Photovoice image).



#### Figure 18 Photovoice image.

"I work with my mental strength. I work with all my courage. I am not literate... I work everywhere with my mental strength... Even if it is painful there is nothing for me to do. If I work, then my health will be good. That is what I think. I find my mental strength through work. And if I quit work then I feel very stressed, very worried" (CL007, 40 years).

Women who suffered violence and neglect from families experienced economic constraints, which not only hurt their ability to get treatment but also contributed to the overall experience of stigma because of poverty. Women who reported support from employers who offered them interest free loans or cash gifts were better able to cope with the effects of intersectional stigma as their immediate financial needs were met:

"I used to talk to the people I work for. I borrowed a lot of money from them too, maybe around Rs. 3000-4000. They were like 'go see a doctor, we know you, you will work and repay the money, where will you go by taking the money after working for us all these years?' So they gave me the money. I won't lie" (CL002, 30 years).

Women obtained support from NGOs through job opportunities, training, and membership in microcredit programs. They also obtained support with their treatment costs in the form of free or subsidized in-patient and out-patient treatment at HIV NGOs; free HIV, viral load, CD4 testing, and medication in government clinics, travel vouchers and direct cash transfers (Rs. 600 annually for 95% adherence). NGO support in the form of job training and volunteer work were a key aspect of getting women back on their feet:

"...you know that when the family they thrown out, these woman in our centre, so usually they don't have any place to go. So, after recovery from the opportunistic infections, more or less they can work, and they have that physical strength, so on that time they have no option, then we offer them vocational training, or some jobs here as a voluntary part of work, and when they start to earn, and they also offering

their financial support to the family, and gradually family understood that a HIV person cannot be a non-productive person" (Official, HIV NGO).

A clinical psychologist felt that self-reliance was key to mental wellbeing as it took away the stress of depending on marital or natal families for financial assistance. It allowed women to rebuild their lives and secure their children's future, all of which contributed to improved mental health:

"Self-reliance helps with coping with a lot of stress, that is my personal opinion, I am not saying this just for HIV, I am saying it for everything. I mean for anything, as soon as I am capable enough to do something for my present and for future of me and my family, that moment I think my self-confidence gets a big boost, which indirectly helps to improve my mental health a lot. I mean this thing, only social support, only mental support or medical support is not enough. This [economic support] is also needed" (Clinical psychologist).

#### 6.2.4 Getting help with daily needs

Women living with HIV who experience stigma-related violence need support to cope with the neglect they experience from family. This support came from a number of different sources, often in the form of help with childcare, medication pick-up, or help with housework. Women sought help to cope with their nutritional needs because of poverty due to lost income and lack of family support. Widows were vulnerable as families were unwilling to provide for them, and so were women with abusive husbands. Several women reported how food rations from different NGOs helped them. Sex workers with HIV were particularly vulnerable to food insecurity as they had lost their incomes and did not have family to demand support. They sought food rations to cope with their nutritional needs:

"...where I live the rent is 2000 rupees, if somehow I can get the rent then I get rice and stuff here and there and I can eat, so I bring home that 2000 rupees and pay

the room rent *didi*... I get rice and *daal* [lentils] here, so I manage. What else to do. God has done such a thing to me that I cannot even work ... what can I do, how will I feed myself?" (CL003, 60 years).

Women also obtained nutritional support from friends and neighbors in the absence of help from family. An older widow who was abused and deprived of food by her marital family described the kindness she received from her neighbors despite them knowing her HIV status:

"They told me to eat well, if something happened they also gave me food, gave me fruits, there is a young married woman, like you, she gave me money, 'take this *bhaabi* [sister-in-law], eat some fruits from outside, I know you won't be able to eat at home, so eat some fruit from outside. Do eat, if you eat then your health will be good then you can work, you can't just work like this', they would explain to me, if they made something nice they would give it to me to eat. As such no one has ever behaved badly with me. Everyone has behaved nicely with me" (CL022, 51 years).

Although help with housework was rarely reported, some women got help with making food when they were sick, from children, neighbors, and sometimes members of the family. A young widow with young children said her children would "cook on the stove, they do everything... My sons would hold me and take me to the bathroom" (CL017, 35 years). Another woman who suffered from severe anxiety described how her "mother-in-law helps me a lot, helps me a lot. She gets up in the morning and does all the work" (CL020, 32 years).

Women were usually diagnosed when their husbands became sick. Sometimes they were sick themselves. During these times, members of the family helped women navigate the health system. Once their HIV status was known by the family, violence often ensued but sometimes support continued, at least from some family members, particularly if the

husband was alive. A woman described how her brothers-in-law made all arrangements for HIV treatment after her husband was admitted to hospital and she too became sick:

"No, they don't say anything bad, everyone ran, the brothers-in-laws and their wives ran, everyone ran around with me, till today the brothers-in-laws wives also keep in touch, brothers-in-laws keep in touch" (CL007, 40 years).

Women explained that they would request help in collecting medicines when they were too sick to do it themselves. A woman living at the HIV NGO since being abandoned described how one of her sisters helped with picking up her medications in the initial period after diagnosis:

"I was so sick at that time that I was not able to collect my medicines on my own at [name of hospital], my older sister used to collect my medicines for me, I need to take the medicines regularly, my sister used to collect my medicines for me" (CL001, 46 years).

Women who are not able to collect medications due to violence at home can also ask for assistance from the PLHIV Network, which provides a package of support for women who experience domestic violence due to HIV. If the ART center notices that a woman is not adhering they can alert the Network and a Network member collects and delivers the medication:

"Yes, yes [women] cannot collect medicines due to problems at home, that happens. In those cases we have a system, that if a patient does not come to collect the medicines then in the initial phase she is given a phone call within 48 hours, if we cannot get a hold of them through the phone call, then we let the Network know, that this month, we have missed [visits] for so and so patients and then they track down those patients. If after tracking them if it is some other reason then they bring them [to the clinic]. Otherwise if it is some problem like this, then

they try to solve it, and in some cases the community people even go to their homes and deliver the medicine" (Medical officer, ART center).

Women described asking for help with childcare, especially if they were being evicted from their marital homes or were trying to leave violent relationships. They would often try to find work as home help and needed a place to keep the children. NGOs that had "homes" for children provided this support and in some cases the family would take care of the children. A woman who was living with a violent, alcoholic husband described how her natal family taking care of the children meant she had one less thing to worry about:

"I have three children, I have kept the older daughter at my natal home, I've put her in my parents' care, they are getting her educated, I am not able to do it myself, he doesn't do it. What to do, if she does not get an education then her life will be useless. So, I have kept the older daughter with my parents and the two boys are with me, how much can I care for them you see" (CL027, 28 years).

Housing support was crucial for women to cope with violence as a result of intersectional stigma, as this often manifested in eviction from the shared household. Women could end up in shelter homes run by the government or by HIV NGOs, if they were lucky enough to get a place. Several participants were residents at the NGO where the study was conducted, mostly working as staff. A woman who had been abandoned by her husband and also had a disability described how NGO support with housing and treatment helped her cope:

"Then my sister went home and told [me this], they gave a date and on that date my sister brought me, then that *didi* [outreach worker] brought me here ... after bringing me I was admitted as a patient, for a long time I was not able to walk, my weight was 25 kgs, they would bring me the medicines, and I would take the medicines on time, till now I take my medicine at exactly the right time. Then they told, our [name of organization head], he did a lot for me, a CT scan was done

here also, they did a lot of my treatment, then with their help when I slowly, slowly, slowly started getting better, as I got better, now where could I go, no one from my marital home enquired about me, they did not keep in touch with me so where could I go? I could go to my parental home and stay there but they will say this and that to me, I can't walk properly, I can't work properly, then this *dada* said 'you stay with us'... Then the senior sister, she is dead now, she said one thing, 'if we can stay here then there will be a place for you here too'. She said those words. And *dada* said, 'if we have a mouthful of food to eat then you will have a mouthful too, don't you worry about this, you take your medicines properly, you will be fine" (CL001, 46 years).

## 6.2.5 Seeking information

Counseling provided by NGOs, the PLHIV Network, ART centers, and awareness programmes held by the government health department were sources of informational support that helped reduce stigma and resulting violence.

Dispelling myths about HIV was a first step to reducing stigma-related violence. Women reported how counseling support helped reduce HIV stigma-related violence by shifting blame away from themselves. A young woman reported a reduction in violence once NGO counselors and doctors convinced the family that the disease came from the husband:

"The doctor said [to the father-in-law] 'we cannot say who it came from, how can we say such things? Most likely your son is sick your son got it first. The one who is sick got it first and then it went to the one who is healthy.' After saying that they don't say anything more" (CL019, 25 years).

According to service providers, stigma reduction counseling from NGOs and ART centers is an essential source of support that women use to cope with stigma-related violence. A

counselor from an ART center talked about women's fears upon getting diagnosed and subsequent emotional distress when they started experiencing violence. Women are counseled individually and as couples and, in cases where the in-laws create conflict, they are counseled as well:

"In that case we tell them to bring at least one member of the family, since they have come to know that you have a disease like this, and because of that only they have confined you to one room or are treating you like an untouchable, talking to you from afar or not talking to you, or talking to you angrily or behaving badly with you, then she is asked to bring a family member, any one of them or even two of them if you think you need, or those who are creating problems, you just bring them here, we will talk to them... In those cases, she convinces the person to come, and when they come we counsel them accordingly about the issues at home. The main issue that crops up is that others at home think this is a contagious disease, the disease she has is a bad disease, now she is there, she will stay in our home and now we will also get the disease. These things happen and in those cases we counsel them in detail about HIV, then the misconceptions that they have are removed, and in those cases such behaviors change" (ART counselor).

Apart from individual and group counseling, larger scale awareness sessions from the state health department also provide support for coping with stigma and related violence. A counselor from a woman's shelter felt that these awareness sessions had a greater impact on residents of the shelter than regular counseling sessions:

"I'll tell you about the home, what the attitude was before it has changed a lot, changed a great deal now. That is really thanks to the health department, it is really because they came so many times and held workshops at our home, with the staff and with the women, and after that a lot has changed. It has become a lot more positive" (Counselor, women's shelter).

Women also sought information from their peers about HIV NGOs, the PLHIV Network, reputable doctors, job vacancies, and free rations. Information from other women who had been living with HIV and had overcome the initial struggles helped newly diagnosed women navigate the different emotions associated with being diagnosed with a heavily stigmatized and potentially life-threatening illness.

"We have the Network and camps, they tell everyone, I mean I only tell people, our Network is in [name of place], contact that place, if you go there they have meetings once a month, they explain, you will feel good if you go there, they will help you, you will be able to let them know your thoughts, they will help you, I only tell them. I am a member there. They have explained to me and I also explain to people when they say this and this is happening, I tell them, give them the contact address, they take the phone number, 'go you will feel better, they will explain, they will be able to get your bad thoughts out of your head, you will feel better'. If you contact them you will get help... Here also when I go to [name of hospital], those who have been diagnosed recently, I tell those who have been diagnosed recently, the Network for this area is in [name of place], go, there will be meetings, go where you have to go, there are camps, attend the camps, attend the meetings, everything will go away, you will get courage, you will not be inhibited, you will be able to live with courage" (CL004, 35 years).

Information about protections offered through the HIV Act or other constitutional protections was also important for the mental wellbeing of women suffering from intersectional stigma-related violence. An official from an HIV NGO said, "Nowadays, we are making them legally aware, that this is your rights, according to constitution, and being a citizen of India you will get remedies. So now they are also accessing their rights." A public health official felt that being aware of the protections offered by the newly enacted HIV Act would give people with HIV much needed mental wellbeing:

"And knowing I have this protection. I will feel better psychologically, that no one can create separate problems for me because of this. Because for a HIV positive person, along with their physical or medical needs, their psychological wellbeing is very important... So, because that psychological wellbeing is important, so this mental support that I have, that people will not create this problem for me... there is a possibility of jail and fine if you do... my self-esteem will improve and I will be more empowered" (Public health official).

Women experiencing violence or denial of property requested help with registering cases with the police or filing cases in court as they were particularly vulnerable to discrimination within the legal system. NGOs and the PLHIV Network not only rescued women from family and community violence, but also assisted with legal aid services. One woman who was able to negotiate help from a neighbor in registering her husband's property in her name felt that help would not be forthcoming if they knew she had HIV. In general, NGOs and the Network were places that women would turn to for this sort of support:

"Also in another village, it happened that there was a woman HIV patient, she was single, her husband had died, so the village folk beat her severely, in that case too we, I mean [name of NGO], brought her here and gave her treatment, there was also a police case, so we helped her in that way, from [name of NGO]" (HIV nurse).

#### 6.3 Discussion

The findings summarized in this chapter can be conceptualized around two different kinds of resources women use to cope with intersectional stigma-related violence: psychological and social. Psychological resources are tools, skills, and personal identities that people use to cope with stressful events in their lives (Turan et al., 2017). These can include resilience, prayer, positive reframing, challenging stigma, relaxation and social interaction, and acceptance. External or social resources may be defined as any concrete or symbolic item that can be exchanged among people (Foa & Foa, 1980). These resources engender feelings of inclusion and of being loved, and support financial

independence, help with daily needs, and acquiring information. The distinction between psychological and external resources is helpful because the former resources draw on a person's innate ability to cope, while the latter are resources that can be obtained from others or from society. More interestingly, often external resources strengthen a person's psychological resources which ultimately help them cope better with life stresses.

Women were asked what gave them the strength to cope with negative experiences of intersectional stigma and related violence. Their answers showed that most took an empowered approach to coping by focusing on positive identities, actively rejecting stigma, rejecting public stereotypes, and gaining strength from stigma experiences, all of which align with Shih's model of empowered coping (Shih, 2004). This has implications for practice and policy. For example, counselors can focus on building on women's positive identities and encourage them to resist stigma. It also has implications for policy as women cope by building financial independence, which is a way of creating positive identity, and therefore offering job training and placement schemes might help women to cope better with stigma. These are described in more detail below by discussing how such coping strategies can utilize a combination of women's internal psychological and external social resources.

Just as intersections of marginalized identities such as sex work and HIV may combine to worsen the stigma experienced by women, similarly positive identities may help support women's strategies for coping with intersectional stigma experiences. Intersectionality theory points to the fact that any one person can have a combination of positive and negative identities, with the privilege coming from positive identities mitigating some of the oppression from the negative ones (Bowleg, 2008). Women were able to use positive aspects of their identities to cope. For example, almost all were mothers and re-framing their identity as good mothers helped them challenge stigma. Similarly, being adherent and seeing themselves as healthy, productive individuals who were good at their jobs helped women cope better. It gave them confidence and pride for being able to support themselves and their children (Kumar et al., 2015). Support with finding jobs or job training

not only helps women financially, but also boosts their self-esteem and confidence and helps them cope with the negative experiences of stigma and violence. People living with HIV have been shown to generate new social identities by having good health, being empowered and supported by others, which have helped them to resist stigmatizing experiences (Campbell et al., 2011; Goudge et al., 2009). None of the women or key informants spoke about the well-established clinical fact that an undetectable viral load means a person cannot transmit the virus, also known as undetectable=untransmittable (U=U). An introduction of this discourse into practice might help reduce internalized stigma by building on the positive identities women already described, and improve adherence, thereby leading to better coping. While counseling sessions that provide information to dispel myths around the illness may be useful, stigma and its negative mental health effects can never be effectively addressed unless the underlying social processes of stigmatization are (Goudge et al., 2009). It has been argued that stigmatization is often a means to exclude individuals and groups from socially valued resources (Reidpath et al., 2005). While gender norms that view a woman living with HIV as 'unproductive' are harder to change, interventions that empower such women with access to resources, such as with jobs and credit, should increase the 'value' of women in society by mitigating some of the underlying social processes of stigmatization. Women must also be equipped with relevant information, such as information about legal services or shelters, so that they are able to access relevant resources and leave violent relationships. Governmental and non-governmental support that helps women find employment, start a business, or get access to legal services will not only aid women in escaping abusive situations but also help them cope with the negative mental health impact of such experiences.

While women often talked about their resilience in the face of adversity, a more interesting finding was that women who had emotional support tended to show more resilience than those who lacked it. Just as social structures such as racism or sexism worsen interpersonal experiences of stigma, supportive structures such as support from NGOs or families help strengthen individual resilience so that women cope better. My findings

confirm previous work that challenges colonial concepts of resilience, which view resilience as an individual trait rather than as one which is strengthened by community support (Dale & Safren, 2018; Greene et al., 2021). Women living with HIV in the US and Canada, experiencing the interlocking oppressions of racism, colonialism, sexism, and HIV did not ground their resilience within themselves, but rather from being part of their communities and families, particularly children (Dale & Safren, 2018; Greene et al., 2021). Children were an important coping resource for women in this setting as well. Children were often cited as the reason to live and a source of mental strength. They provided the emotional support that women often lacked from others, and gave women the positive identity of motherhood. Similar findings have been reported from South Africa, where motherhood was seen as a protective pathway for women experiencing HIV stigma and violence (Hatcher et al., 2016). However, one must be cautious about focusing on motherhood as a coping strategy as it risks further stigmatizing women who do not have children by reaffirming patriarchal stereotypes that place women who are not mothers as devalued individuals in society (Greil et al., 2010).

The role of social support in coping with experiences of stigma could also be seen through women's involvement in HIV NGOs. Apart from the benefits of free or subsidized treatment, NGO involvement gave them a sense of belonging as they saw and shared their troubles with other women living with HIV. People with concealable stigmas, such as HIV, often only feel better in the presence of "similar others" (Frable et al., 1998). The negative experiences of intersectional stigma of HIV and domestic violence often cause women to become isolated as they can no longer turn to their usual support networks (friends and family) for help. Therefore, social support from NGOs and support groups with other women living with HIV become critical for women to cope as they feel safe and included (Rael et al., 2017). Since both HIV and domestic violence are concealable stigmatized identities, women are likely to suppress their thoughts, which leads to more intrusive thoughts about the stigmatized identity (Major & Gramzow, 1999; Wegner & Erber, 1992). Rather than trying to avoid social contact or trying to suppress negative thoughts, interacting with other women living with HIV may be seen as an empowered

way of coping (Shih, 2004). It allows women to feel part of a group and reject negative public stereotypes about themselves, such as associations of HIV status with poor moral character, which improves their self-esteem and social functioning (Shih, 2004).

Overall, these findings point to the importance of acknowledging the role of community and familial support in promoting resilience (Hamby et al., 2016). They also underscore the importance of identifying other "protective factors" that allow women to live well despite experiences of stigma and violence. It might be helpful to identify "role models" who overcame experiences of intersectional stigma and are leading happy, healthy lives. Seeing someone living with HIV who is successful and flourishing may give them the additional boost they need to cope with their own negative experiences. Women have reported viewing their past negative experiences of intersectional stigma as sources of their present strength (Rice et al., 2018). Identifying more such factors that helped women to successfully cope with stigma may allow both women and healthcare providers to use this information to help other women who are presently struggling with experiences and fears of intersectional stigma and violence (Shih, 2004).

#### 6.4 Conclusions

Women experiencing intersectional stigma of HIV, domestic violence, and other marginalized identities were coping with their negative experiences. Their own internal resources, as well as social support from others, strengthened their resilience, which helped them to cope. An empowerment approach to coping, which allows women to live well despite their negative experiences, may help them to cope better. Emphasizing women's positive identities to mitigate stigma and identifying protective factors that have helped them to successfully resist stigma may help newly diagnosed women with HIV to cope better with experiences of intersectional stigma and violence.

As information about HIV anti-discrimination legislation can itself help women cope, this discussion on various coping strategies takes me to my final findings chapter, which is

about the 2017 HIV Act. In the next chapter I examine whether the Act has been able to protect women from HIV-related violence.

# Chapter 7: The utility of the 2017 HIV Act in protecting women living with HIV from domestic violence

My final research question examines the recent HIV/AIDS (Prevention and Control) Act enacted by the Government of India in 2017. The Act was hailed as a landmark step towards eliminating stigma and discrimination against people living with HIV. However, there were delays in implementation, and the Act was notified a year later in September 2018 through an official notification in the national gazette. Although the main objectives of the law are to prevent stigma and discrimination in healthcare, employment, public spaces, education, and shared households, the objectives are less clearly defined in matters of violence against women. In order to understand the Act's effectiveness in protecting women from domestic violence, I will examine the current Indian policy environment with regard to violence and anti-discrimination. I will then discuss my findings from semi-structured interviews conducted with women living with HIV and key service providers, as well as a critical reading of the Act itself, to examine awareness of the Act among women living with HIV, difficulty in women's access due to structural discrimination in the system, and knowledge of the Act among key service providers. Finally, I will examine the particular clauses of the Act as it applies to women living with HIV and whether they can effectively protect women from domestic violence, as it was intended to do.

#### 7.1 Key anti-discrimination and domestic violence Acts in India

In order to contextualize the findings, it is important to discuss the current policy environment in India in terms of violence and anti-discrimination laws. In the last 15 years or so, there has been a significant level of policy action, in that certain sections of Acts have been repealed, while others have been amended and still new ones introduced by the Government or the Supreme Court (Figure 19).

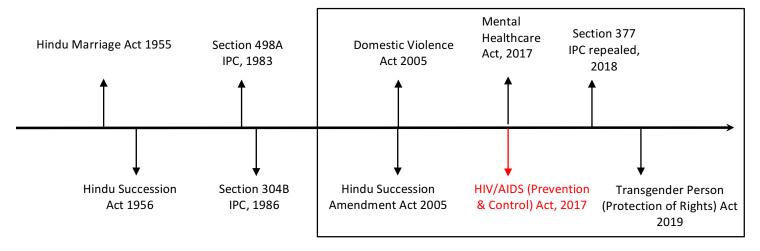


Figure 19 National policies on domestic violence and discrimination.

# 7.1.1 Hindu Marriage Act 1955, Hindu Succession Act 1956, and Hindu Succession (Amendment) Act 2005

As my study participants were mainly married women and widows, it is particularly relevant to discuss the existing Indian laws governing marriage, divorce, and succession rights. Although India is a secular country, the majority of the population and participants in the study were Hindu. Therefore, I will focus on the Hindu Marriage Act rather than going into the specifics of Personal Laws for other religions (Christian, Muslim, Parsi and Jewish). The purpose of the Hindu Marriage Act was to codify the law regarding marriage for Hindus and others (Buddhist, Sikh, Jain). According to this Act, a marriage can only take place between two Hindus if they do not have a living spouse at the time of marriage, are of sound mind, are not related, and are above 21 years of age for males and 18 years of age for females (Ministry of Law and Justice, 1955). The Act also sets out grounds for divorce, which include (1) cruelty, (2) adultery, (3) conversion, (4) insanity, (5) venereal disease, (6) renunciation, (7) desertion, (8) presumption of death, and (9) leprosy (this ground was removed by the Personal Laws (Amendment) Act in 2019 to prevent discrimination against people with leprosy) (Ministry of Law and Justice, 1955). The ground for divorce based on having a communicable venereal disease is particularly relevant for HIV.

The other important Act with relevance to Indian women is the Hindu Succession Act of 1956 and its amendment by the Supreme Court of India in 2005. One hundred years after the enactment of a colonial era law, the Hindu Widows' Remarriage Act 1856, which denied Hindu widows rights to their husbands' property, the Hindu Succession Act of 1956 took a major step forward when it ensured the rights of widows to their husbands' property after remarriage. However, the Hindu Succession (Amendment) Act 2005 went a step further by repealing two major gender discriminatory clauses of the 1956 Act: (1) section 39 did not give daughters rights equal to those of their brothers to the shared ancestral property of the Hindu undivided family and (2) section 24 denied widows the right to their deceased father or brother-in-law's property once they remarried (Gupta; UN Women, 2005). This last piece is important as a large proportion of women living with HIV in India, and in my study, are widows and are often denied their right to property.

# 7.1.2 Section 498A, Section 304B, and Protection of Women from Domestic Violence Act, 2005

Section 498A was incorporated into the Indian Penal Code (IPC) in 1983 to prevent "cruelty to a woman by her husband or any relative of her husband" (The Indian Penal Code, 1860: Section 498A). Its main aim was to prevent dowry deaths, along with Section 304B (The Indian Penal Code, 1860: Section 304B), which criminalizes suspected dowry deaths within seven years of marriage. The Protection of Women from Domestic Violence Act 2005 was enacted, as its name suggests, to protect women from domestic violence. Section 498A and in the case of death 304B of the IPC were until then the only laws available for dealing with cases of domestic violence. Section 498A is a criminal law that is cognizable (immediate arrest), non-bailable, and compoundable (cannot be withdrawn), but it was felt that 498A often led to breakdown of marriages and there were reports of widespread misuse by women (Kumar, 2019). The Domestic Violence Act 2005, on the other hand, is mainly a civil law and provided a milder alternative for dealing with cases of domestic violence while also broadening the definition of domestic violence (physical, sexual, verbal/emotional, and economic abuse) and "domestic relationship"

(wives, unmarried partners, mothers, daughters, and sisters) for the first time in Indian law. Under Chapter III of the Act, a woman has the right to (1) "apply for a protection order, an order for monetary relief, a custody order, a residence order, and/or compensation order", (2) access to "free legal services under the Legal Services Authorities Act, 1987", and (3) "file a complaint under Section 498A of the Indian Penal Code" (Ministry of Law and Justice, 2005). The Act ensures the appointment of Protection Officers who must help women file a complaint, find them a shelter home should they need one, and get them access to free medical aid should they require it (icrw.org). There have been criticisms of the Domestic Violence Act for not living up to its promises: protection officers are often not available, states have no provision of shelter homes specifically for survivors of domestic violence, and the courts take a long time to pass maintenance orders or resolve cases (Gupta, 2020).

#### 7.1.3 Anti-Discrimination Laws

A number of different anti-discrimination laws, which together have implications for HIV control, were passed by the Government of India around the same time as the 2017 HIV Act.

#### Mental Healthcare Act 2017

The Mental Healthcare Act 2017 was enacted to empower individuals with mental illness, giving them agency regarding their own treatment decisions, ensuring their treatment at appropriate facilities, destigmatizing mental illness, and decriminalizing attempted suicide by striking out Section 309 of the IPC (Mishra & Galhotra, 2018).

#### 2017 HIV/AIDS (Prevention and Control) Act (HIV Act)

A group of HIV activists, a small group of lawyers from the Lawyers Collective, policy actors, and programme managers of NACO came together to propose a law specifically for HIV. It took a long time to convince Parliamentarians that there was a need for an HIV-specific law because of the silence and stigma associated with the disease. Finally, in

2014, the HIV Bill, known as the Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Bill, was formally introduced in Parliament by the Minister of Health and Family Welfare (Times of India, 2017). The 2017 Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Act (HIV Act) received Presidential assent on April 20<sup>th</sup>, 2017. The Act was implemented nationwide, a year later, on September 10<sup>th</sup>, 2018 through a notification in the Official Gazette (Ministry of Law and Justice, 2017). The complete Act has been presented in Appendix 7.

The object of the Act is to (1) prevent the spread of HIV/AIDS and (2) to prevent discrimination against people living with HIV. Some key provisions are: people living with HIV cannot be discriminated against in matters of employment, healthcare, living in shared households, other services such as in public spaces, use of public baths, or funeral services. Forcible HIV testing is prohibited as a criterion for employment, school admission, or access to healthcare. People living with HIV cannot be subjected to any kind of medical treatment, intervention, or research without prior informed consent. The law also prohibits disclosure of HIV status without consent, including by a healthcare provider. Welfare measures are to be provided to people living with HIV by the state and central governments. Special provisions for women include prohibition of forced sterilization, the right to live in a shared household, and the right not to disclose their status to partners if there is a reasonable expectation of violence. Penalties for violations include a fine or a jail term.

## Repeal of Section 377 of the IPC

Four days before the notification of the 2017 HIV Act, on September 6<sup>th</sup> 2018, Section 377 of the IPC, which prohibited "carnal intercourse against the order of nature" was repealed by the Supreme Court of India when applied for homosexual sex between consenting adults. Section 377 had previously been used to prosecute homosexual behavior and this landmark judgement effectively decriminalized homosexuality in India

(Tamang, 2020). The modification of Section 377 had positive implications for HIV/AIDS prevention and control efforts and may be seen as complementary to the 2017 HIV Act.

# Transgender Person (Protection of Rights) Act 2019

In India, *hijra* is a commonly used term to describe transgender persons, transsexuals, cross-dressers, eunuchs, and transvestites, who face widespread social discrimination. Individuals belonging to this group are at higher risk of contracting HIV/AIDS. In 2014, the Supreme Court of India passed a landmark ruling that recognized transgender people as a third gender. This was followed by a 2016 Bill, a 2018 Bill and the 2019 Transgender Person Act, all of which were widely criticized for certain provisions that were not in line with the 2014 Bill. Some of the provisions described as regressive were (1) reduced punishment for crimes against transgender people, (2) criminalization of begging by this group, (3) lack of clarity on civil rights and benefits, and (4) the need for gender reassignment surgery in order to obtain a transgender certificate (Seth, 2021). The Act prohibits discrimination against transgender people, gives protection to transgender children, and asks states and institutions to provide welfare measures for transgender persons. Although it does not go far enough, this Act, along with the modification of Section 377 and the 2017 HIV Act, may be a step in the right direction for protection of transgender people, a group with a high risk of both HIV and violence in India.

#### 7.1.4 Constitutional Protections and HIV Case Law in India

Before the enactment of the HIV Act, people living with HIV were protected by certain fundamental rights that extend to all citizens under the Constitution of India. These rights include Article 21, which guarantees the right to life and liberty (including the right to privacy), Article 14, which states that no person shall be denied equality before the law, and Article 15, which prohibits discrimination based on religion, caste, sex, and place of birth (UNDP, 2016). These articles of the Constitution have been the primary means by which people living with HIV have had recourse to the law in cases of discrimination. However, since these are broad protections that are open to interpretation, the outcomes

have been different for different people. Some key rulings from case law invoking these constitutional protections are discussed below.

The Dominic D'Souza Case: The first case of HIV discrimination to be heard in an Indian court was that of Mr. Dominic D'Souza, who was held in an isolation facility under Section 53 of the 1987 Goa Public Health (Amendment) Act, after testing positive for HIV. His mother filed a case in the Bombay High Court, invoking Articles 14 and 21 of the Constitution. The initial court ruling was that isolation was needed on public health grounds, but after 64 days in detention Mr. D'Souza was released, not because he had a fundamental right to liberty but because his HIV blood test was perhaps faulty (Krishnan, 2003). Section 53 was subsequently amended so that isolation for people living with HIV was discretionary rather than mandatory.

MX of Bombay vs M/s Z, 1997: This was a historic ruling by the Bombay High Court involving the case of a casual laborer who sought permanent employment from the company where he was working. Upon testing positive for HIV during the routine medical examination for his permanent posting, he was not only denied the permanent role but was also removed from his present position. The laborer filed a petition invoking Articles 21 and 14 and the court ruled that unless the HIV status of the person interferes with his ability to work or poses a risk to others in the work environment, the employer cannot deem a worker unfit for employment. The court directed the company to compensate the worker for his lost wages and reinstate him in the company (Krishnan, 2003).

Mr. X vs. Hospital Z, 1999: Mr. X from Nagaland was advised to have a surgical procedure. He traveled with a friend to Chennai to undergo surgery, after which he traveled back home. In the meantime, Mr. X was engaged to be married, but sometime before the wedding in 1995, the Nagaland state minister received a call from the Chennai hospital to inform him that Mr. X had tested positive for HIV. Upon hearing this news his wedding was cancelled and he left the state due to ostracism from his community. He went on to file a complaint in the National Consumer Disputes Redressal Commission stating that his right to privacy had been violated by the hospital, but this was dismissed

by the Commission. Mr. X subsequently filed a case in the Supreme Court of India to appeal against the legality of the dismissal of his complaint. Instead of considering his appeal, in 1999 the Supreme Court decided (1) that Mr. X did not have a right to privacy since spreading a communicable disease is a crime under the IPC, and (2) that since having a venereal disease was a ground for divorce in India, people living with HIV did not have a right to marry. The ruling on the right to marry for people living with HIV was reversed in 2003, but the denial of privacy rights remained (Krishnan, 2003; UNDP, 2016).

These examples illustrate how the protections offered by the Constitution have been interpreted by different Indian courts. The 2017 HIV Act takes away the room for (mis)interpretation by clearly defining the grounds for non-disclosure and discrimination.

The Acts and case law described above give a contextual view of the Indian policy environment within which the 2017 HIV/AIDS (Prevention and Control) Act is situated. It provides the backdrop against which I present my findings regarding the usefulness of the 2017 HIV Act in preventing discrimination, including acts of domestic violence, against women living with HIV in India. As described in detail in the methodology (Chapter 3), indepth interviews with women living with HIV and key informants were used to generate the findings for this chapter. The themes identified from the thematic network analysis are presented in Table 18.

Table 18 Examples of themes on the 2017 HIV Act

Global Theme	Organizing Themes	Examples of Basic Themes
The 2017 HIV Act was not designed to protect women against domestic violence.	Women's awareness and perceived effectiveness of the 2017 HIV Act.	Most women are unaware of the Act. Stigma and ambivalence about using the Act.
	Difficulty of access due to structural challenges.	The Police. Legal Aid Services. The Courts. Public Offices.
	Limited knowledge within the system.	Limited implementation of the Act. Limited awareness among healthcare providers. Limited awareness among police and judiciary. Limited understanding among key service providers.
	Weaknesses in certain clauses of the Act.	Non-disclosure clause for women in conflict with existing laws. Inability to guarantee "right to residence". Penal clause too weak. Welfare measures not clearly defined.

## 7.2 Women's awareness and perceived effectiveness of the 2017 HIV Act

The interview included a screening question about awareness of the 2017 HIV Act. Initially, when women responded "no" to the question "Are you aware of the HIV Act", they were asked no further questions in the in-depth interview. For the later interviews, I decided to explain the HIV Act to women and then ask them if "they would use the Act had they known about it" or if "they thought women would use the Act once they got to know about it." I decided to make this change to my interview topic guide because nobody seemed to be aware of the Act and this led to a richer discussion about it even if women were not actually aware of it.

# 7.2.1 Most women are unaware of the Act

In order for any new law to be successful, people must be aware of it, particularly those who need to access it. Women in the study demonstrated very little awareness of the Act, with almost all saying they were not aware that such an Act existed. However, three women showed some awareness of the Act, two of whom were sex workers and had heard from the regular HIV clinics that operate for sex workers in red light areas. The only

other person who was aware was involved with work at an NGO, but did not know of anyone who had used the law yet:

"Then there is this law that has come out, the '17 law that you said, that if you say, call and say, there is a fine, this is being said from everywhere... I don't think anyone has gone yet. I have not heard of anyone going. But I know there is a law." (CL004, 35 years)

In order to get an idea of awareness of the Act among the larger population of women living with HIV, other than women participating in the study, key service providers were asked about their thoughts on awareness among people living with HIV. From their answers, it was clear that awareness was limited. The doctor from an ART center did not think there was much awareness among people living with HIV, despite being informed about the Act:

"Yes, whether patients know is a good question, perhaps not all patients know about this Act, but in our ART centers there is a poster displayed in Bengali, I mean in the local language, not that everyone can read, but they are told that 'you will get this and this', no one can force you to reveal your status, no one can tell you at work that you cannot come to work from tomorrow, [2:40-2:43] because you are positive, that these things are not right and the law is for you, these things are told to them. Maybe it is not told every day because the workload is so high but the community care coordinator who is in front, she tells them about the different facilities that they can get, there are some government schemes where they can get certain benefits, so they are informed of those so that they can avail those ... or their children may be denied admission in school because of HIV ... that these things are not right and that the law is for them, we inform them of these. But it's not like everyone knows or everyone understands, it's not like that. There is still quite a bit of awareness needed, at least in this matter" (Physician, ART Center).

Surprisingly, the ART counselor from the same center had little knowledge of the Act herself and answered, "No, at least I have not seen that" when asked if clients knew anything about it. Similar thoughts were shared by a public health official and a lawyer, which suggested there was little awareness among people living with HIV in the state:

"Very few people know about this Act. Till now the Act, see till the notification is done, Government of India has until now started work on awareness programs, like work is being done about this [Act] in the various IECs [Information, Education, Communication], but this has not yet reached the general public" (Public health official).

"But when we have gone to work for NGOs then we have come face to face with a lot of people like this, those who are living with a lot of fear, they don't know where to go, and till now the common man is not aware of this Act, not conscious of it, so we were not able to inform them about this Act" (Lawyer).

The picture seemed to be the same for the rest of India, as reported by a key informant from the Positive Women's Network (PWN+: an India-wide network of women living with HIV), who said that there was very little awareness of the HIV Act. Some key informants felt that the Covid-19 pandemic was an important cause for delay and there were plans for widespread dissemination through awareness programs soon:

"But a separate awareness about the HIV Act has not been started yet. That will happen. It was supposed to start this year, I mean the work that happens as part of the current financial year, but because of the Covid pandemic situation we are not been able to work. I mean we have talked about incorporating the HIV Act into the rest of our sensitization programs. I hope the awareness will be created by next year. I mean the work of creating the awareness will begin, it will not be created right away, I mean that doesn't happen, there is a time needed for awareness" (Public health official).

## 7.2.2 Stigma and ambivalence about using the Act

When women were explained some of their rights under the Act, such as that no one can stigmatize or discriminate against them or make their status public without their consent, and then asked if they would use these provisions in cases of violations, to file a case, there were ambivalent responses. Some women said they would use the Act against their in-laws if they knew:

"Yes, if I knew I would surely have used this law against my father-in-law. I did not know otherwise I would have" (CL030, 39 years).

Others expressed a degree of hopelessness when asked if they would use the Act when they experienced discrimination, had they known:

"What will I get from taking a step? Whatever has to happen has happened. Now there is nothing left" (CL031, 34 years).

A woman who had never experienced HIV-related discrimination or domestic violence herself felt that she would file a complaint if anyone behaved badly with her, but that people would hesitate to use the law if their status was not generally known:

"Yes 100%, if they behave very badly with me then I must complaint... But people will be afraid to for fear of revealing their status, but if my status is known then I will not be quiet, I will definitely speak up" (CL021, 32 years).

Another expressed the same fear, that if she filed a complaint and her status became known she would experience problems elsewhere (anticipated stigma). Therefore, she felt women would not have the courage to file a complaint:

"They will not have the courage. Say this is where I am working and this is my workplace, my workplace is next door to my home. Say there is something with the landlord and I say I have HIV and so on, say the landlord lets the neighborhood know, then it will be difficult for me to work in the company. They will say we cannot keep you at work. They will not say that it is because you have this disease, they will find an excuse to fire you. This is what isn't it?" (CL029, 34 years).

This sentiment was echoed by key informants who felt that, despite women being made aware of the law, they might be afraid to come forward and use it because of anticipated stigma:

"Fear of society, maybe the police, the law. The thing is, for a woman, they have to face different remarks, the kind of remarks that a lot of women have to face initially, that is a reason, maybe for that fear they do not go forward...but most importantly, the patients must also come forward. We need to tell them so we will [laughs] but how much they will be able to come forward and take the step is another thing" (Counsellor).

However, protection in such matters is afforded by Section 34 of the Act, whereby the name of the HIV-affected person cannot be published "in any manner in any matter leading to the disclosure of the name or status or identity of the applicant" (2017 HIV Act).

"They need to know that when you are going to a court for being discriminated, the law says that you can hide your status, you don't need to reveal, and you know the respondent like don't need to, it protects your identity as well. You can use that clause so that your identity is protected and can still you know fight for your rights. So, lawyers are the ones who have to reassure them to use that clause, without revealing one's HIV status they can access" (HIV Activist).

Although women must be made aware of this clause, it may not be sufficient for them to

feel protected from the discrimination they may encounter in their immediate surroundings, if their status becomes known as a result of filing a case.

Self-stigma might be an additional barrier to accessing the law. Women discussed how they would be unwilling to seek help in cases of HIV-related domestic violence, which is the first step in accessing the law, due to the shame of living with HIV:

"How will I ask [for help] from them? [laughs] How will I be able to tell them? I will be ashamed to even try to say anything" (CL012, 32 years).

The few women who already knew or were told about the Act during the interview did not feel very optimistic about it either. A sex worker who was aware of the Act before the interview felt that "nothing will change" (CL026, 45 years) when asked if such laws would bring about change in people's attitudes. Another woman, who was diagnosed after her husband tested positive and had not disclosed to anyone outside her immediate family, expressed fear and helplessness despite the Act being in place, if her community got to know:

"Even if laws are enacted, despite there being laws we will not be able to do anything... What will we do? If they somehow get to know then will we be able to do anything? We won't be able to do anything. It is a rural area no, they don't understand. That is what I think" (CL020, 32 years).

There is a prevailing attitude in India that the legal system is too slow and often ineffective. This was evident in the words of one participant who was aware of the Act, but felt that women were not going to court because of perceived delays in cases being resolved:

"The law is not yet working, as such no one is going to the law as yet, think it will be a waste of time, some people think time will be wasted. A lot of people don't have time, going to the law means a lot of time of hers will be wasted. Maybe she

will get success, the result will be good, but it is not possible for her to give that time. It takes time to go to the law and it's not like they can take a decision as soon as you go, they cannot do that. They will say will go today, go tomorrow, no one has so much time to spare" (CL004, 35 years).

## 7.3 Difficulty of access due to structural challenges.

Gender discrimination in India makes it difficult for women to register cases with the police or file cases in court. This is particularly true for cases of domestic violence, as the stigma attached to reporting what is considered a private family affair makes it even more difficult to file a case. Combined with HIV stigma, this is likely to make it more difficult for a woman with HIV, who is experiencing violence at home, to file a case. Although none of the women or key service providers could give specific examples of anyone going to court using the HIV Act, there were numerous examples of structural challenges, such as discrimination, faced by women living with HIV when trying to access services in various public offices. This indicates that structural discrimination against women and HIV is likely to be a considerable barrier to women filing a case using the HIV Act, even if they are aware and confident enough to use it.

## 7.3.1 The police

The first step in filing any kind of domestic violence case is usually with the police. Women often face discrimination due to the patriarchy in the system. A key informant from a domestic violence NGO talked about how the first question she would be asked would be "what did you do to provoke the violence?". The situation is worse when the woman has HIV, as described by a key informant from PWN+:

"Women with HIV is more difficult than the normal women...The HIV+ women there will be asked so many questions, even the policeman and also the family member. Very vulnerable questions and all they will ask" (PWN+).

Although almost three-quarters of women in the study had faced some domestic violence during their lives, a very small proportion actually reported it to the police. Two women who had filed a complaint for domestic violence prior to diagnosis felt they would be unable to do so if they had HIV:

That is what! Would they have or not, that's why, now after going to some places I am learning something, hearing things from people at the hospital and getting sharper as well. I don't think they would [register a case] at the time [if she had HIV]" (CL012, 32 years).

However, there were several others who felt that the police would help regardless of HIV status. One woman, who had received help from the police in stopping community violence against her and her husband after their diagnosis, felt that "help can be got from the police" in instances of domestic violence, despite them knowing of the woman's status (CL005, 38 years).

### 7.3.2 Legal aid services

Once a complaint is filed with the police, the woman can choose to take it to court. In order to take a case to court women must engage the services of a lawyer. In India, a large proportion of women are financially dependent on their husbands and may not have sufficient resources of their own to engage the services of a paid lawyer. However, the National Legal Services Authority provides free legal aid, which includes the services of a lawyer, payment of all court fees, preparation of pleadings, drafting of all legal documents, and payment for certified copies of all legal documents, for all women. The service is available at both district and state levels. However, women living with HIV were generally not aware of this service that may make it easier for them to use the Act:

"... the law was enacted in 2017, the HIV Act, that was not there before, so here HIV patients need to be told that they will get it free of cost. So they need to be told as long as they are women they will get it, we have to remember that the

convenience of the Legal Services Authority Act or free legal aid is available to all women. That means if a HIV patient is a woman she will definitely get it ..." (Lawyer).

For those who were aware of the service, though, there were some complaints of bad behavior from those offering legal aid at the district level:

"And the free legal aid they will say 'it's like that only what I can do, go' [shouting]. They'll treat like that only ok. 'So you came no? You wait.' Ok they will torture like anything. They'll never talk politely, they never explain this is the system, you have to do this way, that way, [they] never say, ok? When they do the state level petition only they will talk politely" (PWN+).

## 7.3.3 The courts

Once they overcome the hurdle of accessing free legal aid services or engaging the paid services of a lawyer, women must have cases tried in court. Although there were no examples of cases tried under the HIV Act, there were reports of perceived and actual discrimination within the courts, with a lawyer asserting that if a person living with HIV files a case in court, "of course they will" face stigma and discrimination in courts. This statement from the lawyer was supported by an anecdote from a case in 2018, shared by a counselor, that illustrated the deeply rooted structural discrimination in the legal system for women living with HIV:

"... When the reports were presented to the judge, that she has this report, at the time she was standing quite close to the judge, below, and I was sitting where the benches are, where the advocates sit, I was sitting behind them. So when the judge saw that she was HIV+, I saw that he is a judge, but his thinking is so bad, as soon as he saw that she has this, his way of talking changed completely, he told the girl, 'hey you (insulting way of addressing a person in Bengali) girl, don't stand here, you stand there, stand afar, go stand far from here' and sent her near

the gate. So, I felt really bad but I cannot say anything over there, while the hearing is going on I cannot say anything, even our advocate became really quiet when he talked like this with her. Then the judge asked her, 'where did you go and what have you been up to? That you are HIV+'. She did not even really know that she had it at the time. And all the advocates, usually there aren't that many people there when there is a case with a below-18 then there aren't too many people, but there are many advocates. So, they are there, in front of them only he was saying all this to her, 'what did you do with which guy that you have this diagnosis'" (Counselor).

This case was being tried under the POCSO (Protection of Children from Sexual Offences) Act, but the judge was unaware of the clause of the HIV Act (which was already in place at the time) which clearly states that the identity of a person with HIV cannot be revealed in court. More importantly, the structural discrimination within the legal system meant that the case remained unresolved:

"Our advocate... he did not listen to anything (s)he had to say on that day. Just because he saw that she was HIV+. Even now this case is going on. Just imagine that this is under the POCSO Act, a case under the POCSO Act is supposed to be completed within one year. And this has been going on for the past 3.5 years. Only the charge has been filed, there is still a long way to go" (Counselor).

#### 7.3.4 Public offices

Women often talked about asking for help from local members of the administration in matters of domestic violence. These members would adjudicate matters for families rather than going to the police or to the courts. Therefore, it is important that these offices are a safe space where women can ask for help and be directed to the District Legal Services Authority or the police if needed. However, even here women reported discrimination once their HIV status was known. The HIV Act ensures access to welfare

measures under Section 15. Yet, this story shared by a participant shows the discrimination that happens in public offices, even in 2019, when the HIV Act was in place:

"I said I was not able to run the family with my daughter, so I submitted a written application to a project requesting help from the BDO [Block Development Officer], so as soon as I submitted the letter and told them verbally, then upon hearing he immediately threw me out, 'stand there', then again, he said, 'not here, not here, go to the ration department, this cannot be done here' and sent me there, threw me out immediately, I could understand" (CL030, 39 years).

Although a limitation of local administration for not helping a woman might be its own biases around HIV, there were also reports of the administration being helpless in the face of community violence against those living with HIV, due to general fear and misconceptions about the disease:

"You know sometimes also local administration does not protect this family or this particular woman or HIV infected person because you know they know that they are very vulnerable. And sometimes administration also very helpless, people have the myths and misconception that HIV is very contagious, so police and local administration sometimes they are also helpless because there is no way when violence is happening, there is no way to let the people to understand about the dos and don'ts, and pros and norms of HIV and AIDS, so that sometimes the government have the will to protect the life, for the entitlement, for everything, but you know that a common mass sometimes, if they doesn't want to understand anything, so administration also sometimes helpless" (Official, HIV NGO).

## 7.4 Limited knowledge of the Act within the system

Even if women overcome the first two barriers, their own awareness of the Act and the structural discrimination that they may encounter while trying to use it, the third barrier to the success of the Act is limited implementation and lack of knowledge within the system.

Although many key service providers were aware of the existence of the HIV Act, they had limited knowledge of it. Most had no knowledge of the different clauses of the Act and, for those who did, their understanding was ambiguous. This means that, even if a woman living with HIV is made aware of the Act, she will face difficulties within the system if she tries to use it, as described in the following sections.

# 7.4.1 Limited implementation of the Act

The HIV Act was implemented for the whole of India in September 2018 through a notification in the national gazette. Statewide notification had not been completed for most states, as reported by key informants' familiar with this issue, and was still ongoing in West Bengal at the time of writing. It seemed that the problem with implementation was not restricted to West Bengal. The key informant from PWN+ felt that "there is no implementation planned for every state, it's all in the paper only." However, much progress has been made since the time of interviews in late 2020 and mid-2021. The statewide list of ombudsmen and complaints officers was updated recently on the NACO website and at the time of writing 24 of 28 states had appointed an ombudsman, West Bengal having appointed one for every district. The national rules of the Act had also been framed and updated on the NACO website (NACO, 2018). One key informant reported that the state would be gazetting the Act shortly, following which there will be widespread dissemination. In summary, implementation of the Act remains limited to date, possibly due to pandemic-related delays reported by key informants involved with the process.

#### 7.4.2 Limited awareness among healthcare providers.

Healthcare-related discrimination towards HIV patients is a well-documented phenomenon worldwide. In the interviews, a few women reported experiences of discrimination in healthcare settings:

"That day only the contractions started because I walked around, they admitted me on Sunday. They admitted me on Sunday, the whole of Sunday I had

contractions, had the baby right at the stroke of dawn. The whole day no one touched me because I had HIV" (CL008, 45 years).

The HIV Act is a non-discrimination Act which has a strong healthcare component; that is, no one can be denied treatment due to their HIV status, according to Section 3c: "No person shall discriminate against the protected person on any ground including any of the following, namely: — the denial or discontinuation of, or unfair treatment in, healthcare services" (Section 3(c), 2017 HIV Act). Although most key informants reported that healthcare discrimination was a lot less than previously seen, it was evident that it persisted, especially in private settings:

"In the case of surgeries there are a lot of problems. No matter what they say, I mean they will definitely harass, they will keep postponing, I have seen, non-government won't even touch them, the nursing homes as soon as they hear HIV, they more or less take their hands off [the case]" (Counselor).

Key informants from an HIV NGO discussed how "there has been a slight reduction" in discrimination in Government hospitals. This is likely because the public sector, unlike the private sector, has always come under the purview of constitutional guarantees against non-discrimination, through court rulings on cases of HIV discrimination (UNDP, 2016). However, even within the Government sector providers find covert ways to deny treatment to people living with HIV:

"Government cannot avoid, but they will keep making excuses, get this tested today, get that tested tomorrow, today this is high so we cannot [operate], tomorrow that is high, today we don't have a bed, tomorrow something else, even recently we are facing issues. The thing is they are not saying it, they are not saying it to our faces that we will not take positive patients or anything like that, they won't say it, they won't say it out loud, they know they will get in trouble if they say it, so they don't say it, but they will harass, they will keep making excuses. Today there

is no bed, tomorrow this report is missing, day after tomorrow another report is missing, get an updated report and so on" (Counselor).

Another manifestation of the lack of awareness and implementation of the HIV Act in healthcare settings is the violation of the non-disclosure clause. Disclosure by healthcare personnel to family members without the consent of the patient has been happening while the HIV Act is in place. An elderly woman who had separated from her husband before having HIV discussed how her status was disclosed to her nephew at a government hospital without her being told:

"When they got this report from [name of hospital], they didn't want to give the report, either we will give the report to her grown up son or to her husband. My daughter argued 'please give me the report, my mother is sick, I need to consult a doctor, buy medicines.' So, they said 'who are you' so she said, 'I am the daughter,' they said 'no you bring a man,' so my nephew went and when my nephew went he was given the report, said, 'her mother, she is a woman so we couldn't tell her, we felt uncomfortable, she must have done something bad [sexual] with someone, that's why she has this disease.' My nephew heard that and whether he told other people or not I cannot say" (CL011, 60 years).

In this instance, the woman did not have a husband, but those with husbands must face similar experiences which puts them at risk of violence.

Not everyone in government hospitals was aware of the HIV Act either. A physician at an ART center was aware, but the ART counselor in the same center was barely aware. A nurse at an HIV NGO was unaware of the Act, but the counselor and physician at the same NGO were well aware of it and its clauses. A counselor at a women's shelter and a psychologist at a public hospital had just heard about the Act and not much more. A postgraduate trainee who had been regularly treating HIV patients for several years did not even know that such an Act existed:

"No, I haven't really heard about the Act, but yes, we mainly read the guidelines, but I have not heard about the Act. If there is anything about the Act in the guidelines then it is not very evident" (Post-graduate medical trainee).

# 7.4.3 Limited awareness among the police and judiciary

Penalties under the HIV Act include a fine, a jail sentence, or both. In cases of domestic violence, if a husband or family member discloses the status of a woman without her consent (Section 8, 1(i)) or evicts her from a shared household (Section 29), these will be considered violations of the Act. Since the police and the judiciary are the main agencies who will enforce the penalties for violations of the Act, it is critical for them to be aware. Both the lawyer and the judge interviewed for the study were vaguely aware of the Act until it was brought to their notice. When asked specifically, the judge felt "there is not adequate awareness among the judiciary about the functions and importance of this Act," while the lawyer seemed frustrated by the lack of awareness in the system:

"There is absolutely no awareness! Absolutely no awareness! No one knows that an Act like this exists. Because they have not been informed... So, my opinion is that no one knows, judicial officers do not know, the police do not know, the police do not know what is their duty, what the police need to do, BDO [Block Development Officer] SDO [Sub divisional Officer] do not know, the hospitals, here medical providers have a vital role to play, they do not know what steps they have to take, doctors need to be given trainings, the police need to be given trainings, judicial officers need training, they need to know. If there is a lawsuit in some court today then the judge will also be taken aback that 'such an Act exists?" (Lawyer).

Section 41 describes the penalties under the Act and states that "No court other than the court of a Judicial Magistrate First Class shall take cognizance of an offence under this Act" (Section 41, 2017 HIV Act), but it is unclear whether magistrates are aware of the

#### Act either:

"See the first thing is there is no awareness about it, no one will know this exists, where will I go, from what I understood, which court has been given power? I have at least not seen a specific court being mentioned, that a particular court magistrate triable, we have to assume because this has a punishment for up to 2 years, it is called magistrate triable, meaning a lawsuit can be filed with the magistrate, but I have a feeling that the magistrates have no awareness of it, they will have no awareness of it" (Lawyer).

## 7.4.4 Limited understanding of the Act among key service providers

Even though some key service providers were aware of the Act, understanding of its clauses differed. Even news articles in the popular media (Perappadan, 2018) seemed to present a faulty understanding of the Act. For example, articles said that the right to residence clause, which is pertinent for domestic violence survivors with HIV, is only guaranteed for those <u>under</u> 18 years of age. A reading of section 29 of the Act clearly states that:

"Every protected person shall have the right to reside in the shared household, the right not to be excluded from the shared household or any part of it and the right to enjoy and use the facilities of such shared household in a non-discriminatory manner" (Section 29, 2017 HIV Act).

This is followed by an explanation of the clause:

"Explanation.—For the purposes of this section, the expression "shared household" means a household where a person lives or at any stage has lived in a domestic relationship either singly or along with another person and includes such a household, whether owned or tenanted, either jointly or singly, any such household in respect of which either person or both, jointly or singly, have any right, title, interest or equity or a household which may belong to a joint family of which either person is a member, irrespective of whether either person has any

right, title or interest in the shared household" (Section 29, 2017 HIV Act).

Here, domestic relationship is defined in section 2(e) as:

"...a relationship as defined under clause (f) of section 2 of the Protection of Women from Domestic Violence Act, 2005" (Section 2(e), 2017 HIV Act).

To ensure that my understanding was correct, I asked a judge to explain the clause to me and his answer underscored what was evident from reading the Act:

"Section 29 of the Act safeguards the protected person's 'right to reside' in the shared household. The right contains in itself a 'right not to be excluded' from the shared household and from enjoying the facilities of the household in a non-discriminatory manner. The aforementioned sections operate to provide protection of the rights of HIV-affected persons; any discrimination or any act done to cause hatred or violence against the affected person is prohibited and punishable... The 'right to reside' protects the HIV-positive persons against abandonment and persecution by family members" (Judge).

There was even a misunderstanding about the name and objective of the Act itself, with one key informant calling it the HIV Act and going on to say that it did not have a role in controlling HIV:

"First of all, it is not called HIV Prevention and Control Act, the Act is called HIV Act. This law is not to control HIV [laughs], the main reason for this Act is to give security to HIV+ people" (Public health official).

A reading of the Act and a discussion with the judge provided clarity as he described the two main objectives: (1) to control the spread of HIV and (2) to prevent discrimination against people living with HIV:

"The Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Act, 2017 hereinafter is referred to as the 'said Act' in short, has two primary objects to achieve; *firstly*, prevention and control of the spread of Human Immunodeficiency Virus (HIV in short) and Acquired Immune Deficiency Syndrome (AIDS in short); *secondly*, to protect the human rights of the persons affected by the said virus and syndrome" (Judge).

An important provision for women in the Act was related to disclosure, in that neither healthcare providers (Section 9(2)) nor women themselves (Section 10) were required to disclose their HIV status to their sexual partners if there was reasonable expectation of violence. This clause seemed to be misunderstood by several key informants who were aware of it. Once again, the judge was asked to specifically explain the clause:

"To elaborate, Section 9 of the said Act puts responsibility upon the healthcare worker limited to physician or counsellor to disclose HIV status of the HIV-positive person to the partner. However, under the third proviso to Section 9(2) of the said Act such responsibility to disclose the status vanishes when the HIV-positive person is a woman due to possibility of violence, abandonment which may have severe impact upon the health and safety of the said woman or her children.

Moreover, under Section 10 of the said Act, where it is the infected person's responsibility to prevent transmission by adopting strategies for risk reduction and informing partner in advance about their HIV status, the HIV-infected woman is excluded from such responsibility as well due to possibilities of actions threatening to the health and safety of the woman and her children" (Judge).

One key service provider seemed to understand this clause correctly, that is, that women were not required to disclose to their partners, which meant that the clause toed a fine line between protecting women from violence and controlling the spread of HIV:

"Previously in the guideline they actually could have actually intimate the partner like that if the repeated counseling fails, but now it is more towards the will of the positive woman regarding disclosure to her husband or partner...We have to balance both the situations actually, public health aspect is there and also the gender violence and related issues are also there" (HIV Physician).

When some other key informants were asked about the same clause, their understanding seemed incorrect. For example, the key informant from PWN+ seemed to think that "men also have the same thing [non-disclosure clause] and women also have the same thing [non-disclosure clause];" as did the HIV activist, who was of the opinion that "women have the right to choose whether to or not to disclose, like similarly men can also have the right to disclose". A close reading of the Act as well as the discussion with the judge showed that neither of these interpretations of the clause was correct.

There was also confusion about where a woman should report cases of HIV-related domestic violence: whether to the ombudsman or to the police. An HIV physician with considerable knowledge of the Act suggested that women must go to the ombudsman to file a complaint: "if there is family violence is basically, basically due to the HIV itself, this will also be mitigated [by the ombudsman]." Another key informant seemed unsure about where women should go in case of HIV-related domestic violence:

"Interviewer: So, for domestic violence, ombudsman will not help?

KI013: No. Ombudsman will help only for any discrimination happen in the family within 3 months or 6 months. Not more than that.

Interviewer: Discrimination in the family or ?

KI013: In case they will refer to court or they refer somebody, somewhere else, free legal aid" (PWN+).

A lawyer seemed to think that it was not possible for an ombudsman to handle domestic violence cases and they had to be handled by a magistrate. There was obviously a need

for further clarity around this issue for all key service providers:

"But ombudsman, but generally for cases like this, uhh ombudsman cannot be the authority. Can you understand? In cases like this a magistrate must be given authority, it should not be the authority of the ombudsman. I don't know why they have even brought up an ombudsman here. It is not clear to me... See where there is a penal clause, where there is a penalty, there is mention of punishment, there it has to be magistrate, it is not supposed to be ombudsman. These things need to be clarified further" (Lawyer).

#### 7.5 Weaknesses in certain clauses of the HIV Act

Even if women are able to overcome the first three barriers—their lack of awareness and doubts about the Act, structural discrimination while registering a case with the police or in the courts during trial, and poor knowledge about the Act within the system—a fourth barrier must be rectified through case law followed by amendments to the Act itself. Certain written components of the act significantly undermined its ability to function as a protection mechanism for women experiencing HIV-related domestic violence. This included contradictions within the act itself or in relation to other acts offering similar protection mechanisms. These so-called "fatal flaws" highlight the gaps that need to be addressed in order for the Act to be successful in protecting women from HIV stigma related domestic violence.

# 7.5.1 Non-disclosure clause for women in conflict with existing laws

Under section 9(2) of the Act healthcare providers have been told not to disclose a woman's status to her partner if there is reasonable expectation of violence towards herself or those close to her:

"Provided also that such healthcare provider shall not inform the partner of a woman where there is a reasonable apprehension that such information may result in violence, abandonment or actions which may have a severe negative effect on the physical or mental health or safety of such woman, her children, her relatives

or someone who is close to her" (Section 9(2), 2017 HIV Act).

As described earlier, disclosure by healthcare personnel without consent continues to happen despite the HIV Act being in place. The problem is that under Section 9(3) healthcare providers who disclose to partners will not be liable for any criminal or civil proceedings:

"The healthcare provider under sub-section (1) shall not be liable for any criminal or civil action for any disclosure or non-disclosure of confidential HIV-related information made to a partner under this section" (Section 9(3), 2017 HIV Act).

This considerably weakens the healthcare provider disclosure clause for women in Section 9(2) since providers who disclose to partners cannot be punished for doing so, despite such actions putting women at risk of violence.

The law goes one step further to ensure the safety of women when in Section 10 it states that women themselves do not have to disclose to their partner if there is a reasonable expectation of violence:

"Provided that the provisions of this section shall not be applicable to prevent transmission through a sexual contact in the case of a woman, where there is a reasonable apprehension that such information may result in violence, abandonment or actions which may have a severe negative effect on the physical or mental health or safety of such woman, her children, her relatives or someone who is close to her" (Section 10, 2017 HIV Act).

However, a closer look at this clause reveals that it could actually be dangerous for women not to disclose, as their partner can sue them for fraud (intentional non-disclosure of status), as described by a lawyer:

"Think about it, if she is asked to not inform, then after that she sleeps with her husband he gets infected, is it not an offence? You are knowingly keeping quiet, then the disease goes to someone else, then? This will be a problem! See this is

now going to be fun, this is going to be fun now! The fun is according to our country's law, if someone hides a disease and marries, say a woman is diagnosed with HIV before marriage, now she hides it and gets married, as soon as she marries her husband is infected, let that be, this is an offence!! She hid her disease and got married, this amounts to cheating, cheating! You have concealed [the truth] and married me, that becomes an offence" (Lawyer).

In fact, a protection under the HIV Act is an offence under multiple sections of the IPC, including Section 269 (negligent or unlawful spreading of a communicable disease), Section 270 (malignant or intentional spreading of a communicable disease), and Section 420 (cheating) (hivjustice.net, 2020) (The Lawyers Collective, 2003, pp. 267-276). Simply put, the laws contradict each other. When speaking to the judge informally, he cited a case he knew about, before the HIV Act came into being, in which the bench awarded the man a divorce on the grounds that the woman willfully hid her HIV status before marrying him. Another key informant also seemed to suggest that using this non-disclosure clause could result in divorce:

"KI013: Both the sex, not only for men or women. Both the sex has these rights. Ok, but this is not accepted no? They have to reveal the status. Both of them has to reveal, if one person, can go to the court then they can win a case.

Interviewer: If they don't reveal the status?

KI013: Yeah if they are not reveal the status. Get a divorce. Ok" (PWN+).

The lawyer explained that the Indian divorce appellate could in fact weaken the non-disclosure clause, whereby a husband can choose to divorce his wife (and vice versa) on the grounds of passing on a sexually transmitted disease to him as per the Hindu Marriage Act, 1955:

"Now we have to remember that there is a difference between this Act and the Domestic Violence Act. Domestic Violence Act is violence in ordinary cases and HIV [Act] is when violence happens in cases where there is a possibility of getting

infected from someone. That means, over here if someone says 'if she stays in the home I have the possibility of getting infected from her, I won't stay with her,' then he has a reason. What is that reason you know, now this is interesting, you know what is interesting, the Divorce Law that we have has 7 sections that states the grounds for divorce. It states there that if either the husband or the wife has a communicable disease then it is a ground for divorce" (Lawyer).

Other grounds on which an Indian man may seek divorce from his wife include non-consummation or refusal to consummate a marriage, as well as cruelty and if she refuses sexual activity (The Lawyers Collective, 2003, p. 154). In the past, there have been several court rulings—including from the Supreme Court of India—that a sexless marriage is a ground for divorce as denying sex is a form of cruelty towards a husband (thequint.com, 2016; Times of India, 2014). This means that a man may divorce his wife on the grounds that he could acquire HIV from her through sex. While people with HIV who are virally suppressed cannot transmit the virus (U=U), most women were unaware of this and tended to think that they could not have sex after their diagnosis. The implication is that denial of sex to partners, especially without condoms, might be common for this population and may be a ground for divorce.

"So, if this is a ground for divorce, then I will divorce my wife because I cannot spend my nights with her because of HIV, I will not be able to have sex with her. So, this is a suitable ground for divorce. Then you change the Divorce Appellate, Divorce Law. If the Divorce Law is not changed then I can divorce my wife because if I sleep with her then I can get infected with HIV. So, I will divorce her, beat her and throw her out. Then what will you do? On the one hand, there is the Divorce Law, the Divorce Law which states that where there is communicable disease then it is a ground for divorce. Of course, at that time there was no HIV, at that time leprosy, syphilis, these were kept in mind when writing that Act, then that Act must be changed, am I making sense?" (Lawyer).

## 7.5.2 Inability to guarantee "Right to residence"

Being "thrown out" of the house is a common occurrence for women living with HIV, especially if they are widows. Close to forty percent of women interviewed for the study had to leave their homes for one reason or another once diagnosed with HIV. This means that the right to residence clause of the HIV Act is one of the most significant protections offered to women who face such an extreme form of domestic violence. Although section 29 of the Act gives the right to residence in a shared household for those in a domestic relationship, the fatal flaw in the law does not guarantee it. The law states that "every protected person has the right to reside in a shared household…" but does not say what happens if the man decides not to live in the same household with his wife because of HIV and invokes the communicable disease clause of the divorce law:

"It says they cannot be thrown out, but where will they go, I won't live in the same house as them what will you do? You tell me even though the 2005 Domestic Violence Act was introduced in 2005, you have still not been able to provide me with shelter homes, why? Why are there no shelter homes for HIV patients? Where will they go? Number one. They cannot be thrown out, but if they are thrown out what will happen? If they are thrown out, what will happen? Say I throw out what will you do? If I throw out what will happen, does the law mention that? If I throw out what will happen?" (Lawyer).

In case of maintenance applications, Section 35 of the Act only ensures that "in passing any order of maintenance, shall take into account the medical expenses and other HIV-related costs that may be incurred by the applicant" (Section 35, 2017 HIV Act). Since ART and all related tests are already provided free of cost by the government along with a free pass for travel to ART centers, this clause only guarantees a provision that already exists. What a woman facing domestic violence or eviction for HIV really needs is a place to stay, such as a requirement for a residence order or shelter homes. This is not guaranteed under the Act.

Since there are no separate shelter homes available for women living with HIV, if they are evicted from their homes they must reside in regular shelter homes for destitute women. Here too women living with HIV are disadvantaged due to structural discrimination. As described by the key informant from PWN+, shelter homes find excuses like "these people should get monthly medicines, who will buy, who will go for taking them for monthly medication" or there is downright "denial of HIV, in [that] the infection will spread, that kind of attitude is there for that [women's shelter] home." In addition, HIV-related discrimination from fellow residents and some staff is common in the regular shelters, where women living with HIV must be housed in cases of eviction. A counselor from a shelter described how "when someone's HIV+ status became known, that person was completely ostracized". Some HIV NGOs offer shelter to women through residential staff jobs, such as the one where the study was conducted, but they are few and far between. Therefore, women living with HIV who face abandonment or eviction from their homes will continue to suffer until the right to residence clause is strengthened.

In India, women whose husbands have died of HIV, whether they have HIV themselves or not, experience some of the worst discrimination from in-laws. They are routinely denied their right to their husbands' property and are often thrown out of their marital homes. However, the Act does not ensure rights of widows to their husbands' property even though they could claim it through the "Right to residence" clause. The key informant from PWN+, who had seen many women suffer from denial of their right to property through her work with the Network, felt that the Act needed to have a stronger property rights clause for widows affected by HIV:

"So far very less people have used it. Only for hospital discrimination they used many and then also job. For family related discrimination, the property, very less. The cases are going on and on. There is no end. Ok." (PWN+).

My repeated attempts to contact the Lawyer's Collective, the NGO that drafted the law, to gain clarification on these weaknesses within the Act were rejected. Such an interview

might have shed some light on whether all women, including those with HIV, could just get protection under the Domestic Violence Act and that there was no need to tailor the HIV Act for domestic violence; or that women living with HIV who experience domestic violence might be able to use both laws in conjunction with each other.

#### 7.5.3 Penal clause too weak

The HIV Act has a penal clause under Section 42: "Notwithstanding anything contained in the Code of Criminal Procedure, 1973, offences under this Act shall be cognizable and bailable" (Section 42, 2017 HIV Act). The penalties for violating the clauses of the Act range from a fine of up to 100,000 rupees (~£1000) and a jail sentence ranging from 3 months to 2 years, or both. The Act is cognizable and bailable, which means that the police can make an arrest on the spot, but the perpetrator can get bail right away, unlike arrests made under Section 498A (incorporated into the Domestic Violence Act), which is nonbailable. A physician who was well versed with the Act claimed that it was of a "corrective nature" and that was why the punishment was not as severe:

"...Next thing is that, mostly this Bill is a corrective in nature, supportive in nature, not for the punitive things. If anybody is actually spreading the message of hatred against HIV or spreading some words of discrimination or [22:41-42], first he or she will be counseled properly. If the counseling fails, in that case, there will be, uh if it fails then the punitive actions may be imposed upon" (HIV physician).

While the judge was not allowed to give his opinion on the matter, the lawyer who had tried numerous domestic violence cases over his long career felt that punishment under the HIV Act was too weak to deter perpetrators from committing acts of violence:

"...Then if husband throws [me] out, then if I file a complaint thinking that I will put him in jail, it will be a bailable offence, he will go and come out laughing with a bail, and then once again he will beat the hell out of me... Hence, if I am a victim of violence, if I throw someone out, then in Section 37 where the penalty clause is

given, you cannot save me using that, you cannot give me protection from the hands of my husband ... then it so stands that I am not protected from my family, the law that has been mentioned, that law is not sufficient, the punishment that has been mentioned, the punishment is not sufficient, then why will the administration not provide me with protection? Number two, then will I once again turn to the Domestic Violence Act? Why has the HIV [Act] itself [not] separately kept provisions for a protection home... protection order, shelter home, monetary relief? That means if there is a violation of this HIV Act, well it is not even properly written if it is a violation if my husband throws me out, then can I be incorporated in any other section apart from Section 4? This is extremely, I will once again this does not have any tooth and claw. This Act is toothless and clawless" (Lawyer).

A similar opinion was expressed by the key informant from PWN+, that the Domestic Violence Act rather than the HIV Act had to be invoked in cases of HIV-related domestic violence as "there is no punishment on this no? This one [Domestic Violence Act] it has a punishment. OK, this one [2017 HIV Act] there is no punishment no?"

#### 7.5.4 Welfare measures not clearly defined

Section 15(1) of the Act specifies that Central and State governments must facilitate access to welfare benefits provided to people affected by HIV:

"The Central Government and every State Government shall take measures to facilitate better access to welfare schemes to persons infected or affected by HIV or AIDS" (Section 15(1), 2017 HIV Act).

Section 15(2) states that Central and State Governments must frame appropriate welfare measures for such populations, without defining what these welfare measures must be:

"Without prejudice to the provisions of sub-section (1), the Central Government and State Governments shall frame schemes to address the needs of all protected

persons" (Section 15(2), 2017 HIV Act).

So far, the welfare measures available to all people with HIV in West Bengal (NACO, 2011), much before the enactment of the HIV Act, include the following:

- 1. Ensuring treatment for all people living with HIV.
- Free HIV testing, medical investigations and ART for all people living with HIV.
- 3. Extending the *Antyodaya Anna Yojana* (food grains) scheme under the Targeted Public Distribution System for all people living with HIV at a subsidized price.
- 4. Free travel pass for road transport for people living with HIV.
- 5. 50% travel concession for railways for people living with HIV.
- 6. Travel passes for people coming for treatment using government buses.
- 7. Monetary benefit of Rs. 600/- (~£6) annually for all people living with HIV if they maintain 95% adherence.
- 8. Monetary benefit of Rs. 800/- (~£8) for early infant diagnosis of each baby (up to a maximum of two).

Despite the availability of these welfare measures, women reported difficulties in access due to HIV stigma. For example, HIV stigma precluded them from using travel passes for regular ART center visits. Most did not get travel passes made and those who did said they did not take them out in front of others for shame. This means that existing welfare measures must be re-designed so that women are able to attain the benefits.

"I don't always take it [laughs], first I check if anyone is there in the bus, if they also ask me to take it out I feel ashamed, they must be thinking 'oh my, this kind of woman has this' [laughs], the helper that you show it to, he will think to himself 'oh my, this woman has this disease', a lot of times I don't take it out for fear of that" (CL019, 25 years).

Additional welfare measures such as shelter homes for women living with HIV or empowerment programs, which would be beneficial for women living with HIV who experience violence, were yet to be clearly defined:

"...Number two, this is vital, what are the benefits, what benefits are you giving, meaning what benefit will a HIV infected person get, they need one basic thing, basic thing which is the stigma you mentioned, that a HIV positive person is stigmatized, and they are afraid of showing their face to society, they are ashamed, they are thrown out of the village. Now, where will you keep me? I need a place to stay, I don't have an income, but based on what I have read there is nothing mentioned about these here. Here they talk about welfare schemes, Chapter VII they say 'Welfare measures by the Central government and State government', it has been this long, it has been 3 years that this has been introduced, till today we do not know what welfare measures have been taken by the Central and State governments" (Lawyer).

The HIV Act makes are no special welfare provisions for widows of men who have died of HIV or widows living with HIV. However, they are eligible for the regular Widow Pension Scheme, which provides monthly pension support of Rs. 1000/- (£10) to widows who are residents of West Bengal for the past 10 years, have an income of less than Rs. 1000/- per month, and do not receive any financial support from their family or other schemes. Although West Bengal amended the Widow Pension Scheme in 2021 to remove the age limit (benefiting HIV widows in the state), the problem persists in other states, where young HIV widows below the age of eligibility are denied a widow pension (PWN+). Considering that young HIV widows are a particularly vulnerable group who need additional support, the Act could have incorporated additional and more clearly defined welfare benefits for this group to protect them from violence and eviction by in-laws after the death of their husbands.

These weaknesses in the clauses of the Act must be addressed in order for it to be effective in protecting women living with HIV from domestic violence. The appropriate framing of rules, improvements through case law, and an amendment might be needed for removing this last barrier:

"New laws are introduced but after that when in reality we go on to implement the law, then we see what are the *laches lacuna* in this law, whether there is a need for further amendment, or have rules been framed accordingly. Unless rules are framed we cannot say whether the law can be applied appropriately, meaning appropriate framing of rules is also important. The topics on which this law has been created, I will say, I think this law needs a lot more, how to say it, it needs amendment, addition and alteration" (Lawyer).

#### 7.6 Discussion

Certain constitutional rights protect people living with HIV in India and have been routinely invoked in cases of HIV-related discrimination (Krishnan, 2003; UNDP, 2013, 2016). Because broad protections may be open to interpretation (Krishnan, 2003; The Lawyers Collective, 2003), the Government of India clearly laid out the 2017 HIV Act to not only control the spread of HIV, but also prevent discrimination against people living with HIV. A closer inspection of the Act, however, reveals several barriers to its success to date, particularly when applied to HIV-related domestic violence.

The first barrier identified was the limited awareness of the Act among women living with HIV, as well as a lack of perceived effectiveness once they were informed. The Act cannot be effective unless people who need to use it know about it. A similar barrier was observed among key informants, many of whom were unaware or had limited knowledge of the Act. The HIV Act had been in place for four years at the time of interviews. One might have expected, therefore, awareness amongst professionals for whom it was important and to some degree among women living with HIV. One might also have expected some experience in invoking the Act and examples of challenges. For example,

the POCSO (Protection of Children from Sexual Offences) Act of 2012 was followed by an accumulation of experience that led to an amendment in 2019, whereas we did not find any real evidence that the HIV Act had been used to file court cases. Anecdotal reports of complaints being registered could not be verified.

The lack of awareness could be attributed to poor implementation across the country. The Act had been notified in the national gazette and rules framed at the national level, but this was not matched at state level. Similarly, most states had appointed one ombudsman for the entire state, a few had appointed an ombudsman for every district (as required by the law), while a small number had not managed to appoint an ombudsman at all. This disparity in implementation is not uncommon for national policies, which face challenges in implementation at the sub-national or state level, especially when each state has its own political authority (Hudson et al., 2019). Even in countries with more concentrated governance, implementation may depend on local context, with policies being more successful in some areas than others (Hudson et al., 2019). Policies are generally not designed with knowledge of how multiple interacting forces might shape their implementation (McConnell, 2014): in this case, implementation delays and delays in public awareness campaigns due to the Covid-19 pandemic were beyond the control of policymakers.

Apart from implementation delays, women also expressed ambivalence about using the Act, either because they felt it would not change anything or because of self-stigma (shame) and fear of making their HIV status public (anticipated stigma). Stigma of domestic violence has been shown to reduce help-seeking (Overstreet & Quinn, 2013) and when compounded with HIV stigma it causes women to suffer in silence (Hatcher et al., 2016; Marais et al., 2019; Mukerji et al., 2022). While the Act addresses this need for privacy in Section 34(I) by assuring *in camera* hearings and suppression of identity of the person with HIV in court proceedings, these clauses may not be sufficient for women to take the risk, given the more immediate concern of people in their vicinity finding out their status as a result of filing a case. Apart from stigma, the perception that "nothing will

change" or "it takes too much time" is hard to argue against given the sluggish pace of the Indian judicial system and its track record of unresolved cases (Krishnan, 2003). Despite these perceptions, some women felt that they would use the Act in cases of discrimination. Policies often bring incremental changes rather than sweeping successes (McConnell, 2014), and the fact that some women felt they would use the Act suggests that its introduction might be the first step towards empowering women to come forward against discrimination.

Another important barrier to accessing the HIV Act has been fears or actual experiences of structural discrimination. There were reports of discrimination by the police at the time of registering complaints, by legal aid services, in the courts during trial, and in public offices while trying to access welfare services. Both women and key informants felt that women might face this structural barrier when trying to access the Act for cases of HIVrelated domestic violence. This finding is not surprising given the structural discrimination against women that increases their vulnerability (Sinha et al., 2017). A UNDP report examining the legal framework around HIV in India found that even when laws existed to protect women (such as the Domestic Violence Act), structural weaknesses such as lack of education, financial dependence, and gender discrimination within the system impede women's access to the legal system (UNDP, 2016). Domestic violence and discriminatory laws, such as those denying women property rights, disempower them so that they are less able to cope with HIV-induced violence (UNDP, 2012). Despite it being well established that sexual violence puts women at increased risk of HIV (Dunkle et al., 2006), with this shown to be true for married Indian women (Silverman et al., 2008), India continues to disregard marital rape as a crime (Gable, 2007). The combination of a gender discriminatory legal environment and structural discrimination against HIV and domestic violence will continue to be a deterrent for women trying to access the HIV Act.

One of the most common causes of policy failure, apart from failures in implementation, is poor policy design (Hudson et al., 2019). We should be aware, though, that no policy is a complete failure and even policies that have been dubbed failures have some measure of success (McConnell, 2014). The last barrier to the success of the HIV Act is

the "fatal flaws" that must be amended for it to be successful in protecting women from domestic violence. One of the key clauses for women is the protection it offers them from having to disclose their status to partners. Partner notification has always been a contentious issue in HIV: while it is important to notify partners in the interest of public health, it can be particularly dangerous for women as it can increase their risk of violence and abandonment (Gable, 2007; UNDP, 2012, 2016). The Supreme Court ruling in the case of Mr. X vs Hospital Z (1999) set a precedent for people living with HIV to notify their partners (Krishnan, 2003; UNDP, 2016), but the HIV Act removes this requirement for women if there is an expectation of violence. However, as my findings show, while this clause would protect women from violence, it may not protect them from breakdown of their marriage, which is a problem in the Indian setting given the societal stigma towards divorce and most women still being financially dependent on their husbands. In Indian matrimonial law, the concealment of a sexually transmissible disease is a ground for divorce (Gable, 2007) and the Indian Penal Code imposes criminal sanctions against anyone who willfully spreads an infection (Krishnan, 2003; The Lawyers Collective, 2003). Under the current laws governing divorce and communicable disease, it would simply be too dangerous for women to not disclose their status by invoking Section 10 of the HIV Act. The other weaknesses in the Act—a penal clause too weak to deter men from inflicting violence on their spouses and a right to residence clause that has no provisions for shelter homes or residence orders—mean that it cannot protect women from eviction from their marital homes. Eviction or abandonment has been called "one of the most severe forms of violence enacted against women" (Turan et al., 2016) and is commonly practised in India, especially once the husband dies (UNDP, 2016). The lack of clarity around the clause on eviction, combined with the prospect of divorce or criminal sanctions upon non-disclosure of status, need careful consideration when women try to invoke the Act.

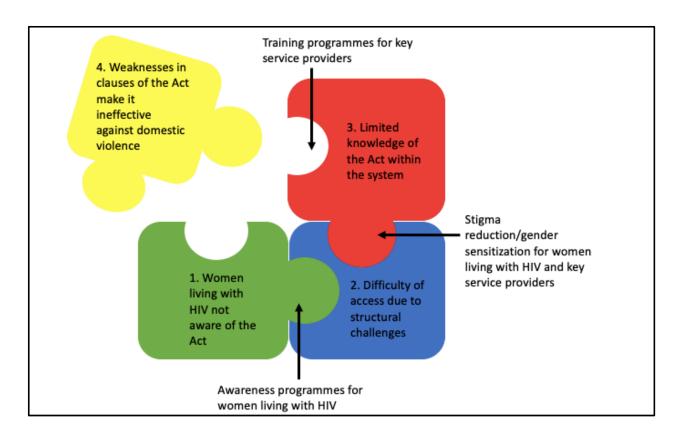


Figure 20 Barriers to the HIV Act in protecting women from domestic violence and interventions that may address these barriers.

In thinking about how the various barriers identified in my analysis interact with one another, I have conceptualized them as pieces of a puzzle (Figure 20). I think this is important because if the pieces do not fit together the puzzle remains incomplete. All of the pieces are important and must fit together for the Act to be effective in protecting women from domestic violence. The first three pieces might fit through awareness and stigma reduction programs (described below), but an amendment to the Act may be needed for the final piece to fall in place.

The first piece—lack of awareness among women—can be shaped through legal awareness programs for women delivered by community health workers, who can be trained in legal literacy and act as peer paralegals (The Global Fund, 2019). The second piece of the puzzle—structural discrimination within the system—can be provided through ongoing gender sensitization programs, domestic violence and HIV stigma reduction training at the institutional level for lawyers, judges, police, healthcare providers, and

others within the system, combined with strict institutional policies against stigma and discrimination (The Global Fund, 2019). The third piece—limited knowledge of the Act within the system—can be moulded by providing regular training about the Act for key stakeholders. The final piece of the puzzle—weaknesses in the Act—will only start to fit with the rest of the puzzle once the Act is used by women for domestic violence cases and accumulation of experience through case law leads to amendments.

Limitations of the study include the fact that interviews with women were restricted to residents of West Bengal; the findings may differ in other states. This limitation was addressed to some extent by including key informants from India-wide organizations who could provide information applicable across the country. A strength of the study was the inclusion of perspectives from a diverse range of stakeholders.

#### 7.7 Conclusions

Perhaps it is easy to judge the HIV Act as a failure. It is probably too soon to do so. An HIV anti-discrimination Act can never be a complete success given that it tackles a particularly "wicked problem" (McConnell, 2014), that of societal stigma around HIV which can never be eliminated through a single Act. As of 2012, 123 countries had some kind of anti-discrimination policies in place for people living with HIV, yet discrimination persists. This is because laws are ignored, poorly enforced, or intentionally flouted, the result being persistent stigma often manifesting as violence, particularly for marginalized groups such as women living with HIV (UNDP, 2012). It is better to have an HIV antidiscrimination Act than none at all. The enactment of the Domestic Violence Act (2005), the HIV Act (2017), the Transgender Persons Act (2019), and the repeal of Section 377 (2018) of the IPC (legalizing same sex relationships) along with the existing Constitutional guarantees on non-discrimination, have meant that India has taken substantial steps forward in HIV control. Recent data suggest that several countries are off track in achieving the United Nations Sustainable Development Goal of ending the HIV epidemic by 2030, and public policies are one reason for this (Kavanagh et al., 2020). Countries that have national laws on non-discrimination and gender-based violence and independent human rights institutions have greater knowledge of HIV status and better viral suppression, putting them in a better position to achieve the UN's 90-90-90 targets than nations that have criminalized drug use, sex work, and same sex relationships (Kavanagh et al., 2021). India's current legal framework for tackling HIV-related discrimination therefore holds much promise, both for sustaining India's declining HIV curve and giving some measure of protection to Indians affected by the epidemic.

# **Chapter 8: Conclusions and recommendations**

In this final chapter I present a summary of my key research findings and conclusions. I discuss how my findings contribute to the literature on intersectional stigma and to existing theory through the development of an overall conceptual framework for the thesis. I go on to make recommendations for stigma-related violence reduction and ways for the HIV Act to be made more effective, and conclude with reflections on my research.

#### 8.1 Summary of research findings

My findings indicate that the domestic violence experienced by women living with HIV is often driven by HIV stigma. A number of women experienced violence for the first time and some experienced a worsening of violence after their diagnosis. However, a small minority of women did not experience violence despite being diagnosed with HIV. This violence may have been worsened by the stigma of domestic violence itself and the stigma of women's other marginalized identities. Perpetrators used verbal abuse and other forms of emotional violence such as blaming and shaming to reinforce HIV stigma. Similarly, the stigma of HIV worsened the stigma of domestic violence through gossip, withdrawal, and reduced help seeking. Additional stigmatized identities such as sex work, widowhood, having only daughters, transgender identity, and poverty often combined with gender and HIV stigma to worsen the overall stigma and violence. The most extreme and common form of violence for widows with daughters was eviction from the shared household after the husband's death and subsequent denial of property. Women were unable to share their experiences of violence for fear of revealing their HIV status and also hesitant to ask for help from formal and informal sources. Contextual factors such as rural residence compounded women's experiences of violence due to multiple stigmas, because of gossip, ignorance about HIV, and greater disparities in women's positions compared to men in rural areas. According to reports by a number of women and key informants, violence was greatest in the initial period after diagnosis and reduced over the years. This was due to (1) a reduction in enacted stigma, as women often left their marital homes and people's fears of HIV transmission and death reduced over time (as they saw women leading healthy, productive lives) and (2) a reduction in internalized stigma which allowed women to resist the violence better (they were less afraid of people finding out and more able to fight back against violence).

Negative experiences as a result of intersectional stigma including violence had an impact on women's health. I explored women's lived experiences of mental health as a result of such adverse experiences and how it in turn impacted their physical health. Women reported feeling worried or troubled and emotionally broken because of the stigmainduced violence they endured from husbands and in-laws. They were unable to leave abusive relationships because of the cultural stigma of divorce, which would be made worse by the presence of HIV. Not being able to speak to others about the real cause of violence added to women's emotional distress. They also felt profound sadness because of their experiences and some felt hopeless and even had thoughts of dying, especially in the initial period after diagnosis. Women were constantly worried and fearful about people finding out about their status and the consequences of it. Women with children were worried about how their own HIV status or the child's HIV status would impact their future. Finally, loss of income either because of death of a husband or directly because of HIV stigma-induced job loss added to women's worries, fears, and feelings of internalized stigma. This was particularly true for sex workers because they had lost their income and often had to resort to odd jobs or work as maids, which not only led to poverty (with its feelings of shame) but also exposed them to additional abuse due to a combination of HIV and poverty stigma. These mental health effects of intersectional stigma and violence led to poor physical health through a number of different pathways. Poor mental health after episodes of violence meant that women did not want to take their medications (as a way to end their lives) or forgot to take them, which resulted in poor health. Some key informants reported that women experiencing severe violence at home could be lost to follow-up. Transgender women were at particular risk as the ridicule and violence they experienced meant that they were reluctant to engage in regular HIV care. Some women felt that the chronic stress they experienced as a result of stigma-related

violence was a reason for their poor health because of low CD4 counts. The stresses of stigma and violence were often reported in terms of poor physical health: most women complained of insomnia, lack of appetite and weight loss, some had headaches, hallucinations, and breathlessness. Poor health could lead to worsened stigma as women would become unproductive in a way that confirmed stereotypes about HIV as a debilitating disease or force them to disclose their status.

Despite reporting lived experiences of poor mental health as a result of intersectional stigma, women were coping by utilizing a combination of internal and external resources. They often spoke about their own mental strength as their biggest strength. They were strong in their faith and prayer helped them cope. This finding held across religions. Some women positively reframed their experiences of stigma and spoke of the good that came out of it. Some challenged stigma by showing anger and reasoning why HIV should be labeled such a "bad disease". Focusing on positive identities such as motherhood or being good at a particular job also helped women cope. These gave a sense of meaning to their lives beyond the identity of an "HIV patient". Women engaged in relaxing activities such as gardening or listening to music to find peace. Their ability to draw on these internal resources was bolstered through external resources such as social and emotional support. Women were able to draw on support from NGOs and government services which helped them build a stable financial future, gave them a place to stay when evicted, and helped with their treatment and nutritional needs. Building a financial future gave women a boost of self-confidence which helped them cope better with stigma. Support from children, friends, and others living with HIV fulfilled their emotional and daily needs and acted as a buffer against the stigma they experienced from others. Women sought help with their informational needs, such as with filing cases and legal redressal against domestic violence.

One legal mechanism in place to protect people living with HIV against stigma and discrimination is the 2017 HIV/AIDS (Prevention and Control) Act. I examined whether the Act was effective in protecting women against HIV stigma-related domestic violence

and came across several barriers. First of all, almost none of the women were aware of the existence of the Act, and those who were aware were ambivalent about using it. This was because of the real and perceived structural discrimination in the system, both against women living with HIV and domestic violence, which made it difficult for women to report to the police and file cases in court. Secondly, there was very limited awareness and understanding of the Act within the system—healthcare providers, police, and the judiciary—which meant that women trying to file a case would run into difficulties. Such gaps in implementation meant that no cases were known to have been filed to date under the Act. The final barrier, and probably the largest, was that there were several weaknesses in the clauses in the Act that would dilute the protections offered to women. One example was the non-disclosure clause for women, which is meant to protect them from domestic violence. Non-disclosure of a communicable disease remains a ground for divorce in India and is a criminal offence under sections of the Indian Penal Code. Unless such clauses are refined and amended through case law, it may be ineffective in protecting women against HIV-related domestic violence.

#### 8.2 Contribution to existing literature

Although the findings have been discussed in relation to the existing literature at the end of each chapter, here I provide a summary of what the study adds to or confirms. First of all, the thesis fills two important research gaps identified in my literature review: (1) understanding how the stigmas of HIV, domestic violence, and other marginalized identities intersect in the lives of women living with HIV to shape their overall experience of violence, and (2) the role of HIV stigma in driving this violence against women living with HIV. My findings confirm findings from previous studies (Aryal et al., 2012; Emusu et al., 2009; Ezechi et al., 2009; Gielen et al., 2000; Hatcher et al., 2016; Hyginus et al., 2012; Iliyasu et al., 2011; Marais et al., 2019; Shamu et al., 2014; Zunner et al., 2015) that show violence commenced or worsened after an HIV diagnosis. They also show that perpetrators may worsen HIV stigma through verbal abuse, reinforcing stereotypes around poor moral character or untouchability for fear of contagion. Similar findings have been reported from a study from South Africa, where partners shamed and blamed

women for contracting HIV (Marais et al., 2019). HIV stigma worsened domestic violence stigma through gossip and blame, causing women to withdraw socially. Finally, I showed that this violence was often temporal. Other studies have shown that internalized stigma reduces over the years (Kumar et al., 2015; Rael et al., 2017; Steward et al., 2011), but none have shown this temporal trend for violence related to HIV. This finding, when combined with findings of violence commencing or worsening after an HIV diagnosis, indicates that the violence occurring after an HIV diagnosis is driven by HIV stigma rather than just being a function of gender norms that position women as lesser than men. This is an important contribution to the literature on HIV and domestic violence, because many studies do not acknowledge the role of stigma in driving domestic violence against women living with HIV.

Although previous studies have examined women's experiences of intersectional stigma (Azhar & Gunn, 2021; Logie et al., 2011; Rice et al., 2018), none have examined how this specifically shapes violence against them. My study adds to this nascent literature on intersectional stigma of HIV by showing that there is a need for context-specific understandings of intersectional stigma. My findings underscore the importance of recognizing that women are not a homogeneous group, and that violence is often amplified when they have multiple stigmatized identities. These identities are contextual and their salience depends on where the study is being conducted. This has been described in the theoretical literature (Turan et al., 2019), but my findings add to the empirical literature by highlighting the importance of the interaction of different stigmas in different cultural settings and how it can amplify the overall experience of violence. I show that the application of an intersectional lens to stigma in different settings is important because it allows one to see the different social identities people may have, the historic oppression that these identities bring with it, such as gender discrimination in India, and how such oppression interacts with new stigmatized identities, such as that brought on by HIV, in complex ways to create new structures of oppression and disadvantage.

While many studies have described the mental health impact of HIV stigma, much less is known about the lived experiences of mental health due to intersectional stigma and related violence. Most studies that examine women's mental health as a result of stigma look at it through a clinical diagnostic lens, such as depression, anxiety or post-traumatic stress (Breet et al., 2014; Rueda et al., 2016). Presenting my findings within a lived experience framework contributes to the literature on mental health effects of stigma by providing an alternative perspective on women's mental health as they experienced it, rather than placing them in clinical diagnostic categories, which is often an interpretation of how healthcare providers think of such experiences. Presenting women's lived experience provided them the opportunity to express what they were feeling and more importantly, have this recognized by others as legitimate. Using this framework also allowed me to see how healthcare providers in India interpreted mental health for women living with HIV, which mostly did not include labels of mental illness. This meant that women did not think of themselves as mentally ill, thereby avoiding further stigmatization, even though they expressed emotions that could be interpreted as symptoms of depression or anxiety. I then examined how women coped with the negative experiences of intersectional stigma and violence. While other studies have looked at coping with intersectional stigma (Logie et al 2011, Rice et al 2018), my study adds to this literature by examining women's coping through an empowerment model of coping against stigma as described by Shih (Shih, 2004). This approach to coping, in which people with stigmatized identities take active measures to remove the stigma or gain strength from their stigma experiences, makes for a more positive experience rather than coping through avoidance of the identity.

Since HIV stigma plays an important role in driving the domestic violence experience by women living with HIV, it was important to evaluate whether the 2017 HIV Act was giving this much-needed protection to women. To my knowledge, such an evaluation of the HIV Act has not been done before. My findings shed light on the different barriers to the success of the Act and provide recommendations on the ways they can be addressed. The HIV Act was a huge step forward in providing protections against discrimination for

people living with HIV, but the lack of implementation and weaknesses in certain clauses need to be addressed before it can effectively deliver on its promises, especially for women living with HIV.

#### 8.3 Contribution to theory

In the previous chapters, I have described the conceptual frameworks that I have developed from my findings to further our understanding of intersectional stigma and health. For intersectional stigma (Chapter 4), a stigma amplification loop was used to show how multiple stigmas, such as from HIV, gender, domestic violence, and others, interact synergistically to worsen the overall experience of stigma and resulting violence. In chapter 5, I show how this amplified stigma feeds into a health cascade, such that stigma from multiple identities worsens mental health, which can then go on to affect physical health. These frameworks add to existing theory by showing the effect of a synergism of stigmas on health outcomes. In Chapter 7, I show the barriers to the success of the HIV Act in protecting women against HIV-related violence in the form of a puzzle, where the pieces must fit for the Act to work. This framework will help with understanding the weaknesses in accessibility of the Act and different points of intervention which can be used to address them. Now, I present an overall conceptual framework of intersectional stigma and its health and social impacts in women's lives (Figure 21). My framework is adapted from the Health Stigma and Discrimination Framework developed by Stangl et 2019.

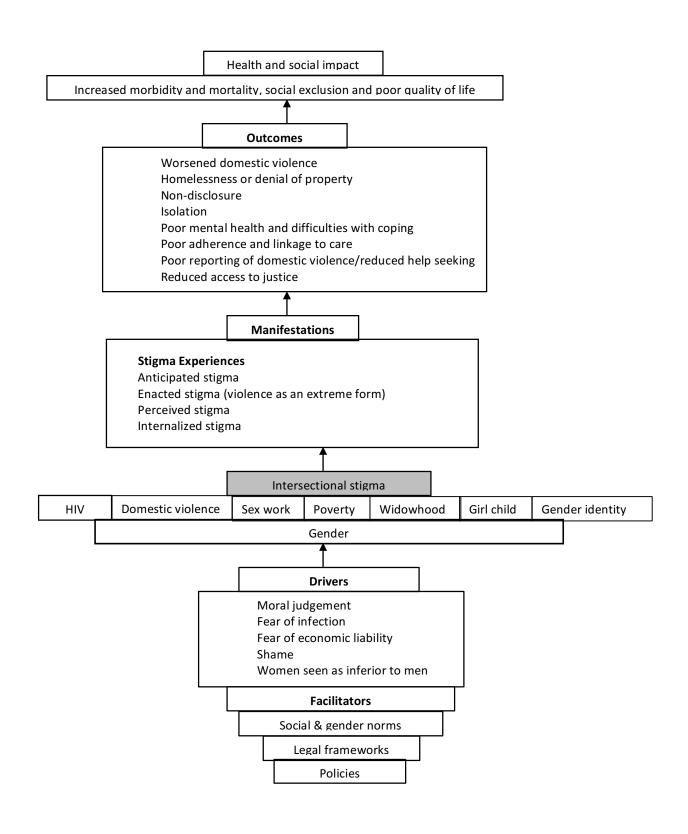


Figure 21 Intersectional stigma framework for women living with HIV in India (adapted from Stangl et al 2019).

Since my study involved an understanding of lived experiences and perceptions of intersectional stigma from the perspective of the stigmatized, I have modified aspects of the model that apply to institutions or stigmatizing practices. While the model was developed for any stigmatized health condition, I have adapted it for HIV. I have combined stigma experiences and practices into a category of stigma experiences to minimize overlap.

This framework contributes to new understandings of intersectional stigma in many ways. While it cannot be generalized to all women living with HIV, it can be applied for women living with HIV in India and others from a similar cultural context. The other stigmas have been adapted for the Indian context: identities such as widowhood, girl child, domestic violence, sex work, and poverty have been added, once again highlighting the importance of understanding intersectional stigma within specific societal and cultural contexts. As gender is the marginalized identity which shapes the other stigmas, this has been shown as underlying all of the other stigmatized identities, including HIV stigma, which is gendered. The drivers of stigma have been adapted to reflect those related to HIV, domestic violence, poverty, and gender (most social identities in this context are a function of gender). Showing the drivers of stigma in one model is an important contribution to the theoretical literature as it shows how drivers of different stigmas may overlap: the inferior position of women to men in society (driver of gender discrimination) can intersect with moral judgement against women (driver of HIV stigma) to worsen the stigma experienced by women as a group. Facilitators of stigma, such as social and gender norms, as well as laws and policies, have also been shown to be distal factors that shape the overall stigma experience. Violence as an extreme form of enacted stigma has been added as a manifestation of intersectional stigma. The different stigma outcomes in the model show how intersectional stigma can impact health and social outcomes in different ways, creating multiple social disadvantages and poor health for women living with HIV. These include worsened domestic violence, denial of property, non-disclosure and isolation, poor reporting of domestic violence, poor mental health and adherence to treatment, and reduced access to justice (Figure 21).

The modification of the conceptual framework to show how gender is an overarching theme that runs across the entire framework underscores the gendered nature of HIV stigma. For a woman living with HIV, stigma is always an intersectional experience, where her marginalization because of her gender is inextricably linked to her experience of HIV stigma, which often manifests as violence. The theory of Gender and Power has shown that power imbalance within relationships is one of the underlying causes of domestic violence (Connell, 1987). My findings add to this theoretical framing, in the context of HIV, by showing that domestic violence is an extreme manifestation of enacted HIV stigma. Stigma reinforces and reproduces this power imbalance within relationships. This is observed in the form of worsened domestic violence experienced by women living with HIV. A strength of this framework, therefore, lies in showing how violence related to intersectional stigma manifests as worsened violence experiences for women living with HIV at different levels: individual (reduced help seeking for violence, isolation), interpersonal (increased domestic violence, eviction, and denial of property), community (reduced support for domestic violence), and policy (reduced access to the HIV Act). It also captures the impact of intersectional stigma on women's health and linkage to care. By showing both the social and health effects of intersectional stigma, it shows how devastating intersectional stigma can be for women's lives.

Application of the theory of Gender and Power can also help demonstrate how bottom-up approaches to resisting stigma (Chapter 6) provide a counterweight or leverage point for improving interventions (Chapter 7). Women who take an empowered approach to coping with intersectional stigma, through participation in paid employment or being part of women's groups, can help make the HIV Act more effective through collective action (Campbell and Cornish). Collective action provides a space for challenging gender norms as well as HIV stigma (which is itself gendered). Having a gender sensitisation component within programmes can help women realise that the stigma they experience is not just because of HIV, but because of gender inequalities more broadly. If women are made aware of such inequalities in power and position, and mobilized to act as a group, they can demand action against HIV stigma-related domestic violence. This has been seen in

other community mobilization projects with marginalized groups and is bound to lead to greater awareness and use of the HIV Act for acts of domestic violence. This might lead in turn to modifications and amendments to remove the weaknesses in the Act, so that women are better protected against stigma-related violence.

When Kimberlé Crenshaw wrote about intersectionality, she wrote about the experiences of Black women in the United States. She highlighted the importance of understanding how interlocking oppressions of race and gender over hundreds of years of American history contributed to the marginalization of Black women today (Crenshaw, 1989). Bowleg talks about the importance of understanding the "sociohistorical realities of historically oppressed groups" when conducting intersectionality research (Bowleg, 2008). My thesis has contributed to this theoretical literature by showing that intersectional experiences of stigma, such as domestic violence, are experienced differently based on different historical and cultural contexts and societal norms. While women have been marginalized in all societies to different extents, the marginalization of women in India and similar cultural settings is different from that of a Black woman in the United States. The violence itself may differ when it intersects with historic legal frameworks that disadvantage women, such as rights to property.

It has been argued that social identities can neither be additive nor can they be ranked (Bowleg, 2012). Rather, the intersectional experience depends on how different identities interact to shape the individual's overall experience of marginalization (Bowleg, 2008). My findings, however, show that a woman's HIV status had the biggest overall impact on her life. It was the one identity that interacted with every other identity to worsen her health and quality of life. This was also reflected in my findings around the temporal nature of HIV stigma-related violence (as HIV stigma reduced over time violence) and the unchanging status of poor mental health (even when active violence stopped, women suffered from poor mental health because of HIV stigma). This could be because HIV is relatively rare in India and there is more silence around it because of strict moral codes of sexuality, especially for women. Once her HIV status is known, a woman's reputation

and that of her family could be damaged forever. Her children could suffer the consequences. The stakes are simply too high. An interesting area of future research may be to explore the impact of HIV stigma compared to other stigmatized identities, in other contexts where HIV is more prevalent, such as in Sub-Saharan Africa. Further research on intersectional stigma can only confirm whether there is a need to recognize the salience of identities when considering the impact of intersectional stigma. This thesis, however, shows the importance of situating theories of intersectional stigma within different social contexts.

### 8.4 Implications for practice, policy, and recommendations

The findings from my research indicate that intersectional stigma clearly has a damaging impact on women's lives. On an interpersonal level, there is a need for actions to reduce stigma-related violence and improve women's access to services. As discussed in previous chapters, firstly, stigma reduction interventions should use an intersectional lens to identify the most vulnerable women and tailor services accordingly. Secondly, services should be provided which help women cope with life after HIV so that they are able to redefine their lives and find purpose beyond their stigmatized identities. My findings on intersectional identities worsening violence and the temporal trend of stigma can be used to improve practice in several ways. First of all, ART centers should screen women for violence on a regular basis and offer intensive stigma reduction counseling sessions in the initial period after diagnosis (Sullivan, 2019). Women's marginalized identities should be recognized and vulnerable women should be offered a more comprehensive package of services. Counseling for women should include interventions to reduce internalized stigma and promote an empowered approach to coping. Mental health services need to improve so that both HIV physicians and counselors look out for signs of mental distress among women. Physical symptoms such as headaches, weakness, and lack of appetite and sleep should be recognized as legitimate signs of mental distress and services provided accordingly (Nichter, 1981). National and State AIDS Control Societies need to implement policies that provide financial assistance and job placements for women while Central and State governments need to consider providing shelter homes for women

living with HIV, with priority given to widows. Currently states only offer a small widow pension to all widows including those with HIV. Considering the large number of HIV widows and their additional burden of stigma due to widowhood and HIV, both governments and NGOs should consider prioritizing this group for welfare measures under the 2017 HIV Act. My findings point to the importance of increasing awareness of the Act itself, among people living with HIV, key service providers, and the general public. So far, I have described the implications of my findings for transforming practice at the individual level. I will go on to discuss how they can be translated into community action and mobilization to tackle intersectional stigma.

Intersectional stigma has been defined as an "interdependent and mutually constitutive relationship between social identities and structural inequities" (Logie et al., 2011). It is therefore important to dismantle these structures of power, privilege, and oppression in order to reduce intersectional stigma. This may be done through community engagement and collective action at the grassroots level to change policy and practice, by breaking down axes of inequality (Sievwright et al., 2022). One example of successful community mobilization can be found in Kolkata itself: the Sonagachi Project (Jana et al., 2004). This project started with the goal of reducing STIs among sex workers, through peer education, in the Sonagachi redlight area of Kolkata. As the project evolved, its goals expanded to improve the social conditions of sex workers through 'transformative communication'. This enabled women to not only develop a 'voice', but created a 'receptive social environment' where their voices would be heard (Campbell & Cornish, 2012). Apart from a receptive social context, a key determinant for the project's success was its ability to build social capital through community mobilization. This included bonding social capital (strong networks within the community), bridging social capital (strong links between the community and powerful outside individuals who are able to support project goals), and linking social capital (building networks between community groups and powerful actors) (Gibbs et al., 2015). Considering the severe stigma surrounding sex work in India (and elsewhere), de-stigmatization of 'prostitution' by relabeling it as 'sex work' (which women engaged in like any other economic activity to support their families), was a major step

towards the acceptance of the project outside of the community (Campbell & Cornish, 2012).

Several lessons from the success of the Sonagachi Project can be learnt and applied to women living with HIV so that they are able to take further steps to resist intersectional stigma. Firstly, it is important to build critical consciousness around the gendered nature of intersectional stigma, which manifests as domestic violence. Women must learn to recognize that the various forms of violence that they experience from the family, such as neglect or forceful continuation with housework despite being ill, are unacceptable. Currently, women feel it is their lot to accept this violence because they are women. Naming systems of oppression, in this case gender discrimination, may be the first step towards dismantling this structure of oppression (Sievwright et al., 2022) and tackling intersectional stigma. The second step might be to engage in effective community mobilization. When Crenshaw first coined the term 'intersectionality', she did not see the social identities in question as the problem, but rather recognized it as the force that would bind people with those identities and spur them on to community action, activism, and resistance (Sievwright et al., 2022). India has a large number of women's self-help groups (SHGs), which promote small savings and empowerment, in every state under the National Rural Livelihood Mission (Desai et al., 2020). Such groups can be formed for women living with HIV at the grassroots level and then brought together through larger networks, such as the PLHIV Network. Groups of women coming together and demanding change may create more receptive social environments, so that they are heard. This might help more women, who now have the courage to step out and demand justice by accessing laws such as the HIV Act or the Domestic Violence Act.

However, one must be cognizant of the challenges to such community action in India. Although the Sonagachi Project was successful in West Bengal, similar projects in South Africa have failed for numerous reasons (Cornish & Campbell, 2009; Gibbs et al., 2015). While SHGs are successful in bringing together women in rural areas, they have been much less successful in urban areas because of the fragmented nature of communities

in urban settings. In the case of HIV, the stigma of the disease might be the greatest impediment to bringing women together. While sex workers in Sonagachi were stigmatized, theirs was a visible stigma and a shared identity, as they were known to be sex workers residing in Sonagachi. HIV is, however, a concealable stigma and 'women living with HIV' are not a homogenous group. A 'respectable housewife' may think it much riskier to lose her reputation in public (by coming out). Her internalized stigma may prevent her from wanting to join forces with a sex worker from Sonagachi who also has HIV. It will therefore be much more difficult to bring women together for such a movement, although not impossible. If a small number of women are empowered and demand their rights to protection from stigma and violence, it may spur others to join, or even demand their rights in quieter ways.

The discussion of community action brings me to India's current HIV control policy and recommendations using the findings from the thesis. India's approach to HIV control to date has involved "targeted intervention" focusing on high risk groups (men who have sex with men, female sex workers, transpersons/hijras, and injection drug users) (NACO, 2008). Such an approach may be important both from a clinical point of view and for identifying multiply stigmatized groups. Yet it could have negative consequences by exacerbating stigma by reinforcing stereotypes associated with HIV. Associating HIV only with high risk groups can serve to stigmatize all people living with HIV by projecting morally devalued characteristics, such as sex work or drug use, on anyone who has HIV. It may be important to tweak public health messaging so that the general public do not continue to view HIV as a disease of sex workers or their clients, but rather as a chronic disease that can happen to anyone and can be managed well with medication.

A targeted intervention approach has also ignored infection in an important group: the general population of women, who have additional stigmatized identities which may not always be evident. An intersectional approach, as shown by my thesis, helps identify these identities, which can then be addressed through stigma-reduction interventions. The last National AIDS Control Plan (NACP-IV) has acknowledged the gradual shift in the

Indian epidemic from high risk groups to women and young people (NACO, 2014). This might be the time to use an intersectional framework, not only to identify the most vulnerable women and girls, but also to tailor stigma-reduction interventions for the historic and social context of gender discrimination in India. The International Council for Research on Women (ICRW) have adapted their global stigma reduction framework for use in India (ICRW, 2013). This framework recognizes the importance of intersectional identities, particularly caste and occupation, for the Indian setting and is said to inform stigma reduction in the NACP-IV. However, there is no mention of an intersectional approach to stigma reduction in either the NACP-IV or the latest National AIDS Response report (NACO, 2021). In this latest report, as well as the strategy for NACP-V, the cornerstone of stigma reduction is the 2017 HIV Act. The implementation of the Act, measured using state-wise framing of rules and the appointment of Ombudsmen, is the key indicator that has been used to measure the "elimination of stigma and discrimination". My findings, however, point to a gap in awareness of the Act, among both people living with HIV and key service providers. Other barriers such as discrimination within the system and flaws in certain clauses of the Act currently make it ineffectual in eliminating discrimination, especially towards women living with HIV. It might, therefore, be too simplistic to assume that implementation of the Act is an indicator of societal elimination of stigma and discrimination against people living with HIV. My findings can be used to inform AIDS control policy in India by: (1) addressing the need to tackle not just HIV stigma on its own, but rather multiple overlapping and interlocking structures of oppression against women, such as deep-rooted patriarchy, with which HIV stigma intersects, (2) paying attention to the current legal frameworks, a legacy of British colonial rule, that favor men through unequal divorce and inheritance laws, (3) creating greater awareness of the HIV Act while also recognizing its inherent flaws when used to protect women against HIV related discrimination.

#### 8.5 Conclusions

I began the research process with an idea of intersectional stigma among women living with HIV that came from the Western literature, particularly the United States and Canada.

As I followed my own research process I understood how intersectional stigma is contextual and complex. An understanding of historic structures of oppression is needed to truly grasp people's fears and experiences of stigma. Recent academic debate has argued that the only way to think of health-related stigma is to do so intersectionally (Stangl et al., 2019), as the experience of a health-related stigma is inextricably linked to other socially marginalized identities. My research has confirmed that the application of intersectionality to stigma research is not just a matter of academic discourse, but that it has real implications for women's lives. We cannot fully understand the stigma experiences of a woman living with HIV in India, without also considering historic gender discrimination and unequal colonial laws that govern her life. Neither should interventions be designed that take a "one size fits all" solution for stigma. Interventions and policies must take an intersectional approach and must be applied at multiple levels for them to be effective. I hope this thesis makes a small contribution to understanding intersectional stigma of HIV, and that it may help inform understandings of experiences of other stigmatized health conditions.

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# List of appendices

- 1. Published mixed methods review for Chapter 2
- 2. Sociodemographic characteristics of women living with HIV.
- 3. Topic guides (key informants, women living with HIV)
- 4. Information sheet and consent form for key informants
- 5. Information sheet and consent form for women living with HIV
- 6. Supplementary audit trail for Chapter 3
- 7. Publication of the 2017 HIV Act (supplement for chapter 7).

# **Appendix 1: Published mixed methods review**





# **AIDS Care**

Psychological and Socio-medical Aspects of AIDS/HIV

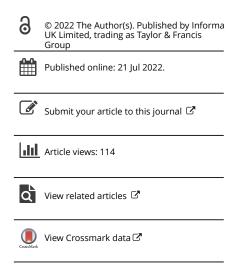
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# Mixed studies review of domestic violence in the lives of women affected by HIV stigma

Reshmi Mukerji, David Osrin & Jenevieve Mannell

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# Appendix 2: Sociodemographic characteristics of women living with HIV

Women living with HIV	Number (%)
Туре	
General population	26 (84)
Sex worker	5 (16)
Age	
Below 35	11 (35)
Above 35	20 (65)
Religion	
Hindu	26 (84)
Muslim	5 (16)
Marital status	
Married	13 (42)
Separated/ Single	9 (29)
Widowed	9 (29)
Partner Serostatus	
Seroconcordant	24 (77)
Serodiscordant	2 (7)
Not known/ not applicable	5 (16)
Total	31 (100)

# **Appendix 3: Topic Guides**

# Key informant interview topic guide

Thank you for taking part in this study. As you know, we want to understand the situation regarding stigma, discrimination and violence against women living with HIV (WLHIV) in Kolkata. At any time, you can call a stop to the interview, or say that you do not wish to answer a particular question. Do you have any questions before we start?

- 1. Can you please tell me a bit about yourself? The work that you do?
- 2. How long have you been working with HIV+ patients? How has that been?

As we discussed, over the years HIV has changed from a killer disease to a more manageable infectious disease. Yet HIV stigma persists. It would be helpful if we could discuss this aspect of HIV, ie stigma and discrimination against people living with HIV/AIDS (PLHA), in greater depth in the following section.

- 3. Can you share with us some examples of areas where you see improvements and areas where things have remained the same?

  (Probes: clinical treatment, drug effects, opportunistic infections and other HIV related illnesses, HAART, emergence of VCTC centers offering free medication and counselling, life span, quality of life, stigma).
- 4. How do you think the level of stigma towards PLHA is today compared to what you saw when you first started working with PLHA? What do you think might be some reasons for the change? (Probe: awareness, acceptance of HIV)
- 5. Can you share some stories/experiences that your patients/other PLHA getting treatment at healthcare facilities might typically face (probes: during VCTC visit, during regular doctor visit, during ART collection, during planned surgeries in hospitals or emergency situations, during pregnancies)? [Adjust this question for appropriate interviewee eg faith leaders, teachers, social care workers, policy actors etc]
- 6. What do you think causes people to stigmatize PLHA? (Probes: moral judgement, blame, fear of contagion) Do you think there is a difference in how PLHA are viewed or treated (especially in healthcare settings) if people know how they were infected? (Probe: sexual routes, sex work, injection drug use, MSM, trafficking vs blood transfusions, spouses of bridge populations)
- 7. Do you think that women with HIV are stigmatized differently than men? Why do you think so? In what ways is the stigma different? (Probes: societal

- attitudes towards women, violence at home or elsewhere, moral judgment, association with sex work, infidelity).
- 8. Do you think women disclose their HIV status to their partners or in-laws? Can you think of reasons for non-disclosure? (Probe: violence, stigma) Can you share some stories of how partners/in-laws reacted upon hearing of a woman's positive diagnosis? (Probe: Positive and negative reactions)
- 9. Do you think violence is a problem in the lives of women with HIV? (Probe: gender based violence, domestic violence). Can you tell us a bit more why you think or do not think violence may be a problem for WLHA? (Probes: traditional gender norms, blame, stigma).
- 10.Do you think women who experience domestic violence are stigmatized? (Probe: family affair, shame) In what ways do you think that the stigma of domestic violence might be different for HIV+ women compared to other women? (Probe: blame, HIV stigma)
- 11.Do you think women living with HIV seek support or report domestic violence? (Probe: friends, family, neighbors, NGO, police, healthcare providers, women's commission) Why do you think they do or do not report violence? Do you think the pattern of reporting (who they report to or seek help from) is different compared to women who do not have HIV? Can you think of any reasons for this difference?
- 12. Can you suggest ways in which violence reporting rates can be improved for HIV+ women? (Probe: violence screening programmes at VCTC/ART centers, support services)
- 13. How do you think violence impacts HIV+ women's ability to access care or adherence to treatment? (Probe: difficulty going for clinic appointments, taking medications on time, hiding medications from family, family not knowing HIV status)
- 14. Are you aware of the HIV/AIDS Prevention and Control Act 2017? Can you tell us a bit more about it and how it works? Do you think the Act is actually working in terms of reducing discrimination against PLHA?
- 15. What do you think we can do to reduce the stigma against HIV+ people? How can the HIV/AIDS Prevention and Control Act be made more effective in your opinion?
- **16.** How would you like to see society change to become more accepting of women infected with HIV? In what ways could these changes be accomplished?

Is there anything I have not asked you about that you think I should know about? (i.e., what have I missed in this conversation?)

Thank you very much for your time. Your responses will be very helpful for improving services for women living with HIV/AIDS.

# Topic guide for women living with HIV

# QUALITATIVE INTERVIEW GUIDE RELATED TO HIV AND DOMESTIC VIOLENCE STIGMA

## **Theme**

#### INTERVIEW QUESTIONS

# Icebreaker/intro

- 1. Tell me more about your family? How many people are there in your family? How was it when you first got married? What is your family setup like?
- 2. Thank you for sharing that. Can you share with me the story of when you were first diagnosed with HIV?

Probe:

- What were the initial signs and symptoms?
- How did you feel when you were first told about your diagnosis?

# **Transition**

One experience that many people with HIV talk about are stigma (the negative ways that that people are viewed or feel because of their differences) and discrimination (being treated badly by others because of these differences). I would like to talk more about these topics now. I understand that these are sensitive topics, and some of these questions may bring to mind painful experiences. You are welcome to share only what you feel comfortable with, and can stop or take breaks at any time.

# Types and effects of stigma and discrimination

In what areas of life (e.g. health care, work, family, community gatherings) have you experienced stigma or discrimination related to having HIV? Has this (stigma) changed over the years?

# **Enacted stigma**

# Probes:

- Were there other reasons you were discriminated against in that instance? (probe: because of religion/caste, gender, poverty)
- Who was the discrimination coming from?
- How did you feel at that time?
- What did you do at that time?
- How did you feel afterwards?
- 3. Do you think your HIV status affects your children? Are they treated differently because their mother has HIV or maybe because they have HIV?

# Probes:

- is the mother only blamed?
- Is the father blamed?
- Are the children blamed?
- Where does the blame come from? Family, neighbors, healthcare providers

# Perceived stigma

4. Let's go back to your diagnosis once more. How do you think you may have acquired HIV? Do you think people are treated differently based on how they think a person acquired HIV? (Probes: modes of transmission, sources of the stigma, how does this make you feel)

5. What kinds of opinions or attitudes do you think people have about women living with HIV? What stereotypes do you hear about women living with HIV? (Or what assumptions do people make about women living with HIV?)

## Probes:

- What do people say about them as women?
- What do people say about them as mothers?
- What about their lifestyle? (substance use, sex life, etc.)
- In your opinion, what is going through the minds of people who discriminate against women living with HIV?
- 6. How about men living with HIV?

#### Probes

- Are men and women living with HIV viewed differently? In what ways?
- Are they treated differently? In what ways?

# Internalized stigma

7. Let's go back a bit further in time once more. Do you remember how you felt about people with HIV before you were diagnosed? How do you think those feelings impact the way you see yourself now?

People experience stigma and discrimination based on many other things besides HIV, including being poor, having experienced violence, being trafficked or engaging in sex work. Stigma may also differ based on how people think you were infected.

8. Can you describe any experiences you have with discrimination based on other parts of who you are? Are there some things about you / aspects of your identity that you think may cause some people to judge you negatively or treat you differently than others?

# Probes:

- Your religion/caste?
- Your income level?
- Your educational level?
- Your age?
- Your having children / not having children?
- Your way of earning money? (e.g., sex work)
- Having experienced violence (domestic/other sexual)
- 9. How does facing more than one type of discrimination affect you? Affect other women that you know?

# Disclosure and Anticipated stigma

- 10. How do you think the negative ways you may have been viewed or treated by others because of your HIV status may impact your health? (Probes: HIV care seeking, collecting/taking HIV medication, other health issues)
- 11. Did you disclose your HIV status to anyone after you found out? Can you share stories of how people reacted when you told them?

# Domestic Violence

- Reaction of your partner/in-laws/others (violence, abuse, support)
- Reasons for non-disclosure

12. Have you ever been beaten or humiliated by your husband or in-laws? Why do you think the violence happened? Why do you think men do this?

#### Probes:

- Types and frequency of violence
- Reasons for violence
- 13. Did this (violence) change after you were diagnosed with HIV? What do you think might be some reasons for this change?

# Probes:

- Reasons for violence before and after HIV (gender norms, blame, stigma)
- Difference in the types and frequency of violence (increase/decrease)
- 14. Did you ever seek support or report these violent episodes? Has there been a change in where and who you seek help from since your HIV diagnosis?

## Probes:

- Source of formal/informal support/reporting
- Reasons for seeking/not seeking help (HIV related/un-related reasons)
- 15. How did people react when you reported the violence? Do you think being HIV+ makes it more difficult to seek help for domestic violence? Can you please explain why?

### Probes:

- Fear of revealing HIV status
- HIV stigma

# Mental health and support

- 16. How has this domestic violence impacted your adherence to HIV medications or your ability to go to the hospital for HIV care?
- 17. Today we have talked about many negative experiences that you have gone through. Can you tell me a little more about how this impacts your mental health?

# Probes:

- Sadness, stress, worry, hopelessness related to stigmatizing experiences
- How this impacts medication adherence/physical health
- How this impact other areas of life (childcare responsibilities, household chores, work if any)
- 18. How have these feelings impacted your adherence to HIV medications or your ability to go to the hospital for HIV care?
- 19. Have you sought any help for the negative feelings that you have just described? Are you aware of services that are available that can help you with mental health issues?

### Probe:

- Mental health counselling services
- Psychiatric services
- 20. How are some ways you cope or manage some of these negative experiences? What gives you strength?

# Probes:

- Social support, friends/family
- Support groups

- Clinical support (doctors, therapists, social workers delivering HIV care)
- · Religion, spirituality
- Relaxation
- Focusing on work
- Other
- 21. Can you talk about the extent to which women with HIV that you know accept (or do not accept) themselves?

## Probes:

- Accept one another?
- Support one another?
- 22. How do you create/sustain friendships or other close relationships? How do you approach meeting new people?

# HIV/AIDS Prevention & Control Act 2017

23. (Put it at the start/ask screening Q) Are you aware of the new law that prohibits discrimination against people living with HIV/AIDS? Can you tell me a bit more about it?

## Probes:

 Do they plan to take action against acts of discrimination using this new law? If not, why?

# Wrapping up

24. How would you like to see society change to become more accepting of women infected with HIV? How could these changes be accomplished?

Is there anything I have not asked you about that you think I should know about? (i.e., what have I missed in this conversation?)

Thank you very much for your time. Your responses will be very helpful for improving services for women living with HIV/AIDS.

# Appendix 4: Information Sheet and Consent form (Key Informants)

Removed for purposes of data protection and participant anonymity. Will be available from the author upon request.

# Appendix 5: Information sheet and consent form (Women living with HIV)

Removed for purposes of data protection and participant anonymity. Will be available from the author upon request.

# **Appendix 6: Audit trail for methodology**

# **Data Collection:**

- Reviewing literature on HIV stigma, domestic violence stigma, intersectional stigma, and qualitative methods
- Getting approval letter from local NGO and ethics approval from University College London
- Developing contacts and networking for recruitment
- Establishing rapport with NGO partner
- Recruitment of participants
- Arranging online interviews with key informants and face-to-face interviews with women living with HIV.

# **Preparing for data analysis:**

- Data collection through semi-structured interviews with women living with HIV and key informants and photovoice with women living with HIV.
- Detailed field notes prepared after each interview to record non-verbal cues,
   appearance, impressions of participants, key findings etc.
- Preliminary analysis of interviews.
- Transcription and translation of recorded interviews with removal of any identifiers
- Familiarization with interview transcripts.
- Veryfing findings with participants.

# Data analysis:

- Data coded in Nvivo using a combination of deductive and inductive coding.
- Organizing themes generated from the Nvivo codes
- Overarching global themes developed (iterative process through multiple discussions with supervision team).
- Thematic maps created based on research questions and related themes.
- Each theme written up with supportive quotations and modified along the way.

# Appendix 7: HIV/AIDS Prevention and Control Act, 2017

Downloaded from http://naco.gov.in/sites/default/files/HIV%20and%20AIDS%20Act-%20English.pdf

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असाधारण

EXTRAORDINARY

भाग II — खण्ड 1

PART II — Section 1 प्राधिकार से प्रकाशित

PUBLISHED BY AUTHORITY

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नई दिल्ली, शुक्रवार, अप्रैल 21, 2017/ वैशाख 1, 1939 (शक)

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NEW DELHI, FRIDAY, APRIL, 21, 2017/VAISAKHA 1, 1939 (SAKA)

इस भाग में भिन्न पृष्ठ संख्या दी जाती है जिससे कि यह अलग संकलन के रूप में रखा जा सके। Separate paging is given to this Part in order that it may be filed as a separate compilation.

# MINISTRY OF LAW AND JUSTICE

(Legislative Department)

New Delhi, the 21st April, 2017/Vaisakha 1, 1939 (Saka)

The following Act of Parliament received the assent of the President on the 20th April, 2017, and is hereby published for general information:—

# THE HUMAN IMMUNODEFICIENCY VIRUS AND ACQUIRED IMMUNE DEFICIENCY SYNDROME (PREVENTION AND CONTROL) ACT, 2017

No. 16 of 2017

 $[20th\ April, 2017.]$ 

An Act to provide for the prevention and control of the spread of Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome and for the protection of human rights of persons affected by the said virus and syndrome and for matters connected therewith or incidental thereto.

Whereas the spread of Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome is a matter of grave concern to all and there is an urgent need for the prevention and control of said virus and syndrome;

AND WHEREAS there is a need to protect and secure the human rights of persons who are HIV-positive, affected by Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome and vulnerable to the said virus and syndrome;

AND WHEREAS there is a necessity for effective care, support and treatment for Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome;

AND WHEREAS there is a need to protect the rights of healthcare providers and other persons in relation to Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome;

AND WHEREAS the General Assembly of the United Nations, recalling and reaffirming its previous commitments on Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome, has adopted the Declaration of Commitment on Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (2001) to address the problems of Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome in all its aspects and to secure a global commitment to enhancing coordination and intensification of national, regional and international efforts to combat it in a comprehensive manner;

AND WHEREAS the Republic of India, being a signatory to the aforesaid Declaration, it is expedient to give effect to the said Declaration.

BE it enacted by Parliament in the Sixty-eighth Year of the Republic of India as follows:—

# CHAPTER I

#### Preliminary

Short title, extent and commencement.

- **1.** (1) This Act may be called the Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Act, 2017.
  - (2) It extends to the whole of India.
- (3) It shall come into force on such date as the Central Government may, by notification in the Official Gazette, appoint.

Definitions.

- 2. In this Act, unless the context otherwise requires,—
- (a) "AIDS" means Acquired Immune Deficiency Syndrome, a condition characterised by a combination of signs and symptoms, caused by Human Immunodeficiency Virus, which attacks and weakens the body's immune system making the HIV-positive person susceptible to life threatening conditions or other conditions, as may be specified from time to time;
- (b) "capacity to consent" means ability of an individual, determined on an objective basis, to understand and appreciate the nature and consequences of a proposed action and to make an informed decision concerning such action;
- (c) "child affected by HIV" means a person below the age of eighteen years, who is HIV-positive or whose parent or guardian (with whom such child normally resides) is HIV-positive or has lost a parent or guardian (with whom such child resided) due to AIDS or lives in a household fostering children orphaned by AIDS;
- (d) "discrimination" means any act or omission which directly or indirectly, expressly or by effect, immediately or over a period of time,—
  - (i) imposes any burden, obligation, liability, disability or disadvantage on any person or category of persons, based on one or more HIV-related grounds; or
  - (ii) denies or withholds any benefit, opportunity or advantage from any person or category of persons, based on one or more HIV-related grounds,

and the expression "discriminate" to be construed accordingly.

Explanation 1.—For the purposes of this clause, HIV-related grounds include—

- (i) being an HIV-positive person;
- (ii) ordinarily living, residing or cohabiting with a person who is HIV-positive person;

(iii) ordinarily lived, resided or cohabited with a person who was HIV-positive.

Explanation 2.—For the removal of doubts, it is hereby clarified that adoption of medically advised safeguards and precautions to minimise the risk of infection shall not amount to discrimination;

- (e) "domestic relationship" means a relationship as defined under clause (f) of section 2 of the Protection of Women from Domestic Violence Act, 2005;
- (f) "establishment" means a body corporate or co-operative society or any organisation or institution or two or more persons jointly carrying out a systematic activity for a period of twelve months or more at one or more places for consideration or otherwise, for the production, supply or distribution of goods or services;
- (g) "guidelines" means any statement or any other document issued by the Central Government indicating policy or procedure or course of action relating to HIV and AIDS to be followed by the Central Government, State Governments, governmental and non-governmental organisations and establishments and individuals dealing with prevention, control and treatment of HIV or AIDS;
- (h) "healthcare provider" means any individual whose vocation or profession is directly or indirectly related to the maintenance of the health of another individual and includes any physician, nurse, paramedic, psychologist, counsellor or other individual providing medical, nursing, psychological or other healthcare services including HIV prevention and treatment services;
  - (i) "HIV" means Human Immunodeficiency Virus;
- (j) "HIV-affected person" means an individual who is HIV-positive or whose partner (with whom such individual normally resides) is HIV-positive or has lost a partner (with whom such individual resided) due to AIDS;
- (k) "HIV-positive person" means a person whose HIV test has been confirmed positive;
- (l) "HIV-related information" means any information relating to the HIV status of a person and includes
  - (i) information relating to the undertaking performing the HIV test or result of an HIV test:
    - (ii) information relating to the care, support or treatment of that person;
    - (iii) information which may identify that person; and
  - (*iv*) any other information concerning that person, which is collected, received, accessed or recorded in connection with an HIV test, HIV treatment or HIV-related research or the HIV status of that person;
- (m) "HIV test" means a test to determine the presence of an antibody or antigen of HIV:
- (n) "informed consent" means consent given by any individual or his representative specific to a proposed intervention without any coercion, undue influence, fraud, mistake or misrepresentation and such consent obtained after informing such individual or his representative, as the case may be, such information, as specified in the guidelines, relating to risks and benefits of, and alternatives to, the proposed intervention in such language and in such manner as understood by that individual or his representative, as the case may be;
  - (o) "notification" means a notification published in the Official Gazette;
- (p) "partner" means a spouse, *de facto* spouse or a person with whom another person has relationship in the nature of marriage;

43 of 2005.

(q) "person" includes an individual, a Hindu Undivided Family, a company, a firm, an association of persons or a body of individuals, whether incorporated or not, in India or outside India, any corporation established by or under any Central or State Act or any company including a Government company incorporated under the Companies Act, 1956, any Limited Liability Partnership under the Limited Liability Partnership Act, 2008, any body corporate incorporated by or under the laws of a country outside India, a co-operative society registered under any law relating to co-operative societies, a local authority, and every other artificial juridical person;

1 of 1956. 6 of 2009.

- (*r*) "prescribed" means prescribed by rules made by the Central Government or the State Government, as the case may be;
  - (s) "protected person" means a person who is—
    - (i) HIV-Positive; or
  - (ii) ordinarily living, residing or cohabiting with a person who is HIV-positive person; or
  - (iii) ordinarily lived, resided or cohabited with a person who was HIV-positive;
- (t) "reasonable accommodation" means minor adjustments to a job or work that enables an HIV-positive person who is otherwise qualified to enjoy equal benefits or to perform the essential functions of the job or work, as the case may be;
  - (u) "relative", with reference to the protected person, means—
    - (i) spouse of the protected person;
    - (ii) parents of the protected person;
    - (iii) brother or sister of the protected person;
    - (iv) brother or sister of the spouse of the protected person;
    - (v) brother or sister of either of the parents of the protected person;
  - (vi) in the absence of any of the relatives mentioned at sub-clauses (i) to (v), any lineal ascendant or descendant of the protected person;
  - (vii) in the absence of any of the relatives mentioned at sub-clauses (i) to (vi), any lineal ascendant or descendant of the spouse of the protected person;
  - (v) "significant-risk" means
    - (a) the presence of significant-risk body substances;
  - (b) a circumstance which constitutes significant-risk for transmitting or contracting HIV infection; or
  - (c) the presence of an infectious source and an uninfected person.
  - Explanation.—For the purpose of this clause,—
  - (i) "significant-risk body substances" are blood, blood products, semen, vaginal secretions, breast milk, tissue and the body fluids, namely, cerebrospinal, amniotic, peritoneal, synovial, pericardial and pleural;
  - (ii) "circumstances which constitute significant-risk for transmitting or contracting HIV infection" are—
    - (A) sexual intercourse including vaginal, anal or oral sexual intercourse which exposes an uninfected person to blood, blood products, semen or vaginal secretions of an HIV-positive person;
    - (B) sharing of needles and other paraphernalia used for preparing and injecting drugs between HIV-positive persons and uninfected persons;

- (C) the gestation, giving birth or breast feeding of an infant when the mother is an HIV-positive person;
- (D) transfusion of blood, blood products, and transplantation of organs or other tissues from an HIV-positive person to an uninfected person, provided such blood, blood products, organs or other tissues have not been tested conclusively for the antibody or antigen of HIV and have not been rendered non-infective by heat or chemical treatment; and
- (E) other circumstances during which a significant-risk body substance, other than breast milk, of an HIV-positive person contacts or may contact mucous membranes including eyes, nose or mouth, non-intact skin including open wounds, skin with a dermatitis condition or abraded areas or the vascular system of an uninfected person, and including such circumstances not limited to needle-stick or puncture wound injuries and direct saturation or permeation of these body surfaces by the significant-risk body substances:

Provided that "significant-risk" shall not include—

- (i) exposure to urine, faeces, sputum, nasal secretions, saliva, sweat, tears or vomit that does not contain blood that is visible to the naked eye;
- (ii) human bites where there is no direct blood to blood, or no blood to mucous membrane contact;
- (iii) exposure of intact skin to blood or any other blood substance: and
- (iv) occupational centres where individuals use scientifically accepted Universal Precautions, prohibitive techniques and preventive practices in circumstances which would otherwise pose a significant-risk and such techniques are not breached and remain intact;
- (w) "State AIDS Control Society" means the nodal agency of the State Government responsible for implementing programmes in the field of HIV and AIDS;
- (x) "State Government", in relation to a Union territory, means the Administrator of that Union territory appointed by the President under article 239 of the Constitution; and
- (y) "Universal Precautions" means control measures that prevent exposure to or reduce, the risk of transmission of pathogenic agents (including HIV) and includes education, training, personal protective equipment such as gloves, gowns and masks, hand washing, and employing safe work practices.

# CHAPTER II

## PROHIBITION OF CERTAIN ACTS

**3.** No person shall discriminate against the protected person on any ground including any of the following, namely:—

Prohibition of discrimination.

- (a) the denial of, or termination from, employment or occupation, unless, in the case of termination, the person, who is otherwise qualified, is furnished with—
  - (i) a copy of the written assessment of a qualified and independent healthcare provider competent to do so that such protected person poses a significant risk of transmission of HIV to other person in the workplace, or is unfit to perform the duties of the job; and

- (ii) a copy of a written statement by the employer stating the nature and extent of administrative or financial hardship for not providing him reasonable accommodation;
- (b) the unfair treatment in, or in relation to, employment or occupation;
- (c) the denial or discontinuation of, or, unfair treatment in, healthcare services;
- (d) the denial or discontinuation of, or unfair treatment in, educational, establishments and services thereof;
- (e) the denial or discontinuation of, or unfair treatment with regard to, access to, or provision or enjoyment or use of any goods, accommodation, service, facility, benefit, privilege or opportunity dedicated to the use of the general public or customarily available to the public, whether or not for a fee, including shops, public restaurants, hotels and places of public entertainment or the use of wells, tanks, bathing *ghats*, roads, burial grounds or funeral ceremonies and places of public resort;
- (f) the denial, or, discontinuation of, or unfair treatment with regard to, the right of movement;
- (g) the denial or discontinuation of, or, unfair treatment with regard to, the right to reside, purchase, rent, or otherwise occupy, any property;
- (h) the denial or discontinuation of, or, unfair treatment in, the opportunity to stand for, or, hold public or private office;
- (i) the denial of access to, removal from, or unfair treatment in, Government or private establishment in whose care or custody a person may be;
- (*j*) the denial of, or unfair treatment in, the provision of insurance unless supported by actuarial studies;
  - (k) the isolation or segregation of a protected person;
- (1) HIV testing as a pre-requisite for obtaining employment, or accessing healthcare services or education or, for the continuation of the same or, for accessing or using any other service or facility:

Provided that, in case of failure to furnish the written assessment under subclause (i) of clause (a), it shall be presumed that there is no significant-risk and that the person is fit to perform the duties of the job, as the case may be, and in case of the failure to furnish the written statement under sub-clause (ii) of that clause, it shall be presumed that there is no such undue administrative or financial hardship.

**4**. No person shall, by words, either spoken or written, publish, propagate, advocate or communicate by signs or by visible representation or otherwise the feelings of hatred against any protected persons or group of protected person in general or specifically or disseminate, broadcast or display any information, advertisement or notice, which may reasonably be construed to demonstrate an intention to propagate hatred or which is likely to expose protected persons to hatred, discrimination or physical violence.

# CHAPTER III

# Informed consent

- **5.** (1) Subject to the provisions of this Act,—
  - (a) no HIV test shall be undertaken or performed upon any person; or
- (b) no protected person shall be subject to medical treatment, medical interventions or research,

except with the informed consent of such person or his representative and in such manner, as may be specified in the guidelines.

Prohibition of certain acts.

Informed consent for undertaking HIV test or treatment.

Informed consent not

required for

conducting HIV tests in

certain cases.

- (2) The informed consent for HIV test shall include pre-test and post-test counselling to the person being tested or such person's representative in the manner as may be specified in the guidelines.
  - **6.** The informed consent for conducting an HIV test shall not be required—
  - (a) where a court determines, by an order that the carrying out of the HIV test of any person either as part of a medical examination or otherwise, is necessary for the determination of issues in the matter before it;
  - (b) for procuring, processing, distribution or use of a human body or any part thereof including tissues, blood, semen or other body fluids for use in medical research or therapy:

Provided that where the test results are requested by a donor prior to donation, the donor shall be referred to counselling and testing centre and such donor shall not be entitled to the results of the test unless he has received post-test counselling from such centre:

(c) for epidemiological or surveillance purposes where the HIV test is anonymous and is not for the purpose of determining the HIV status of a person:

Provided that persons who are subjects of such epidemiological or surveillance studies shall be informed of the purposes of such studies; and

- (d) for screening purposes in any licensed blood bank.
- **7.** No HIV test shall be conducted or performed by any testing or diagnostic centre or pathology laboratory or blood bank, unless such centre or laboratory or blood bank follows the guidelines laid down for such test.

Guidelines for testing centres, etc.

# CHAPTER IV

# DISCLOSURE OF HIV STATUS

8. (I) Notwithstanding anything contained in any other law for the time being in force,—

Disclosure of HIV status.

- (i) no person shall be compelled to disclose his HIV status except by an order of the court that the disclosure of such information is necessary in the interest of justice for the determination of issues in the matter before it;
- (ii) no person shall disclose or be compelled to disclose the HIV status or any other private information of other person imparted in confidence or in a relationship of a fiduciary nature, except with the informed consent of that other person or a representative of such another person obtained in the manner as specified in section 5, as the case may be, and the fact of such consent has been recorded in writing by the person making such disclosure:

Provided that, in case of a relationship of a fiduciary nature, informed consent shall be recorded in writing.

- (2) The informed consent for disclosure of HIV-related information under clause (ii) of sub-section (1) is not required where the disclosure is made—
  - (a) by a healthcare provider to another healthcare provider who is involved in the care, treatment or counselling of such person, when such disclosure is necessary to provide care or treatment to that person;
  - (b) by an order of a court that the disclosure of such information is necessary in the interest of justice for the determination of issues and in the matter before it;
  - (c) in suits or legal proceedings between persons, where the disclosure of such information is necessary in filing suits or legal proceedings or for instructing their counsel;

- (d) as required under the provisions of section 9;
- (e) if it relates to statistical or other information of a person that could not reasonably be expected to lead to the identification of that person; and
- (*f*) to the officers of the Central Government or the State Government or State AIDS Control Society of the concerned State Government, as the case may be, for the purposes of monitoring, evaluation or supervision.
- 9. (1) No healthcare provider, except a physician or a counsellor, shall disclose the HIV-positive status of a person to his or her partner.
- (2) A healthcare provider, who is a physician or counsellor, may disclose the HIV-positive status of a person under his direct care to his or her partner, if such healthcare provider—
  - (a) reasonably believes that the partner is at the significant risk of transmission of HIV from such person; and
    - (b) such HIV-positive person has been counselled to inform such partner; and
    - (c) is satisfied that the HIV-positive person will not inform such partner; and
  - (d) has informed the HIV-positive person of the intention to disclose the HIV-positive status to such partner:

Provided that disclosure under this sub-section to the partner shall be made in person after counselling:

Provided further that such healthcare provider shall have no obligation to identify or locate the partner of an HIV-positive person:

Provided also that such healthcare provider shall not inform the partner of a woman where there is a reasonable apprehension that such information may result in violence, abandonment or actions which may have a severe negative effect on the physical or mental health or safety of such woman, her children, her relatives or someone who is close to her.

- (3) The healthcare provider under sub-section (1) shall not be liable for any criminal or civil action for any disclosure or non-disclosure of confidential HIV-related information made to a partner under this section.
- 10. Every person, who is HIV-positive and has been counselled in accordance with the guidelines issued or is aware of the nature of HIV and its transmission, shall take all reasonable precautions to prevent the transmission of HIV to other persons which may include adopting strategies for the reduction of risk or informing in advance his HIV status before any sexual contact with any person or with whom needles are shared with:

Provided that the provisions of this section shall not be applicable to prevent transmission through a sexual contact in the case of a woman, where there is a reasonable apprehension that such information may result in violence, abandonment or actions which may have a severe negative effect on the physical or mental health or safety of such woman, her children, her relatives or someone who is close to her.

# CHAPTER V

# OBLIGATION OF ESTABLISHMENTS

Confidentiality of data.

Duty to prevent

of HIV.

transmission

11. Every establishment keeping the records of HIV-related information of protected persons shall adopt data protection measures in accordance with the guidelines to ensure that such information is protected from disclosure.

Explanation.— For the purpose of this section, data protection measures shall include procedures for protecting information from disclosure, procedures for accessing information, provision for security systems to protect the information stored in any form and mechanisms to ensure accountability and liability of persons in the establishment.

Disclosure of HIV-positive status to partner of HIV-positive person. **12.** The Central Government shall notify model HIV and AIDS policy for establishments, in such manner, as may be prescribed.

HIV and AIDS policy for establishments.

#### CHAPTER VI

Anti-retroviral Therapy and Opportunistic Infection Management for people Living with HIV

13. The Central Government and every State Government, as the case may be, shall take all such measures as it deems necessary and expedient for the prevention of spread of HIV or AIDS, in accordance with the guidelines.

Central
Government
and State
Government
to take
measures.

14.(I) The measures to be taken by the Central Government or the State Government under section 13 shall include the measures for providing, as far as possible, diagnostic facilities relating to HIV or AIDS, Anti-retroviral Therapy and Opportunistic Infection Management to people living with HIV or AIDS.

Antiretroviral
Therapy and
Opportunistic
Infection
Management
by Central
Government
and State
Government.

(2) The Central Government shall issue necessary guidelines in respect of protocols for HIV and AIDS relating to diagnostic facilities, Anti-retroviral Therapy and Opportunistic Infection Management which shall be applicable to all persons and shall ensure their wide dissemination.

# CHAPTER VII

Welfare measures by the Central Government and State Government

- **15**. (1) The Central Government and every State Government shall take measures to facilitate better access to welfare schemes to persons infected or affected by HIV or AIDS.
- (2) Without prejudice to the provisions of sub-section (1), the Central Government and State Governments shall frame schemes to address the needs of all protected persons.

Welfare measures by Central Government and State Government.

**16.** (*I*) The Central Government or the State Government, as the case may be, shall take appropriate steps to protect the property of children affected by HIV or AIDS for the protection of property of child affected by HIV or AIDS.

Protection of property of children affected by HIV or AIDS.

(2) The parents or guardians of children affected by HIV and AIDS, or any person acting for protecting their interest, or a child affected by HIV and AIDS may approach the Child Welfare Committee for the safe keeping and deposit of documents related to the property rights of such child or to make complaints relating to such child being dispossessed or actual dispossession or trespass into such child's house.

*Explanation.*—For the purpose of this section, "Child Welfare Committee" means a Committee set-up under section 29 of the Juvenile Justice (Care and Protection of Children) Act, 2000.

17. The Central Government and the State Government shall formulate HIV and AIDS related information, education and communication programmes which are age-appropriate, gender-sensitive, non-stigmatising and non-discriminatory.

Promotion of HIV and AIDS related information, education and communication programmes.

- **18**. (1) The Central Government shall lay down guidelines for care, support and treatment of children infected with HIV or AIDS.
- Women and children infected with HIV or AIDS.
- (2) Without prejudice to the generality of the provisions of sub-section (1) and notwithstanding anything contained in any other law for the time being in force, the Central Government, or the State Government as the case may be, shall take measures to counsel and provide information regarding the outcome of pregnancy and HIV-related treatment to the HIV infected women.

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(3) No HIV positive woman, who is pregnant, shall be subjected to sterilisation or abortion without obtaining her informed consent.

#### CHAPTER VIII

### SAFE WORKING ENVIRONMENT

Obligation of establishments to provide safe working environment.

- 19. Every establishment, engaged in the healthcare services and every such other establishment where there is a significant risk of occupational exposure to HIV, shall, for the purpose of ensuring safe working environment,—
  - (i) provide, in accordance with the guidelines,—
  - (a) Universal Precautions to all persons working in such establishment who may be occupationally exposed to HIV; and
    - (b) training for the use of such Universal Precautions;
  - (c) Post Exposure Prophylaxis to all persons working in such establishment who may be occupationally exposed to HIV or AIDS; and
  - (*ii*) inform and educate all persons working in the establishment of the availability of Universal Precautions and Post Exposure Prophylaxis.

General responsibility of establishments.

20.(1) The provisions of this Chapter shall be applicable to all establishments consisting of one hundred or more persons, whether as an employee or officer or member or director or trustee or manager, as the case may be:

Provided that in the case of healthcare establishments, the provisions of this sub-section shall have the effect as if for the words "one hundred or more", the words "twenty or more" had been substituted.

- (2) Every person, who is in charge of an establishment, referred to in sub-section (I), for the conduct of the activities of such establishment, shall ensure compliance of the provisions of this Act.
- Grievance redressal mechanism.
- **21.** Every establishment referred to in sub-section (*I*) of section 20 shall designate such person, as it deems fit, as the Complaints Officer who shall dispose of complaints of violations of the provisions of this Act in the establishment, in such manner and within such time as may be prescribed.

# **CHAPTER IX**

# PROMOTION OF STRATEGIES FOR REDUCTION OF RISK

Strategies for reduction of risk.

22. Notwithstanding anything contained in any other law for the time being in force any strategy or mechanism or technique adopted or implemented for reducing the risk of HIV transmission, or any act pursuant thereto, as carried out by persons, establishments or organisations in the manner as may be specified in the guidelines issued by the Central Government shall not be restricted or prohibited in any manner, and shall not amount to a criminal offence or attract civil liability.

Explanation.—For the purpose of this section, strategies for reducing risk of HIV transmission means promoting actions or practices that minimise a person's risk of exposure to HIV or mitigate the adverse impacts related to HIV or AIDS including—

- (i) the provisions of information, education and counselling services relating to prevention of HIV and safe practices;
  - (ii) the provisions and use of safer sex tools, including condoms;
  - (iii) drug substitution and drug maintenance; and
  - (iv) provision of comprehensive injection safety requirements.

#### Illustrations

- (a) A supplies condoms to B who is a sex worker or to C, who is a client of B. Neither A nor B nor C can be held criminally or civilly liable for such actions or be prohibited, impeded, restricted or prevented from implementing or using the strategy.
- (b) M carries on an intervention project on HIV or AIDS and sexual health information, education and counselling for men, who have sex with men, provides safer sex information, material and condoms to N, who has sex with other men. Neither M nor N can be held criminally or civilly liable for such actions or be prohibited, impeded, restricted or prevented from implementing or using the intervention.
- (c) X, who undertakes an intervention providing registered needle exchange programme services to injecting drug users, supplies a clean needle to Y, an injecting drug user who exchanges the same for a used needle. Neither X nor Y can be held criminally or civilly liable for such actions or be prohibited, impeded, restricted or prevented from implementing or using the intervention.
- (d) D, who carries on an intervention programme providing Opioid Substitution Treatment (OST), administers OST to E, an injecting drug user. Neither D nor E can be held criminally or civilly liable for such actions or be prohibited, impeded, restricted or prevented from implementing or using the intervention.

## CHAPTER X

#### APPOINTMENT OF OMBUDSMAN

23. (1) Every State Government shall appoint one or more Ombudsman,—

Appointment of Ombudsman.

- (a) possessing such qualification and experience as may be prescribed, or
- (b) designate any of its officers not below such rank, as may be prescribed, by that Government,

to exercise such powers and discharge such functions, as may be conferred on Ombudsman under this Act.

- (2) The terms and condition of the service of an Ombudsman appointed under clause (a) of sub-section (1) shall be such as may be prescribed by the State Government.
- (3) The Ombudsman appointed under sub-section (1) shall have such jurisdiction in respect of such area or areas as the State Government may, by notification, specify.
- 24.(1) The Ombudsman shall, upon a complaint made by any person, inquire into the violations of the provisions of this Act, in relation to acts of discrimination mentioned in section 3 and providing of healthcare services by any person, in such manner as may be prescribed by the State Government.

Powers of Ombudsman.

- (2) The Ombudsman may require any person to furnish information on such points or matters, as he considers necessary, for inquiring into the matter and any person so required shall be deemed to be legally bound to furnish such information and failure to do so shall be punishable under sections 176 and 177 of the Indian Penal Code.
- (3) The Ombudsman shall maintain records in such manner as may be prescribed by the State Government.
- **25.** The complaints may be made to the Ombudsman under sub-section (1) of section 24 in such manner, as may be prescribed, by the State Government.

Procedure of complaint.

**26.** The Ombudsman shall, within a period of thirty days of the receipt of the complaint under sub-section (I) of section 24, and after giving an opportunity of being heard to the parties, pass such order, as he deems fit, giving reasons therefor:

Orders of Ombudsman.

Provided that in cases of medical emergency of HIV positive persons, the Ombudsman shall pass such order as soon as possible, preferably within twenty-four hours of the receipt of the complaint.

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Authorities to assist Ombudsman.

**27.** All authorities including the civil authorities functioning in the area for which the Ombudsman has been appointed under section 23 shall assist in execution of orders passed by the Ombudsman.

Report to State Government. **28.** The Ombudsman shall, after every six months, report to the State Government, the number and nature of complaints received, the action taken and orders passed in relation to such complaints and such report shall be published on the website of the Ombudsman and a copy thereof be forwarded to the Central Government.

## CHAPTER XI

# SPECIAL PROVISIONS

Right of residence.

29. Every protected person shall have the right to reside in the shared household, the right not to be excluded from the shared household or any part of it and the right to enjoy and use the facilities of such shared household in a non-discriminatory manner.

Explanation.—For the purposes of this section, the expression "shared household" means a household where a person lives or at any stage has lived in a domestic relationship either singly or along with another person and includes such a household, whether owned or tenanted, either jointly or singly, any such household in respect of which either person or both, jointly or singly, have any right, title, interest or equity or a household which may belong to a joint family of which either person is a member, irrespective of whether either person has any right, title or interest in the shared household.

HIV-related information, education and communication before marriage. **30**. The Central Government shall specify guidelines for the provision of HIV-related information, education and communication before marriage and ensure their wide dissemination.

Persons in care or custody of State.

- **31.** (1) Every person who is in the care or custody of the State shall have the right to HIV prevention, counselling, testing and treatment services in accordance with the guidelines issued in this regard.
- (2) For the purposes of this section, persons in the care or custody of the State include persons convicted of a crime and serving a sentence, persons awaiting trial, person detained under preventive detention laws, persons under the care or custody of the State under the Juvenile Justice (Care and Protection of Children) Act, 2000, the Immoral Traffic (Prevention) Act, 1956 or any other law and persons in the care or custody of State run homes and shelters.

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Recognition of guardianship of older sibling.

- **32**. Notwithstanding anything contained in any law for the time being in force, a person below the age of eighteen but not below twelve years, who has sufficient maturity of understanding and who is managing the affairs of his family affected by HIV and AIDS, shall be competent to act as guardian of other sibling below the age of eighteen years for the following purposes, namely:—
  - (a) admission to educational establishments;
  - (b) care and protection;
  - (c) treatment;
  - (d) operating bank accounts;
  - (e) managing property; and
  - (f) any other purpose that may be required to discharge his duties as a guardian.

Explanation.—For the purposes of this section, a family affected by HIV or AIDS means where both parents and the legal guardian is incapacitated due to HIV-related illness or AIDS or the legal guardian and parents are unable to discharge their duties in relation to such children.

**33.** (1) Notwithstanding anything contained in any law for the time being in force, a parent or legal guardian of a child affected by HIV and AIDS may appoint, by making a will, an adult person who is a relative or friend, or a person below the age of eighteen years who is the managing member of the family affected by HIV and AIDS, as referred to in section 33, to act as legal guardian immediately upon incapacity or death of such parent or legal guardian, as the case may be.

Living wills for guardianship and testamentary guardianship.

- (2) Nothing in this section shall divest a parent or legal guardian of their rights, and the guardianship referred to in sub-section (I) shall cease to operate upon by the parent or legal guardian regaining their capacity.
- (3) Any parent or legal guardian of children affected by HIV and AIDS may make a will appointing a guardian for care and protection of such children and for the property that such children would inherit or which is bequeathed through the will made by such parent or legal guardian.

#### CHAPTER XII

#### SPECIAL PROCEDURE IN COURT

**34.** (I) In any legal proceeding in which a protected person is a party or such person is an applicant, the court, on an application by such person or any other person on his behalf may pass, in the interest of justice, any or all of the following orders, namely:—

Suppression of identity.

- (a) that the proceeding or any part thereof be conducted by suppressing the identity of the applicant by substituting the name of such person with a pseudonym in the records of the proceedings in such manner as may be prescribed;
  - (b) that the proceeding or any part thereof may be conducted in camera;
- (c) restraining any person from publishing in any manner any matter leading to the disclosure of the name or status or identity of the applicant.
- (2) In any legal proceeding concerning or relating to an HIV-positive person, the court shall take up and dispose of the proceeding on priority basis.
- 35. In any maintenance application filed by or on behalf of a protected person under any law for the time being in force, the court shall consider the application for interim maintenance and, in passing any order of maintenance, shall take into account the medical expenses and other HIV-related costs that may be incurred by the applicant.

Maintenance applications.

**36.** In passing any order relating to sentencing, the HIV-positive status of the persons in respect of whom such an order is passed shall be a relevant factor to be considered by the court to determine the custodial place where such person shall be transferred to, based on the availability of proper healthcare services at such place.

Sentencing.

# CHAPTER XIII

## **PENALTIES**

**37.** Notwithstanding any action that may be taken under any other law for the time being in force, whoever contravenes the provisions of section 4 shall be punished with imprisonment for a term which shall not be less than three months but which may extend to two years and with fine which may extend to one lakh rupees, or with both.

Penalty for contravention.

- **38.** Whoever fails to comply with any order given by an Ombudsman within such time as may be specified in such order, under section 26, shall be liable to pay a fine which may extend to ten thousand rupees and in case the failure continues, with an additional fine which may extend to five thousand rupees for every day during which such failure continues.
- Penalty for failure to comply with orders of Ombudsman.
- **39**. Notwithstanding any action that may be taken under any law for the time being in force, whoever discloses information regarding the HIV status of a protected person which is obtained by him in the course of, or in relation to, any proceedings before any court, shall

Penalty for breach of confidentiality in legal proceedings. be punishable with fine which may extend to one lakh rupees unless such disclosure is pursuant to any order or direction of a court.

Prohibition of victimisation.

- **40**. No person shall subject any other person or persons to any detriment on the ground that such person or persons have taken any of the following actions, namely:—
  - (a) made complaint under this Act;
  - (b) brought proceedings under this Act against any person;
  - (c) furnished any information or produced any document to a person exercising or performing any power or function under this Act; or
    - (d) appeared as a witness in a proceeding under this Act.

Court to try offences.

**41.** No court other than the court of a Judicial Magistrate First Class shall take cognizance of an offence under this Act.

Offences to be cognizable and bailable.

**42.** Notwithstanding anything contained in the Code of Criminal Procedure, 1973, offences under this Act shall be cognizable and bailable.

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# CHAPTER XIV

#### Miscellaneous

Act to have overriding effect.

**43.** The provisions of this Act shall have effect notwithstanding anything inconsistent therewith contained in any other law for the time in force or in any instrument having effect by virtue of any law other than this Act.

Protection of action taken in good faith.

**44.** No suit, prosecution or other legal proceeding shall lie against the Central Government, the State Government, the Central Government or AIDS Control Society of the State Government Ombudsman or any member thereof or any officer or other employee or person acting under the direction either of the Central Government, the State Government, the Central Government, or Ombudsman in respect of anything which is in good faith done or intended to be done in pursuance of this Act or any rules or guidelines made thereunder or in respect of the publication by or under the authority of the Central Government, the State Government, the Central Government or AIDS Control Society of the State Government Ombudsman.

Delegation of powers.

**45.** The Central Government and State Government, as the case may be, may, by general or special order, direct that any power exercisable by it under this Act shall, in such circumstances and under such conditions, if any, as may be mentioned in the order, be exercisable also by an officer subordinate to that Government or the local authority.

Guidelines.

- **46.** (1) The Central Government may, by notification, make guidelines consistent with this Act and any rules thereunder, generally to carry out the provisions of this Act.
- (2) In particular and without prejudice to the generality of the foregoing power, such guidelines may provide for all or any of the following matters, namely:—
  - (a) information relating to risk and benefits or alternatives to the proposed intervention under clause (n) of section 2;
  - (b) the manner of obtaining the informed consent under sub-section (1) and the manner of pre test and post test counselling under sub-section (2) of section 5;
  - (c) guidelines to be followed by a testing or diagnostic centre or pathology laboratory or blood bank for HIV test under section 7;
    - (d) the manner of taking data protection measures under section 11;
  - (e) guidelines in respect of protocols for HIV/AIDS relating to Anti-retroviral Therapy and Opportunistic Infections Management under sub-section (2) of section 14;

- (f) care, support and treatment of children infected with HIV or AIDS under sub-section (1) of section 18;
- (g) guidelines for Universal Precautions and post exposure prophylaxis under section 19:
- (h) manner of carrying out the strategy or mechanism or technique for reduction of risk of HIV transmission under section 22;
- (i) manner of implementation of a drugs substitution, drug maintenance and needle and syringe exchange programme under section 22;
- (*j*) provision of HIV-related information, education and communication before marriage under section 30;
- (k) manner of HIV or AIDS prevention, counselling, testing and treatment of persons in custody under section 31;
- (*l*) any other matter which ought to be specified in guidelines for the purposes of this Act.
- **47.** (I) The Central Government may, by notification, make rules to carry out the provisions of this Act.

Power of Central Government to make rules.

- (2) In particular, and without prejudice to the generality of the foregoing provision, such rules may provide for all or any of the following matters, namely:—
  - (a) manner of notifying model HIV or AIDS policy for the establishments under section 12;
  - (b) any other matter which may be or ought to be prescribed by the Central Government.
- **48**. Every rule made under this Act shall be laid, as soon as may be after it is made, before each House of Parliament, while it is in session, for a total period of thirty days which may be comprised in one session or in two or more successive sessions, and if, before the expiry of the session immediately following the session or the successive session aforesaid, both Houses agree in making any modification in the rule or both Houses agree that the rule should not be made, the rule shall thereafter have effect only in such modified form or be of no effect, as the case may be; so, however, that any such modification or annulment shall be without prejudice to the validity of anything previously done under that rule.

Laying of rules before both Houses of Parliament.

- **49**. (1) The State Government may, by notification, make rules for carrying out the provisions of this Act.
- (2) In particular, and without prejudice to the generality of the foregoing power, such rules may provide for all or any of the following matters, namely:—
  - (a) measures to provide diagnostic facilities relating to HIV or AIDS, Antiretroviral Therapy and Opportunistic Infection Management to people living with HIV or AIDS and for the prevention of spread of HIV or AIDS in accordance with the guidelines under section 14;
  - (b) qualification and experience for the appointment of a person as an Ombudsman under clause (a) or rank of officer of the State Government to be designated as Ombudsman under clause (b) of sub-section (1) of section 23;
  - (c) terms and conditions of services of Ombudsman under sub-section (2) of section 23;
  - (d) manner of inquiring into complaints by the Ombudsman under sub-section (1) and maintaining of records by him under sub-section (3) of section 24;
    - (e) manner of making the complaints to the Ombudsman under section 25; and
  - (f) manner of recording pseudonym in legal proceedings under clause (a) of sub-section (I) of section 34.

Power of State Government to make rules and laying thereof. (3) Every rule made by the State Government under this Act shall be laid, as soon as may be, after it is made before the Legislature of that State.

Power to remove difficulties.

50. (I) If any difficulty arises in giving effect to the provisions of this Act, the Central Government may, by order published in the Official Gazette, make such provisions, not inconsistent with the provisions of this Act, as may appear to be necessary for removing the difficulty:

Provided that no order shall be made under this section after the expiry of the period of two years from the date of commencement of this Act.

(2) Every order made under this section shall be laid, as soon as may be after it is made, before each House of Parliament.

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DR. G. NARAYANA RAJU Secretary to the Govt. of India.

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# **CORRIGENDUM**

# THE GOODS AND SERVICES TAX (COMPENSATION TO STATES) ACT, 2017

No. 15 of 2017

In the Goods and Services Tax (Compensation to States) Act, 2017 (15 of 2017) published in the Gazette of India, Extraordinary, Part II, Section I, dated 12th April, 2017, issue No. 15, at page 3, in line 20, *for* "onstitution", *read* "Constitution".