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**Weaving through the intricate realities of the HIV-positive women in
Eastern Indonesia: The case of HIV in Nusa Tenggara Barat**

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List of Acronyms

ARV	Antiretrovirals
BPJS	<i>Badan Penyelenggara Jaminan Sosial</i> (Social Security Administrator for Health)
HIV/AIDS	Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome
IDU	Injecting Drug Users
MSM	Men who have Sex with Men
NTB	Nusa Tenggara Barat
PLWH	People Living With HIV
PMTCT	Prevention of Mother to Child Transmission
RSUP	<i>Rumah Sakit Umum Mataram</i> (Mataram Public Hospital)
SRHR	Sexual Reproductive Health and Rights
STI	Sexually Transmitted Diseases

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To all of the women, I interviewed, for sharing your stories and allowing me to write what you have been going through in dealing with this battle. Thank you for giving me a chance to see what resilient means.

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When I knew I was getting this disease I suddenly disappeared for a year because I didn't believe the diagnosis and I was afraid to tell my partner, what if he left me after knowing my HIV-positive status?
(EM, 44 Years old)

The moment I realized that I'm positive, instantly I pulled myself out from any kind of social interaction that I used to have, including ending my relationship.
(KS, 39 years old)

Initially the health care worker from the community health center near my house told me they will help to provide infant formula for my daughter when they knew I was not married, had no stable income and was struggling with HIV while living far from my family, but then they told me to ask for it to the hospital instead.
(HY, 30 years old)

If only they told me earlier that my husband was HIV-positive, I would definitely bring my daughter for testing and treatment before it was too late. This is why I was so resentful to the doctors and my in-laws who kept this from me.
(NW, 44 years old)

I had really bad experiences when accessing health care services, because the health care worker could not maintain the confidentiality of my HIV status and treated my daughter in a very discriminatory way, which eventually strengthen the stigma towards us
(FM, 37 years old)

For women living with HIV, their diagnosis felt like a death penalty towards their social lives and made them feel more precarious than their experiences prior to their diagnosis. The dynamics of multifaceted social factors influenced the extent that these women could attain sufficient intervention and care for their illnesses. Nevertheless, these dynamics have been concealed and attempts to address HIV have often been limited to a healthcare solution, thus ignoring the root causes that are at the foundation of these women's experiences of power relations and inequality.

Abstract

HIV cases in Nusa Tenggara Barat, Indonesia, have continued to surge, particularly among the population of subordinated women. However, the analysis of structural inequalities and violation of women's sexual and reproductive rights are still absent in interventions to address the problem. This research study explored the relationship between the multi-dimension of social identities and structural inequalities of HIV-positive women in Nusa Tenggara Barat focusing in urban location and for further contextualization using the data from shorter visit in rural area. In this paper, I investigate intersecting multi-layers of HIV-related stigmas and challenges for women to access HIV health care and treatment. I further unpack opportunities for different coping strategies these women have in dealing with the negative implications of living with HIV. The research was conducted with qualitative investigation using in-depth semi-structured interviews to understand the lived experiences of women living with HIV in encountering stigma and discrimination to access adequate sexual and reproductive health and care services using the multi-level intersectionality approach and focusing on co-constructing the knowledge with 12 HIV-positive women. The findings of this research study highlight the significance of recognizing the intricate aspects of the lives of women living with HIV. Therefore, integrated interventions that aim to reduce the multi-dimensional challenges of HIV-positive women require the involvement of intersectoral social actors in advancing sexual and reproductive health and care services for women.

Relevance to Development Studies

The research provides insights for developing proper HIV intervention and strengthening access to healthcare services for women living with HIV in Eastern Indonesia, which continues to encounter difficulties, stigmatization, and discrimination. HIV has become an issue in the field of development that can no longer be neglected. HIV is often marked as a health issue that affects only particular people, thus concealing the threat that HIV infection poses to the development and the fact that it could affect anyone regardless of their social identities (Cornwall and Wellbourn, 2002)

Keywords

HIV-positive women, Sexual and Reproductive Health Rights, HIV Intervention, healthcare services, intersectionality

Chapter 1 Exploring the experiences of women living with HIV in Eastern Indonesia

1.1 Introduction

Ever since the first reported cases occurred in 1987, the number of HIV cases in Indonesia including in Nusa Tenggara Barat has continued to surge particularly among the population of marginalized women. However, discussions regarding the transmission and intervention to address the problem have been strongly stigmatized, gendered, and sexualized followed by the absence of recognition on the structural inequalities and violations of women's sexual and reproductive rights. Consequently, this has further exacerbated the negative implication of the disease towards the affected groups. The prevalence of HIV in Indonesia has been reported to be the highest in Southeast Asia (0,4%), with 680.000 people living with HIV in 2018 (WHO, 2018) and the transmission of HIV among women has rising each year. In 2019, the Ministry of Health reported that 38% of HIV transmission in Indonesia is among women (UNICEF, 2019). Moreover, since the last few years, the transmission among women whose partners are/were clients of sex workers is surging. As a result, the highest accumulative AIDS cases from 1987 to 2014 have been among a population of housewives, with 6.516 total reported cases (MoH, 2015).

The latest trend of infection rates shows that heterosexual married women have become one of the highest groups that contracted HIV (Halimatusa'diyah, 2019) However, this population continues to be seen as a non-susceptible group to carry the virus as the disease has been heavily associated and stigmatized with shame and prejudice towards certain key population groups, consisting of: drug users, sex workers, and men who have sex with men (MSM). Women from the key-population groups (sex workers and drug users) continue to be vulnerable towards transmission, while the intersection of their social identities and unaddressed structural inequalities pose challenges and hardships for these women to access adequate sexual and reproductive health rights, including access to HIV care and treatment. The emergence of HIV-related stigma that women with complex social identities experience has been reproduced in multiple social locations and produced harmful practices that hinder women to actualize their sexuality and reproductive rights.

Even when adequate health care services for testing, treatment, care and counselling are available, women may be hindered from accessing them out of fear of being judge and discriminated against (Bell *et al.*, 2007) In the context of HIV, women with complex social identities, such as married women, are often denied care as they are not considered as a high-risk group and can be incorrectly seen as immune to "*immoral*" sexually transmitted diseases.

HIV-positive women in the Eastern parts of Indonesia, especially in Nusa Tenggara Barat, have encountered and experienced various barriers and challenges in accessing healthcare services for HIV tests and treatment given the poor accessibility and availability of HIV/AIDS-related services in the area. Generally, the Eastern parts of Indonesia, including Nusa Tenggara Barat, have limited infrastructure development. Only 9% of hospitals in Indonesia are located in the eastern regions, while 49.9% of healthcare providers and hospitals are located in Java and Bali islands (Mahendradhata *et al.*, 2017). Since the hospitals in eastern Indonesia have to serve larger geographical areas, this has limited the accessibility to healthcare and resulted in residents' poor health outcomes in this region. For HIV/AIDS services, not all the regions in Nusa Tenggara Barat have the same facilities. The main HIV-related programs and activities are only available in the urban central Mataram area. Inequal provision of healthcare services in the region creates a much larger issue for people in rural areas, such as Dompu district, to access healthcare services

related to HIV/AIDS, a problem that is exacerbated by the socioeconomic and cultural factors that have been overlooked and neglected.

The patriarchal idealization of women's sexuality, constructed through the notion of *womanhood* perpetuated by religious, social, cultural and political discourses, contribute to a limited understanding of the complex HIV epidemic, particularly as experienced by women in Nusa Tenggara Barat. This idea surrounds women's sexuality has reproduced HIV-related stigma and the social barriers that violate women's sexual and reproductive rights, including their ability to access HIV testing and treatment, which has been deteriorated due to the absence of health intervention and HIV programs that recognize the marginalization of women and the social inequalities they have experienced both at national and regional levels. Therefore, this research study aims to identify how the intersecting adversities stemming from women's intricate social realities construct multi-level intersectionalities of challenges for women to access sexual and reproductive health rights. The discussion in this research will be done in relation to women's access to healthcare services for HIV and the opportunities for coping strategy these women have in dealing with the negative implications HIV-related stigma. My research is situated and focuses in urban Mataram city with shorter fieldwork in a rural area for contextualizing the experiences of women in urban area in Eastern part of Indonesia, Nusa Tenggara Barat.

1.2 Justification of Research

Globally, in 2007 over 40 million people projected to be infected with the HIV virus and 48% of those infected were women of reproductive age (Harman, 2011). However, the recognition of the feminisation of the epidemic has not demolished the vulnerability of women to the infection (p.214) and their accessibility to healthcare services. According to Hudiono (2006), the feminisation of HIV/AIDS in Indonesia is rooted in gender inequality and poverty, yet the government still lack any interventions to address these issues. The existing interventions for women living with HIV in Indonesia demonstrate a limited understanding of gender and sexuality discourses and health-related stigmas that have been hindering women to access adequate healthcare services (Nevendorff *et al.*, 2018). In the context of women with HIV in Indonesia, it is predicted a lot of new cases are occurring among low-risk women who did not engage in what constitutes high-risk behaviors (National AIDS Commission, 2014). Housewives have become one of the vulnerable groups, given the current trend of HIV transmissions through heterosexual sex (MoH, 2017). Women are particularly in a vulnerable situation if the idea of masculinity persisted and prioritized in the society where it consists men's rights to sex within a marriage and women's obligation to comply (Bennett, Linda R., Andajani-Sutjahjo and Idrus, 2011), which may stop women from speaking up against unsafe sex practices even in relationships where HIV transmission is a known risk.

Studies have also revealed how people living with HIV are engaging in risky sexual behavior in the form of refusing condoms when they have sex with their spouses or partners, which is often perpetrated by high-risk populations including IDUs or MSM. Such risky sexual behavior can put spouses and partners at high risk of contracting the virus through unprotected spousal intercourse (Morineau *et al.*, 2012; NAC, 2010). Although has been diagnosed women are still facing constraints in accessing health care services including treatment for the disease due to the existing social stigma and norms that hinder them to receive adequate health intervention. Recent studies on women living with HIV in Indonesia have mainly focus on the experiences of women in majority ethnic groups (Javanese women) in relations to how health-related stigma and existing social norms are affecting women's access to HIV test and treatment (Ismail *et al.*, 2022; Najmah,

Andajani, Davies, 2020) and the experience of pregnant women who engage in PMTCT (Prevention mother-child transmission) in Papua (2017).

Little information is known regarding the lived experiences of women in different socio-cultural contexts particularly from the eastern regions of Indonesia, including Nusa Tenggara Barat and how particular marginalized social identities of these women affect their abilities in accessing HIV tests and treatment. Hence, it is important to unpack the challenges that HIV-positive women encounter in multiple social realities that could shape their ability in attaining sexual and reproductive health rights and the coping strategy they employ to challenge the negative implications of being diagnosed with HIV within their localities. Therefore, engaging with these discussions will shed light on issues such as sexuality and power dynamics that play a role in shaping the socioecological and health conditions of HIV-positive women. Furthermore, it allows us to offer a more comprehensive analysis on the root causes of problems women face to access adequate SRHR and health care services that can be used to inform interventions needed for protecting their fundamental rights.

These women's vulnerabilities remain unaddressed, although the situation is alarming, female partners of PLWH are unlikely to be considered at high risk of getting HIV, and often remain undiagnosed until they develop symptoms or lose a child due to HIV/AIDS. This delay in HIV detection in women poses a serious risk that could cause sexual and reproductive health problems (Rahmalia *et al.*, 2022) Furthermore, this particular health condition is highly stigmatized among Indonesian society due to the existing social norms, prevalent negative stereotypes, and prevalent widespread of misinformation regarding the illness (Sianturi *et al.*, 2019)

1.3 The Context of HIV Epidemic in Nusa Tenggara Barat

The violation of women's sexual and reproductive rights in Nusa Tenggara Barat have taken various forms that overlap with one another including the high rate of child marriage and HIV infection among housewives. More than 31% of girls aged 19-24 in Nusa Tenggara Barat are married before the age of 18, which is much higher than the national average of 23% in 2015 (UNFPA, 2018). Jacobowski's (2008) study conducted nationally in Indonesia showed that HIV infection vulnerability on women is one of the consequences of early marriage, as gender norms are strengthened by age differences between grooms and brides. In many cases men are expected to be sexually experienced prior marriage and this may increase the risk of HIV infection for their wives (Jacobowski, 2008a).

This issue is further reinforced through the *Merariq Culture* in Nusa Tenggara Barat, which is a phenomenon of forced marriage that involves girl-brides being kidnapped by the men-groom. This practice has potentially increased the rate of child marriage in Nusa Tenggara Barat that further undermines women's agency to access proper sexual and reproductive health rights and may increase chances of sexually transmitted diseases, such as HIV/AIDS (Fibrianti and Azizah, 2020). In 2021, there were 1.212 recorded HIV cases in Nusa Tenggara Barat and married women were the second most infected group, with 255 recorded cases (DINKES NTB, 2021) My main research site, located in the urban area of Mataram City, the capital of West Nusa Tenggara (NTB), has the highest number of HIV cases in the province. Of the 116 cases recorded in this area, 94 people were receiving ART treatment. Meanwhile, the second site that I visited, Dompu District, located in the rural regions in Nusa Tenggara Barat, reported 12 HIV cases in 2021 and none of the patients were receiving HIV ART treatment from the report released by the Department of health in Nusa Tenggara Barat (2021).

The Department of Health in Nusa Tenggara Barat has recognized three ways that women in Nusa Tenggara Barat are being diagnosed with HIV/AIDS and are affected by the social stigma that follows:

1. Pregnant women who receive HIV tests under the PMTCT scheme or triple elimination mechanism in community health centers – these women face a double burden as they encounter the gendered expectations to be a ‘good’ mother and are prone to be blamed for the transmission of the disease to their children.
2. Women whose partners are from key-populations or high risk groups (IDUs, MSM, and clients of sex work) and are being diagnosed through ‘couple notifications’ scheme from local health care facilities (public hospitals) – these women often have limited information regarding the disease and poor access to health care services due to financial dependency and patriarchal construction of gender-ascribed roles.
3. Women who have double social identities as sex workers but prefer to identify themselves as housewives are often diagnosed from the key-population screening programs conducted by health department and NGOs in Urban areas – these women face social stigma and experience social exclusion due to their perceived status as virus carriers who are responsible for the transmission of the disease.

Although the different ways in categorizing women who are infected with HIV/AIDS have been recognized by the government, the gender and sexuality lenses to address different forms of oppression or marginalization experienced by women are still poorly applied in designing interventions or programs for HIV/AIDS both at national and regional levels.

1.4 Socio-cultural and religious impediment in accessing healthcare services for people living with HIV in Indonesia

People’s access to healthcare services for HIV/AIDS treatment in Indonesia is shaped by different social, cultural, political, and economic factors. The cultural norms in relations to sexuality restricts sex only within marriages. Therefore, sexual and reproductive health services are mainly aimed for married people and focused on regulating reproduction, thus marginalizing young and unmarried people (Hudiono, 2006) HIV/AIDS often triggers an ‘othering process’ that affects how society perceives the disease and eventually shape the approaches used to address HIV.

One of the challenges for women living with HIV to access health care services is the existence of HIV-related stigma reproduced through the tendency of HIV/AIDS programs that mainly focus on the high-risk or key population groups (Agnes and Songwathana, 2021) This focus has reinforced the idea that HIV/AIDS is a disease that only affects certain populations, such as foreigners, homosexual men, sex workers, and people who engage in pre-marital sex (Gunawan. and Suesen.,1998) The beginning of HIV-related stigma evolved from the first HIV case that was found in Indonesia, when a Dutch homosexual man died in Bali in 1987. Since then, Indonesian society widely perceived HIV as a foreign disease and a disease of *immoral women* after, in 1991, new HIV cases were found among female sex workers. This has worsened the stigmatization of these groups and consequently posed significant challenges for sex workers and women in general, especially those who are HIV-positive, to access adequate health services (Agnes and Songwathana, 2021)

As a predominantly Muslim country, the influence of religious beliefs also shape people’s perceptions regarding HIV/AIDS, as it can pose a moralistic stance that can hinder the provision of universal access to HIV healthcare services. The belief that HIV/AIDS is a form of punishment from God or a warning not to engage in illicit behavior is common and entrenched among conservative Muslim society (Badahdah, 2010) Therefore, often times people are taking a moralistic stance towards the disease and people affected by it, thus refusing to believe in or give serious attention to intervention for heterosexual groups, non sex-workers, and women who are framed as the morally non-possible affected populations (Hudiono, 2006)

In addition to this, the kind of interventions and policies formulated by government institutions have mainly used the dominant discourse of religious morality that is strongly based on heteronormativity as the only socially acceptable values, which have contributed to further

stigmatization and generate harm towards people living with HIV. For instance, the ‘ABC approach’ of HIV prevention (Abstinence, Be faithful, and Condom), has been widely used with A and B promoting sexual monogamy based on Islamic morality, and C that was only meant to target key-population groups (Halimatusa’diyah, 2019). Following this, married women or housewives continue to be considered as low-risk groups, although for the past few years the HIV positive cases found among this population are far greater than sex workers. And yet, there has not been any programs nor interventions that are directly targeting this female group (Hudiono, 2006) One reason is the assumption surrounding the development of sexual health program that overlook women’s vulnerability, both in contracting HIV and accessing healthcare services.

Political factors also influence the provision of HIV programs and countermeasure activities, as the lack of government attention and support has contributed to the poor access to health care services. Through the mechanism of decentralization¹, the regional government has much more authority in designing and providing health programs and healthcare facilities in the region, which means HIV/AIDS-related programs could disproportionately be affected by the local political environment (Prystay and Mapes, 2004) For instance, according to the Department of Health in Nusa Tenggara Barat (2022), the increase of implemented HIV/AIDS programs was highly influenced by political decisions formulated separately by government authorities in various districts, which can explain the differences between HIV programs and activities provided in urban Mataram city and rural Dompu district.

1.5 HIV responses by the government in Indonesia and Nusa Tenggara Barat

The government of Indonesia has been recognizing the importance of promoting women’s sexual and reproductive rights through the ratification of several international conventions on women’s rights that cover and advocate for the protection of women’s access to appropriate HIV/AIDS treatment and accurate information regarding the disease, including UNGASS, ICPD, the Beijing Declaration, CEDAW, and the Millennium declaration. However, the implementation of these international instruments is still far from sufficient given the poor recognition of the barriers women encounter in accessing healthcare services (Hudiono, 2006). In relations to this, the international advocacy on sexual/reproductive rights such as ICPD has emerged as a revolutionary action that calls for recognizing the definitive links between sexual/reproductive rights and the social and economic status of women (Cornwall and Wellbourn, 2002). There has been a growing emphasis on sexual health that is centered on the ‘enhancement of life and personal relations’ as ‘counselling and care related to reproduction and sexually transmitted disease’ (ICPD 1994, paras 7.2, 7.3 cited in Cornwall and Wellbourn, 2002).

Moving into the internal strategy, the general attempts of the Indonesian government to address the HIV epidemic is through formulating several committees and key strategies as part of the solution for ending the HIV epidemic. For instance, in 1994 the National HIV Commission Management was formed under the control of Minister of Social Welfare through the Presidential Decree number 36/1994. The main objective of the committee was to accelerate the prevention, control, and countermeasures on HIV/AIDS.

In January 2004, the committee released what is called the Sentani Commitment where it urged government ministries, provincial governments, and relevant stakeholders to take concrete action on the prevention of HIV transmission and ensure the access for HIV treatment for people living with HIV (Hudiono, 2006). Yet not all of the regional actors including municipalities and

¹ Decentralization is a reform policy introduced in 1999 after the end of authoritarian military-led political system of the second president Soeharto that allows subnational governments a greater autonomy in determining programmes that are considered more aspirational to the interest of the community and to local and regional development objectives (Talitha, Firman and Hudalah, 2020).

regencies have incorporated the strategy into their policies due to the lack of resources, that range from limited funding, poor healthcare infrastructure, and different socio-cultural factors. In 2013, the Minister of Health attempted to incorporate gender equality as one of the principles within HIV intervention mechanism through the formulation of Minister of Health Regulations number 21/2013². A similar approach can also be seen in the HIV and Sexually Transmitted Infection services guidelines that incorporate a gender dimension in constructing the design, implementation, and services evaluation in Indonesia.

However, these guidelines do not explain how to apply the principle of gender within the services³ and they have not been implemented equally in all healthcare facilities in Indonesia, including Nusa Tenggara Barat. In the national context of Indonesia, data shows HIV infection rates increasing among women who are not part of the key population groups. However, the regulations generated to address HIV/AIDS have not been considering women's challenges to acquire and benefit from HIV interventions and the extent to which gender inequality contributes to the severity of HIV/AIDS (Nevendorff, et al. 2018). Current HIV interventions have paid only little attention to the existing gender and sexual norms that prevent certain populations from accessing HIV prevention and treatment services. There are limited interventions that use the dimension of sexuality, gender, and reproductive justice to identify the underlying problems of women's precariousness, marginalization, stigmatization, and discrimination that affect women's access to healthcare services. There have been only limited attempts to address gender and sexual norms that have been undermining the women's access HIV/AIDS treatment.

It is also noteworthy that most eastern regions in Indonesia still experience high levels of inequality and underdevelopment compared to the Western parts where most economic activity and services, including healthcare services, are concentrated (Robinson Sihombing, 2019). In the context of Nusa Tenggara Barat, although all healthcare providers should adopt the same minimum service standard based on the Ministry regulations number 4/2019, several HIV/AIDS intervention programs or activities for PLWH are only available in urban Mataram area and not provided in rural areas like the Dompu district. Such as the PMTCT program, mandatory early screening for pre-married couple, health promotion for young people in schools and universities, and mapping on key populations and peer support group (KDS) activities are only provided in the Mataram region. Besides that, there are several active NGOs operating in Mataram that enable the provision of facilitators for every HIV patient. The presence of facilitators is crucial and significant to ensure the patients to undertake ARV treatment and reduce stigma and discrimination from family and community members by giving correct and clear information regarding HIV. Moreover, most patients also acknowledge the benefits of having facilitator to help them in address issues they face in accessing healthcare services. Further adding to this, the facilitators have managed to build trust and good relationships with patients, which in return could accelerate the number of patients who get treated.

² See Minister of Health regulations number 21/2013 Chapter 2 article 4 (b) (page 5)

³ See Guidelines for the implementation of comprehensive HIV-STI services on ongoing basis (page 4) (Ministry of Health, 2012)

1.6 Research Objectives

This research study aims to identify how HIV-positive women in Nusa Tenggara Barat with different social identities and adversities face intricate social realities from living with HIV. This paper will look at the intersection of various social factors that form different challenges experienced by women in Nusa Tenggara Barat in accessing healthcare services for HIV treatment and care. It is also important to unpack how these HIV-positive women reclaimed their agency and turned the predicament into an opportunity for dealing with the negative implications of the disease by analyzing the multi-level intersectionality of their experiences living with HIV.

The main research question of this research is:

- How do HIV-positive women in Nusa Tenggara Barat encounter challenges for accessing healthcare interventions due to the intersecting stigma, discrimination, and social exclusion?

With the sub question:

- How do HIV-positive women in Nusa Tenggara Barat deal with the negative implications of HIV-related stigma and their marginalized condition?

In order to answer this research question, I would focus on the research study conducted in the main selected site urban Mataram city and using the data from secondary site Dompu region to contextualize the experiences of HIV-positive women in Nusa Tenggara Barat. The main research location is where most of the data were gathered, given how facilities or access to health care services for HIV test and treatment are concentrated in this capital city of the province. The secondary site, Dompu district is located in the further east area of Nusa Tenggara Barat where the infrastructure and facility rate are lower than Mataram and shape the contrast between the access to health care services and resources for coping strategy HIV-positive women in urban area acquired.

The organization of the paper

This paper starts with an Introduction to the issue where the context of the HIV epidemic, socio-cultural and political impediments to the accessibility of HIV services and responses were placed in Indonesia and Nusa Tenggara Barat. Chapter 2 presents the conceptual framework and rationale for adopting an intersectionality and multi-levels analysis, sexual and reproductive health rights framework, women's sexuality, marriage and HIV intervention in Indonesia. Chapter 3 describes the methodological selection and data analysis process. Followed by Chapter 4 presents the analysis of challenges to SRHR encountered by HIV-positive women and opportunities for coping strategy they could manage to perform. Chapter 5 entails a conclusion and proposed.

Chapter 2 Conceptual Framework

In this study, I incorporated the concept of intersectionality and multi-levels analysis to identify the multi-layered challenges that WLWH face when accessing HIV test and treatment in Nusa Tenggara Barat, including HIV-related stigma and discrimination. HIV intervention discourse often put aside the wellbeing of women's sexual and reproductive health, and is strongly influenced by the patriarchal construction of sexuality based on heteronormativity and religious values. Consequently, this has configured HIV-positive women's different experiences depending on their various social identities and marginalized conditions that affect their abilities to realize their rights, including sexual and reproductive health rights. Therefore, this research study adopted the SRHR framework to understand how the problem with HIV is beyond reproductive issues and has a broader dimension of sexuality and human rights that often remain unaddressed.

2. 1 Intersectionality and multi-levels analysis

The concepts of intersectionality and HIV-related stigma have been used to understand how the intersection of HIV status and other forms of marginalization, oppression and social inequalities due to the gender, economic status, race and ethnicity have constructed and intensified stigma (Celeste Watkins-Hayes, 2014). The combination of stigma associated with a person's HIV status and social adversities caused by discriminated social identities such as gender-ascribed identity, judgment on sexuality, and poverty could yield to their seclusion, social exclusion even isolation that hinder them to access health care services, employment, and education (Rai *et al.*, 2020). The intersectional connection between health-related stigma and other forms of oppression indicate that stigma and challenges caused by health conditions is not merely a public health issue but also a social justice problem (Turan *et al.*, 2019); (Corrigan *et al.*, 2005)

The concept of intersectionality was first introduced by Kimberly Crenshaw. It offers comprehensive analysis on the complexity and multidimensionality of lives and places social marginalization as stemming from an intersection of multiple social identities/inequalities rather than single-axis framework of oppressed identity (Crenshaw, 1994)(Hankivsky, 2014). Intersectionality is considered to be interdependent and mutually constitutive relations between identities and inequalities based on sexuality, gender, and ethnicity (Bowleg, 2008). In understanding the intricate intersectionality of women living with HIV, a multi-level analysis is used to identify the link between individual experiences to broader structures and systems as it is crucial to reveal how multiple dynamics of power relations and inequalities are shaped and experienced (Hankivsky, 2014)

The concept of intersectionality has been used and incorporated by different researchers in constructing the model to analyze how the dynamics of intersected social identities and adversities are shaping the conditions of people living with HIV and how it is influenced by multi-levels of factors encountered by people living with HIV. These multi-levels form of influence could be located in three different levels including macro, meso and micro (Cook *et al.*, 2014) (Logie *et al.*, 2011) (Rai *et al.*, 2020). The micro-level which is also known as the interpersonal level is reflected in an individual's attitudes and beliefs. This is where the experiences from the macro and meso levels add up to negative internalized feelings among HIV patients. Meso-level is located in the community/social networks and pertains to interactions with other societal actors that can result in further reinforcement of discrimination against people who suffer from oppression due to prevalent negative stereotypes of PLWH in the society. Finally, macro-level is stemming from the structural factors consisting of organizational/political power, public policies and social norms that marginalize and discriminate PLWH (Cho, Crenshaw and McCall, 2013) (Cook *et al.*, 2014) (Rai *et al.*, 2020)

A previous study by Logie et al. (2018) used multi-level intersectionality to investigate multiple levels of HIV-related stigma that intersect with other forms of adversities and social inequalities experienced by women living with HIV. The study also looked at multiple levels of coping methods by HIV-positive women in producing opportunities to challenge the negative implications of HIV-related stigma.

Figure 1 Multi-level conceptualization of Intersectionality

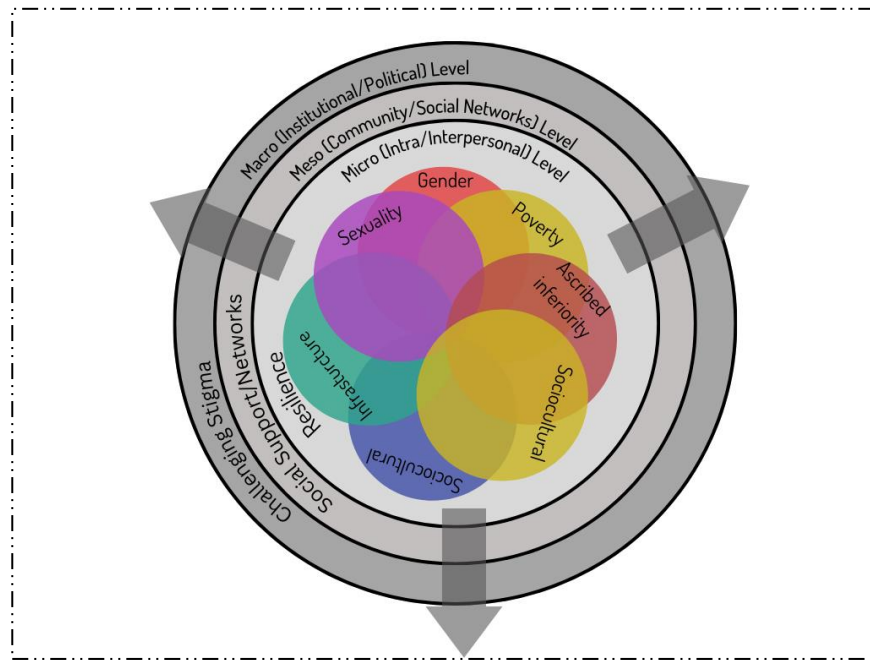


Figure 1: Adopted multi-level conceptualization of intersectionality and coping strategy among women living with HIV in two locations across Nusa Tenggara Barat, Indonesia intended to portray the experiences of multi-level intersecting marginalized situation encountered by HIV-positive women such as HIV-related stigma and challenges in accessing sexual and reproductive health rights. Respondents also elucidated different opportunities for coping strategy, including: Resilience, Social Network, and Challenging Stigma Strategy.

This conceptualization will help to highlight the intersectionality of multiple factors that shape women’s experiences living with HIV by intensifying the prevalence of stigma, reducing their access to healthcare services, and undermining women’s sexual and reproductive rights. For instance, the intersection between HIV-related stigma and gender discrimination encountered by HIV-positive women that form internalized stigma of anxiety, fear of being judged and, shame for being diagnosed and getting HIV treatment. HIV-related stigma is reported to be higher towards women than men as women are traditionally expected to sustain the moral fabric of society. Hence, women tend to experience stronger social rejection and internalized stigma, which often leads them to conceal their HIV status for fear of receiving HIV/AIDS discriminations from family, friends and larger community (Ataro *et al.*, 2020). Moreover, financial capacity and poverty experienced by women also influence their ability in accessing ARV treatment. In the other hand other social factors such as sexuality, religion beliefs, and sociocultural aspect have also influenced the intersecting experiences of marginalized situation encountered by HIV-positive women.

2.2 Sexual and Reproductive Health and Rights (SRHR) Framework

One’s rights to sexual and reproductive health cannot be isolated from other forms of human rights such as the rights to: bodily integrity, human dignity, health/highest attainable standard of

health, privacy and freedom from violence and all form of discrimination (Chivusia, 2021). International organizations such as WHO has described sexual and reproductive health as ‘a state of physical, mental and social well-being in relation to sexuality’ (see WHO, 2015), whereas the ICPD has defined reproductive health as concerning people’s ability to formulate informed consent through free and responsible decision-making regarding their reproductive behavior based upon their access to a range of reproductive health data, facilities and services (ICPD, 1994 cited in Chivusia).

In 1994 the Programme Action of ICPD launched comprehensive reproductive health care recommendation that encompass; family planning, safe pregnancy and delivery services, abortion where legal, prevention and treatment of sexually transmitted infections (including HIV/AIDS); correct and clear information/counselling of sexuality; and advocacy against harmful practices against women (including genital mutilation and forced marriage) (Ashford, 2004). However, SRHR discussions continue to spark debate as they are often considered controversial in many community levels despite receiving international recognition.

SRHR extends beyond ‘just’ sexual and reproductive health care to underlying determinants and basic human rights, such as access to safe and portable water, adequate food and nutrition, housing, safe and healthy working conditions, health-related education and information and effective protection from all forms of violence, torture, and discrimination that have negative implication on the realization of sexual and reproductive rights (Chivusia, 2021) However, the issue of sexuality and reproduction is often treated as less of a priority that should be put aside until after the actualization of other basic human needs. Therefore, the proposal to construct better and equal access to healthcare services related to sexual and reproductive health often neglect including women’s right to achieve sexual and reproductive health and treatment; leaving SRHR to be inadequately promoted and protected.

Often times, even interventions to end violence against women tend to reproduce more harmful practices that misrecognize women’s sexual wellbeing and expressions of sexuality that undermining women’s agency and self-esteem. For instance, HIV-positive women are often advised to abandon sex and having children regardless of their own desires (Andrea, Jolly and Kate, 2013). Women living with HIV tend to experience the pain of forced asexuality, as ‘both forced sex and asexuality deny women our rights to our own autonomy with regard to our sexuality – and reproductive – pleasure.’ (Welbourne cited in Jolly, Cornwall and Hawkins, 2013, p.11). The existing unequal power relations also construct difficulty for women in practicing their own agency to make decisions on reproductive matters in regard to unintended pregnancy. Studies reveal that HIV-positive women’s choice (or lack of) to have children is often shaped by their relationship and the number of children they already had rather than by their HIV status (Cornwall and Wellbourn, 2002)

As Cornwall (2002) conveyed, sexuality has been generally represented in development discourses as a source of problem and harm. Sex is often reduced to a risk-laden practice and as a cause of disease, which leads to the simplification of understanding sexuality. As such, the kind of interventions for sexually transmitted disease has merely focused on mitigating the harms of the HIV epidemic. The focus on the subordination of women in the discussion related to women’s sexuality and vulnerability to sexually transmitted disease has been mainly emphasized on the patriarchal values embedded in the society and how it constructs both women’s ascribed gender roles and sexuality. HIV-positive women in Nusa Tenggara Barat reveal how patriarchal framings on sexuality and the discriminatory approaches on HIV and sexuality have resulted in negative impacts, such as the policing of women’s sexuality and depriving the rights of women to actualize their SRHR in different social locations.

2.3 Women's sexuality, marriage, and HIV intervention

Discourses on women's sexuality, family, and marriage have become an important analysis given how families are known to be sites of power and the reproduction of social relations and inequality. The political approval of coercive and violent abuse against women by their own kin, for instance, has been widespread and normalized as a form of control over women's body and their sexuality (Folbre Nancy, 2021). The patriarchal hegemony within families have allowed fathers, brothers, and husbands to treat women in their families as a property that could be devalued by sexual experience and placed as a subordinate gender (Elson, 1981).

The social hierarchy created in families through the process of defining women's social status based on their marital status and identities as housewives allow other family members to gain political and ideological control over them; a process that is described as the *housewifization*, has become a naturalized and internalized practice to suppress women's agency (Mies Maria, 1986). Marriage has signified the recognition of women's gendered role in the nation. In the context of Indonesia, gender roles ascribed to women are limited to the responsibility of managing household and family, serving the husband, and taking care of children (Blackwood, 1995). The construction of femininity and motherhood have become a central focus of the Indonesian government, where motherhood, for instance, has been actively promoted by the state as a crucial part for women to becoming successful members of Indonesian society, unlike fatherhood for men (Bennet, 2011). The way the state is positioning motherhood as central to women's identities can be detrimental for women who are living with HIV. Indonesian women's status is strongly influenced by traditional customs and religious values (Jacubowski, 2008b).

Historically, during the colonial period, the position of Indonesian women changed due to the emergence of the colonial concept of nuclear family (Dzuhayatin, 2004). With this, married women's engagement in commercial activities became considered as inappropriate, thus limiting their role to the domestic sphere (Jacubowski, 2008). This has been strengthened through the formulation of the gendered ideology of motherhood, which was first built during the New Order Regime under President Soeharto. The agenda of *housewifization* or what has been described in the national context as '*State Ibuism*' reproduced a narrow ideal of a socially acceptable women figure that was based on their systemic domestication and endorsed the patriarchal construction of womanhood (Bennett, Linda Rae, 2012)(Suryakusuma, 1996) (Wieringa, 2015).

Most public policies, including HIV intervention strategies, focus on HIV prevention among married groups due to prevailing sexual norms which restrict sexual activities outside of the marriage (Jacubowski, 2008). However, this does not effectively reduce the HIV prevalence within marriages. A survey conducted in 31 countries showed that 80% of HIV transmission among women is due to unprotected sexual encounters within heterosexual marriages (Bruce and Clark, 2004). This has been reinforced through the notion that married women's duty is to satisfy their husband's sexual needs regardless of their own sexual desires and agency (Riyani and Parker, 2018). Women's sexuality is strongly controlled and regulated through the characterization and internalization of women's sexuality as passive and submissive, which hinders women from exploring sexual desires and pleasure (Wieringa, 2015).

In Indonesia, traditional customs and patriarchal values have been using religious principles, particularly Islam, to control women's bodies. For instance, the use of the Islamic term '*zina*' for premarital sexual relations has disproportionately emphasized women (Bennet, 2005 cited in Riyani and Parker, 2008). Several progressive Muslim Scholars have spoken up against the misinterpretation of religious values by describing how the Al-Qur'an defines sexuality as a consensual act based on reciprocal desires, however, this has been corrupted by many Islamic Jurists that promote hierarchical relations between husband and wife in a marital relationship (Ali, 2016).

The dominant discourse of women's sexuality has also affected the design and implementation of HIV interventions. For instance, as women are supposed to be sexually

vulnerable, and men are not supposed to express vulnerability around sexuality (Cornwall and Jolly, 2006), the conception of heterosexual femininity and masculinity have affected the process of HIV testing and treatment. Social norms that surround sex reinforce unhelpful gender stereotypes that can be problematic for those who are within the heterosexual framework (Cornwall and Jolly, 2006). In the case of HIV testing and treatment for women, services for testing are often located in sexual and reproductive health services, such as antenatal clinics, to focus on mother-to-child prevention (PMTCT). However, focusing HIV testing and treatment in antenatal clinics leaves men and women who are not in the group of pregnant women out of the picture (Bell *et al.*, 2007)

On the other hand, dominant discourse of HIV/AIDS in Indonesia from the early 1980s, centralized the blame on two particular populations, homosexual foreigners and Indonesian female sex workers (Kroeger, 2003). Media reports on the topic demonstrated how the Indonesian government was in denial and refused to acknowledge the continued spread of the HIV epidemic. The reluctance to give attention to public health promotions on safe sex was evident, as both the government and Islamic groups who informed HIV countermeasures considered such efforts equivalent to promoting promiscuity and extramarital sex (Hegarty, 2021). In the 1990s the discourse on HIV/AIDS was centered around framing female sex workers as scapegoats, as pervasive media information and societal beliefs were asserting that only sex workers were vulnerable to HIV (Kroeger, 2003)

The construction of normative sexuality presented a dichotomy between a moral 'woman with passive sexuality' or wife and 'a woman without morals' or prostitute and the notion that men are sexually active and naturally possess stronger sexual desires, leaving women responsible over channeling, satisfying, and controlling men's sexual drives (Kroeger, 2003)

Chapter 3 Methods of Data Collection and Analysis

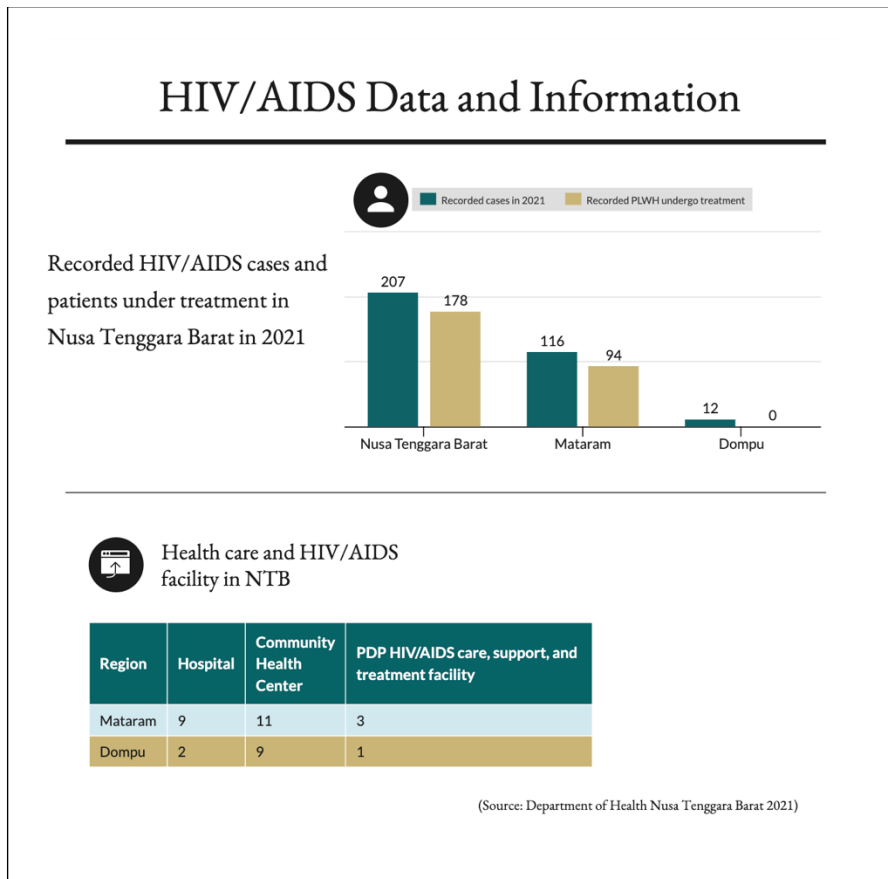
3.1 Data Collection and Analysis

The research findings are gathered from the main research site in urban Mataram located in Lombok Island and a secondary site in rural Dompu area located in Sumbawa island for further contextualization in one of the provinces in the eastern part of Indonesia known as Nusa Tenggara Barat. Initially, the research sites were selected to compare urban and rural areas, especially to examine the challenges and opportunities faced by WLWH in accessing health care services, including access to tests and treatment, based on the social locations and characteristics of both areas. However, I could only access most of my data from an urban site, with 11 interviews conducted with HIV-positive women in Mataram and one interview with a HIV-positive woman born in the Dompu district. Given this situation, I decided to focus on analysing the experiences of HIV-positive women in urban central Mataram. Therefore, the interviews in the two locations complement each other by further contextualizing the accessibility of healthcare services in Nusa Tenggara Barat.

Urban Mataram City has more healthcare facilities that allow HIV-positive women to access better HIV tests and treatment, given the provision of healthcare infrastructure, programs, and global funds this city acquired (DIKES NTB, 2022). For instance, there is only one viral load unit in Nusa Tenggara Barat to conduct genetic HIV diagnosis, and it is located in RSUP hospital in Mataram. Regarding the development of healthcare and program coverage, the Dompu district has limited capacity and resources. The gap is evident in the provision of hospitals and community health centers (*puskesmas*) that are equipped with care, support, and treatment training for HIV/AIDS and ARV medications. In 2021, it was reported that Dompu district only had one care, support, and treatment facility (PDP)⁴ for HIV/AIDS (DIKES NTB, 2021), and only recently in July 2022, ARV treatment was provided in the district. Meanwhile, Mataram City has nine hospitals and 11 community health centers with three care, support, and treatment facilities for HIV/AIDS (DIKES NTB, 2021). These two social locations have different resource mobilization that informs the access to healthcare services, which are also influenced by multiple sociocultural factors that intersect with various other forms of social realities that eventually affect the experiences of HIV-positive women.

⁴ PDP is a service facility for HIV/AIDS testing, clinical check-up, counselling, and treatment that could be located in healthcare services, both in hospital and community health centers (*Puskesmas*).

Table 1 HIV/AIDS Data and Information

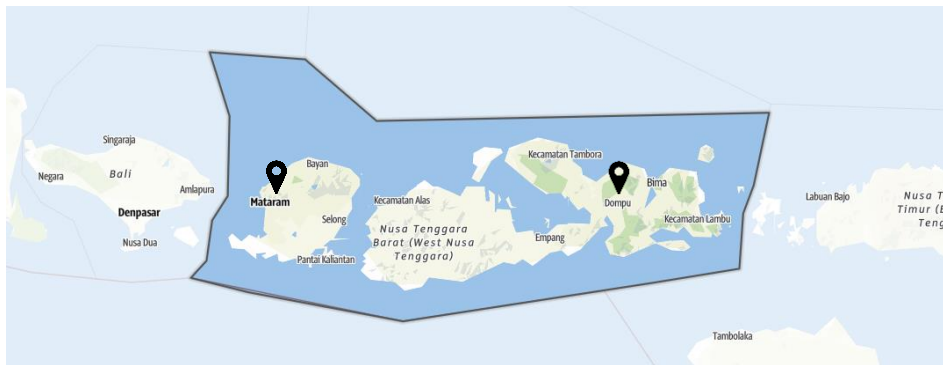


Map 1 Map of Indonesia



Source: Indonesia Map alamy.com

Map 2 Map of Nusa Tenggara Barat



Source: Peta Nusa Tenggara Barat outdooractive.com

This research used qualitative research methods with a constructivist approach where knowledge is both produced and constructed through conducting semi-structured interviews, which are regarded as production site of knowledge (Brinkmann and Kvale, 2009). The research aims to focus on the narratives and life experiences generated from the interviews with participants, particularly with women living with HIV. I do this by analyzing how women themselves reflect on their experiences and make sense of their realities, and including healthcare providers and NGO staff who work with people living with HIV in Nusa Tenggara Barat. This approach allows the researcher to co-construct knowledge with the interviewees, and simultaneously in the process it acknowledges the researcher's positionality and reaffirms reflexivity through the data interpretation (Brinkmann and Kvale, 2009).

Furthermore, this research also uses a feminist standpoint research practice as a way of understanding distinct points of reality that begins and is constructed from the experiences of women (Hesse-Biber, 2014). Feminist literature surrounding HIV infection and the impact of it has been shifting the assumptions about who are the 'risk groups' and disrupting the taboos regarding gender and power relations. Furthermore, the issue of feminization of HIV/AIDS has become a phenomenon that is largely discussed and identified by national governments, international organizations, donor and non-governmental organizations that have constituted the global response toward the epidemic (Harman, 2011). Conducting research with sensitive subjects and hard-to-reach populations may pose challenges in collecting the number of participants due to the susceptible nature of specific trait that characterizes its group (Faugier and Sargeant, 1997). Therefore, this study applies snowball sampling as an appropriate strategy for getting the samples from hard to access population (King, Horrocks and Brooks, 2019). In this case the study of life experiences of WLWH is a sensitive subject that is intricated with prejudice and discrimination.

My fieldwork was conducted within a limited amount of time, just over four weeks, from July 2022 to August 2022. This research uses primary data from in-depth interviews with 12 HIV-positive women in Mataram and Dompu District with the following criteria: women in their reproductive age (15-49 years old) that contracted HIV through sexual transmission and have accessed ARV treatment from the health care facility in Nusa Tenggara Barat. The selection criteria were initially planned to gain knowledge regarding the experiences of WLWH in accessing health care services in Nusa Tenggara Barat. In addition to interviews with HIV-positive women, I also conducted one in-depth interview with a healthcare worker in Dompu District to attain information from the perspective of health workers who worked for PLWH in the community health center and one in-depth interview with a facilitator from a local NGO called INSET in Mataram. Informal conversations with the representative of Department of Health in Nusa

Tenggara Barat also yielded some more information regarding the HIV program and how it is carried out in Nusa Tenggara Barat. These interviews and conversations were useful to see the role of facilitators in assisting WLWH to access healthcare services.

NGO INSET is based in Mataram City and has become the only NGO focused on HIV/AIDS assistance. Since 2005, INSET has been facilitating HIV/AIDS patients in their treatment and conducting community outreach for HIV/AIDS tests and screening. As the only NGO representation in the province, INSET has a crucial role in reaching out to HIV/AIDS patients in the Mataram region. Therefore, I managed to connect and conduct interviews with HIV-positive women through this NGO, and selected the participants based on the criteria I informed earlier. Meanwhile, in the Dompu district, there is no civil society or NGO representation operating in the district, which means the role of the facilitator is assigned to the health workers who have engaged with HIV/AIDS patients. In reaching out to the participant in the Dompu district, I received access through a health worker who works in a community health center (*puskesmas*) in Dompu and has a double role as facilitator for the patient.

Most interviews with respondents in Mataram or Lombok island were conducted in Bahasa Indonesia and were accompanied by the gatekeeper who is the representative of NGO INSET and is an assigned facilitator of the HIV program in referral HIV hospital of RSUP Mataram. The gatekeeper played a significant role in providing access to the respondents and information regarding the experiences of HIV-positive women in accessing health care services in the hospital. One in-depth interview in Dompu District was done fully using the local language of Dompunese to facilitate the participant in delivering her story and information during the interview. This research study also received assistance from facilitators that were working at one of the biggest healthcare providers and referral hospitals in the Nusa Tenggara Barat province, called RSUP Mataram that provided healthcare services to women living with HIV. Whereas, in Dompu district most programs could not be implemented due to a lack of funding, poor healthcare infrastructure and attention from the government. Consequently, until last year all of the HIV patients in Dompu could only access the ARV treatment at RSUP Mataram or the neighboring district of Bima. Even as I write this research paper, the provision of facilitators, activities for people living with HIV, and the cross sectoral collaborations in formulating specific measures to promote access to healthcare services for WLWH is still not available in the Dompu district.

The conversations with the participants followed the interview guide and questions to explore the complex dimension of intersected social realities that formed challenges and opportunities for WLWH in accessing sexual and reproductive health rights in Nusa Tenggara Barat. Departing from the feminist standpoint epistemology that acknowledges concrete experiences of women as central to co-creating the knowledge in this study (Brooks 2007), to understand the reality of women's lives the production of knowledge must be drawn upon their actual lived experiences. Therefore, this research was putting the experiences of women living with HIV as a source of investigation in examining the reality of women in accessing their sexual and reproductive health rights in relations to their access to HIV treatment and understanding the barriers and opportunities for these women to attain their sexual and health rights in the specific socio-cultural context in Nusa Tenggara Barat.

3.2 Data Analysis Process

The narratives from the interview were transcribed both in Bahasa Indonesia and English. After that, the data were imported to (Atlas.ti) qualitative analysis software to be later analyzed and coded using thematic analysis to enhance the understanding of the experiences of women living with HIV in encountering challenges to access health care facility and intersectional stigma in their original language and English. The coding process was carried out in two ways. The first is inductively (generating code from the data). Several codes were derived from the personal perception of HIV-positive women, such as the difficulties they encountered due to the

intersection of discrimination of their intricate social identities that influence the possibility of accessing health care services. The second is deductively (using existing concepts/theory through observation).

This approach used the existing idea of sexuality and intersectionality to interpret the data and find the connection between how women's social identities, structural inequalities, and resources intersect and interact and how different factors influence their ability to both access healthcare services and develop coping strategy for dealing with HIV. Further, this analysis strategy resulted in various open codes that were later collected to construct a codebook in a Microsoft Excel Sheet. Afterwards, the available codes were grouped, where several codes that referred to the same themes were transformed into axial codes, which were later used to present the three multi-level intersectional challenges and opportunities for coping strategy that are useful to describe the narratives of HIV-positive women. The two interviews with the representatives of NGOs and healthcare workers were used to complement the data and information from HIV-positive women.

3.3 Study Scope

In relations to the research questions and research objectives, this research study is limited to addressing the challenges encountered by HIV-positive women in accessing sexual and reproductive health rights in regards to HIV treatment and care and opportunities to coping strategy of WLWH in tackling negative implications of HIV-related stigma. Therefore, the research findings do not address specific social identities or other factors that influenced the emergence of social adversities that intersect with other forms of marginalization experienced by women in Nusa Tenggara Barat.

3.4 Methodology and Method's Limitations

The use of method and methodology in this research present several limitations and challenges. Given the sensitivity of the subject, the chosen sampling method may result to some biases and homogeneous data due to some similarities that these women have in common. Furthermore, my positionality as an outsider with particular education and class background that does not live with HIV has hindered me to have deeper conversations with the respondents. Building trust and safe spaces with WLWH were also a challenge for me during this process. I had to ensure that I did not reproduce harmful practice of stigma and prejudice when conducting these interviews. However, due to time limitations, the fieldwork could only be conducted for a few weeks with the three first weeks I stayed in the main research site Mataram city and a week of short visit in rural Dompu site which have resulted in the inability to allocate sufficient time to build trust with participants. Consequently, some interviews only lasted for 20 minutes with participants only offering short answers to my questions. Where it held back the process of data construction and limits the cultivation of knowledge from the interviews.

3.5 Reflexivity

During this research, I adopted a qualitative and feminist geographers research approach, mainly to understand the ambivalences of conducting fieldwork and how to deal with uncertainties in situating the knowledge while working with the data from in-depth interviews (Rose, 1997) Feminist epistemology has contributed to situating the knowledge produced in this research by acknowledging the importance of having specified and partial knowledge that recognizes the power relations and positionality of the researcher, the researched, and the research context (ibid).

As an attempt to critically reflect on the knowledge production process, it is important to acknowledge my positionality and status as a researcher and the privileges I hold in the process of

creating this work, mainly when I decided to ‘represent’ the voices of underrepresented HIV-positive women from Eastern part of Indonesia in Nusa Tenggara Barat through my research paper. My positionality has influenced the knowledge and data collected in this study regarding gender, ethnicity, age, and social and economic status. This research also adopted qualitative research methodology in conducting the fieldwork to understand the research positionality as both insiders and outsiders and how it is shaped by different personal and research experiences (Adu-Ampong and Adams, 2020). I had to constantly negotiate my status as an insider-outsider during my fieldwork. I felt self-conscious of how my attached status as a young woman researcher from Nusa Tenggara Barat and master student from a *Western* European institute who has not married and did not live with HIV affected my ability to interview HIV-positive women who are marginalized and to understand their challenges and opportunities in accessing health care services.

Given how sensitive the subjects are and the complexity of the research context, I had to constantly emphasize that the ‘data’ I collected was going to be presented abroad and far from ‘home’ in order to gain participants’ trust. The participants’ perception of me as a fellow woman from Nusa Tenggara Barat concerned about a highly stigmatized issue sparked some sense of acceptance. This way, I was able to navigate my role as an outsider to conduct the interviews. On the other hand, I realized how my outsider status had hindered me from attaining some detailed information regarding their story in accessing the test and treatment on the basis that I was not considered as ‘part of the researched’ group. However, this outsider identity has given me the chance to perform my incompetency and eagerness to learn. This allowed participants to become my main source of knowledge and it intrigued most of them enough to open up about their ‘vulnerable’ stories and journeys with HIV. By maintaining a non-threatening demeanor, I was able to compel participants to share their experiences. This research study used specific and limited knowledge produced through interactions with 12 HIV-positive women in Nusa Tenggara Barat. Therefore, this work does not intend to generalize the experiences of HIV-positive women in Nusa Tenggara Barat nor in Indonesia. The stories are specific to the women I talked to but through repeated themes the findings can offer some insights to what other HIV-positive women in NTB and Indonesia might be experiencing.

Chapter 4 Research Findings and Result

4.1 Demographic profile and HIV status of the participants

I interviewed 11 HIV-positive women from Mataram city and 1 participant from Dompu district with different social identities such as marital status, age, ethnicity, and occupation. Among all of the respondents, seven of them identified as housewives. The rest are informal workers that engage in different economic sectors, including former sex workers that have become online sellers and were divorced or have never been married. The seven housewives I talked to had early marriages, which contributed to their vulnerability in contracting HIV from their husbands/partners who are also HIV positive. Most of the respondents conveyed they had limited capacity in protecting themselves from risky sexual behavior and performing sexual and reproductive agency due to financial dependency on their husbands/partners and insufficient information related to SRHR that hindered them from realizing their rights. These women learned they were infected with HIV through the PMTCT mechanism or when their husbands fell ill or passed away.

Most of the participants who contracted HIV from their husbands decided to stay in the relationship and continue to receive ARV treatment without informing other family members/friends. On the other hand, five respondents who were sex workers mentioned how they found out their HIV status from different mechanisms, including PMTCT, health check-ups, and key-populations screening schemes. The former sex workers tried to conceal their HIV status and isolate themselves to limit social interactions with family and community members. These women immediately received ARV treatment from RSUP hospital Mataram through the supervision of a facilitator who also opened up access to the coping strategy they could acquire, such as peer-supporting groups arranged by a facilitator from NGO INSET and attain social aid distributed by the NGO representatives.

4.1 Challenges to accessing sexual and reproductive health rights

Respondents revealed intersectional experiences that result in social inequality and barriers to access healthcare services related to HIV treatment that intersect with other forms of adversities and formulate HIV-related stigma. In this context the intersection of internalized stigma and gender discrimination have led to the undermining of women's agency to realize their sexual and reproductive health rights. Meanwhile, the intersectional challenges and HIV-related stigma also appeared in community and social sphere particularly in the form of negative judgments, stereotypes, and discrimination the participants receive from family and community members. Whereas, participants also described their experience in social services and health sector domain including the public policy and social norms that shaped their access to healthcare services. The discrimination and stigmatization in healthcare settings and the social norms they encountered at the structural level would often inflict negative thoughts about their HIV status that the participants internalized.

4.1.1 Internalized stigma and HIV gender discrimination.

Most of the respondents reported to develop negative feelings of fear, anxiety, guilt, and shame due to dominant assumptions of HIV that framed the disease as infecting those who have immoral behavior and deviants from morally acceptable attitude. Internalized stigma of their health conditions and the different identities they have, such as being women and pregnant, caused respondents to self-isolate and be in denial of their HIV status. Consequently, several respondents experienced delays in their treatment after being diagnosed with HIV, especially for participants

who was diagnosed through PMTCT scheme but did not have any financial support from family members and was not married due to her status as sex worker. One participant mentioned, *“At first, I didn’t want to go to the hospital for getting treatment because I was afraid and kept having negative thoughts of this disease, adding to this, I was thinking how can I pay for the C-section because they told me I could not have natural birth,”* (HY, 30 years old). Vogel et al. (2013) described internalized stigma could be manifested in different feelings like shame and limited interactions with others.

Another respondent who was also an ex sex-worker also revealed it took quite some time for her to eventually embrace the HIV positive status and committed to take ARV treatment. As a result, she decided to take herself out of any social interactions, even avoiding to be in a relationship, due to her fear of other people finding out about her HIV status. She was worried that if people knew she was HIV-positive, she would experience more stigmatization and discrimination. One respondent told me:

For the first 5-6 months after being diagnosed I was still in denial and isolating myself by avoiding going outside and meeting other people because I did not feel comfortable at all with myself after knowing that I have HIV... Therefore, I have limited my social interactions because I’m afraid that they will know my status if I keep hanging out with them and I was even thinking if one day someone is attracted to me, I don’t know how to tell him about my illness. So, it’s better to limit and even stop socializing with other people. (KS, 39 years old).

On the other hand, housewives who contracted HIV from her husband mentioned about the fear and shame of getting judged and abandoned by her family members if they found out about the source of the transmission and implied the need for protecting her husband’s dignity from the stigmatization by covering their HIV status, *“I’m afraid that my family will judge and leave me if they know that I contracted HIV from my husband, I’m sure they will blame and vilify him. Therefore, I don’t want my husband gets associated to such despicable activity”* (NW, 36 years old). The construction of gender-ascribed roles emphasizes that the responsibility to protect the well-being of family and sustain the relationship in marriage lies with women. This has forced them to conceal their HIV status and undergo treatment in secrecy.

4.1.2 Social judgement on sexuality and Sex Work Stigma

From this interview, respondents showed the tendency to internalize the negative association of HIV with ignominious actions – where in this context, the society norms existed believe women who are being sexually active before marriage is considered to be 'bad' women and even labelled as a prostitute. A previous study on women's sexuality conducted in Lombok Island where the capital Mataram is located in Nusa Tenggara Barat, showed that for single (non-married) women, the social regulation of women's sexuality is based on their identities as single Muslim women, in which their virginity is perceived to be highly valued and must be safeguarded before marriage (Bennett, Linda, 2005) In this case, the social judgment on women's sexual activities is often coming from other people's opinion including family members, who are associating HIV/AIDS as a negative consequence of pre-marital sex. Therefore, this has reinforced the negative image of HIV/AIDS as the disease of 'others' and punishment for those who engage in such behavior. This image has reinforced how HIV-positive women perceive themselves as sinners who have conducted immoral sexual activities.

During an interview with a respondent in Mataram, one of my respondents explained how she has internalized social prejudice on women's sexuality and HIV/AIDS, *“Nevertheless, my family knew that I got this virus because of my past actions who actively engaged in pre-marital sexual activity with my ex-boyfriends but now I have repented and reflected on my actions”* (AH, 28 years old). Most of the women who hide their HIV-positive status from family members also believe that their family won't accept their HIV status and are afraid they will receive more discrimination and further disrespect from family and community members. One respondent perceived her HIV-positive status and past occupation as a sex-worker is a disgrace for her family and if other people find out about this

situation, it will lead to the deterioration of the respondent's mental health, *"I'm afraid to tell my family about my HIV condition and disclose my dishonorable past behavior as a sex worker, I don't want to be known as the 'bad girl' in the family and getting mocked because of this disease. If that's the case I certainly can commit to suicide,"* (HY, 30 years old). This negative judgment from family and community members towards women living with HIV and their sexual activities, which are labeled as reprehensible actions, could contribute to the increase of self-stigma experienced by women. The respondent continued to say, *"Whenever I visited my family's house I would not sleep on their bed and use their pillows/blanket, I would rather sleep on the floor and use this piece of cloth as the pad"* (HY, 30 years old). The negative implication of sex work stigma is reproduced through the social judgement from family and community which influenced the social interaction of HIV-positive women and their ability to cope with the illness.

4.1.3 Socioeconomic factors linking poverty and access to healthcare services

Most of the participants conceived their financial situation as contributing to the difficulties, particularly in accessing healthcare services for their HIV treatment. Hence, their financial struggle is considered as one of the most crucial aspects on the intersectional adversities that shape the experience of stigma and hinder women's access to sufficient treatment. Anti-retroviral treatment is covered by the government. However, for HIV patients that do not have BPJS or national health insurance they could not receive free treatment and must still pay 35.000 IDR (2.30 EUR) for the administration fee and cover transportation costs of about 50.000 IDR (3.20 EUR). Most respondents were secondary school graduates coming from low-income families. In a patriarchal context, the existing gender norms and expectations forced girls to leave school early when they just entered their reproductive age (Cornwall and Jolly, 2006). As a result, their opportunities to enter the job market and get formal employment are also restricted.

Many of the respondents identify as housewives or informal workers who have high financial dependency on their partners and heavily rely on low/unstable monthly income. Both women in urban and rural areas are facing the same economic difficulties due to the lack of income and poor financial conditions. Women who cannot afford to cover their health insurance sometimes found it difficult to access the medication as they could not pay for the administration and transportation fees. Although they were able to attain free diagnosis through healthcare mechanisms, such as PMTCT at the community health center (*Puskemas*) and screening programs from the Department of Health, this does not ensure they could receive free and accessible medication unless they have health insurance and sufficient financial income to cover the administration and transportation cost *"I don't have any vehicle, so I need to go with public transportation 'ojek' and the distance from here to RSUP is quite far. Therefore, the expense of transportation sometimes become a burden for me,"* (KS, 39 years old).

One respondent linked poverty and access to sexual and reproductive health rights, *"I do face difficulties particularly for transportation costs because it costs me around 50.000 Rupiahs to take 'ojek' to RSUP each month. I don't have a vehicle and sometimes it is even difficult for me to make ends meet let alone save money for transportation to pick up my medicine,"* (EM, 44 years old). A respondent in rural Dompu District remarked that due to the lack of financial stability her family had to halt their treatment due to unpaid health insurance or social security administrator for health (BPJS) bills and the absence of government support, *"Three years ago my husband was trying to stop taking the medicine for two months, but his health condition suddenly dropped. At that time our BPJS was inactive for a year due to unpaid bills that we could not pay to the health insurance. We needed 3,5 million rupiah to activate the BPJS so we tried to find the money (loan) for covering our BPJS bill from a moneylender,"* (NA, 34 years old). The experience of my respondent in Dompu District was different from the experience of several HIV-positive women living in Mataram City who are also coming from low-economic households. The HIV-positive women living in Mataram city that I talked to had access to support and aid from the government and civil society organisations who work for PLWH in Mataram City.

One participant noted initially she thought she had to discontinue her treatment due to her financial inability to pay for health insurance after she was divorced by her husband, and she was dispelled from the BPJS coverage. However, shortly after that, thanks to collaboration with the local NGO INSET who reported her situated and advocated on her behalf to the Department of Welfare in Nusa Tenggara Barat, she was able to receive free health insurance targeted for poor citizens called BPJS PBI. Another respondent from Mataram also reported that although she has not received the BPJS PBI, when she does not have any money to pay for the administration bill to collect ARV from the hospital she is able to continue her treatment due to the assistance from the facilitator who works at the hospital and also a representative of local NGO concerned about PLWH. *“If I don’t have any money left to pay for the administration bill, I will contact my facilitator Mbak Ning and she will be picking up my medicine and drop it at my house,”* (HY, 30 years old).

Meanwhile, in rural Dompu District there is limited government support for HIV-positive women with low income. Municipality-level government does not provide any social security support to PLWH and there aren’t any civil society organizations or community-based programs operating in the district that could assist HIV-positive women from low-income households to acquire adequate healthcare and social intervention. As such, my respondent from rural Dompu District did not receive any support from the government or any organization for her treatment. When she could not afford her insurance bills nor cover natal costs in Mataram City, as the Dompu District lacked any PMTCT equipment to help HIV-positive woman to give birth safely, she was forced to travel to Mataram City and rely on loans from a third party and her family. While this one respondent from Dompu District cannot represent all HIV-positive women in her district, limited access to healthcare facilities in the area would mean that her experience is not uncommon for women that share her socioeconomic and HIV-positive status.

4.1.4 Gender inequality and asymmetric power relations within families (restricted support from family member)

Participants who identified as housewives revealed how perceptions and expectations surrounding their role as wives in their families could affect their ability in accessing ARV treatment and experience of health-related stigma. One HIV-positive women discussed that one of the crucial factors for her adherence in taking ARV treatment is her husband’s support because to get ARV treatment she needs permission from or be accompanied by her husband, who is also a HIV patient, to collect her medication from the hospital. She told me, *“I had to discontinue my treatment months ago for 3-4 months because my husband was out of town for work and I could not go by myself to collect the medicine at the hospital because my husband would not give me permission to go without him,”* (PH, 26 years old). Meanwhile, another respondent mentioned her access to healthcare services and proper treatment was dependent on her ex-husband’s health insurance, *“I was really down and confused on how to afford the treatment and medication for my illness and HIV when I no longer have a health insurance that was initially paid by my ex-husband,”* (FT, 30 years old).

The status of being an HIV-positive mother has also shaped respondents’ experience of stigma and exclusion by healthcare providers. Several women shared their experiences facing discrimination in accessing healthcare services for their children. One respondent said, *“I was receiving negative comments from healthcare providers in a community health center. They refused to give my daughter vaccination because I have HIV, even though my daughter is HIV negative,”* (HY, 30 years old). Another respondent explained she had to postpone her treatment due to pregnancy. She had not intended to get pregnant again after losing her first child and found out about her HIV-positive status but the decision was determined by her husband, *“Initially, I wanted to focus on receiving ARV treatment but my husband was telling me to get pregnant again so I had to stop taking the medication, even though I actually have not fully recovered from the grief after my first baby passed away,”* (PH, 26 years old). She was eager to learn about preventing mother-to-child transmission and make informed choices regarding breastfeeding, but she had limited information about her own sexual health and body choices.

One respondent recalled how she was ostracized by her family members through constant attacks and pressure to leave her parents' house due to the negative stigma she received after being diagnosed with HIV and was divorced by her husband. She started being labeled as a 'filthy sex worker' that could become the source of transmission, *"For two years I was attacked by my family members who live nearby my parents' house. They were throwing rocks on my door and roof causing damage, even the head of village had to interfere. It finally stopped when I decided to move out from my village,"* (FN, 37 years old). As Link and Phellan (2004, p. 367) explained, stigma includes elements such as 'labeling, stereotyping, separating, status loss, and discriminations that co-occur in a power situation that allow these processes to unfold'.

The social stigma towards women's marital status intersects with HIV-related stigma and reinforces gender inequality and exacerbate sociocultural impediments for both married and non-married women, to actualize their rights. This stigma is based on structural expectations that project the ideal figure of a woman who is responsible for the relationship and the well-being of family (Konstam *et al.*, 2016). An HIV-positive woman who is also a widow received patronizing behavior from family and healthcare workers who emphasized the importance of asexuality for HIV-positive women. One respondent mentioned *"They even told me not to be in relationship again because I could harm my partner by spreading HIV. One time a healthcare worker asked me whether I'm aware of my HIV status and if I understood that I should not be socializing or interacting too close with other people and I should just stay at home. That nurse kept reminding me on how my husband and I are HIV positive and consequently now my daughter has to suffer from it because of me,"* (WA, 44 years old).

4.1.5 Provision of access to anti-retroviral treatment for women living in Urban and Rural eastern area of Nusa Tenggara Barat

It is important to understand how the location of where these women reside also affects their ability in accessing healthcare facilities given the unequal development of infrastructure in Eastern Indonesia. For women living in urban area, the accessibility to health care services is in a bigger rate than any other region in the province, participant mentioned the health care providers through facilitator assisted them to attain the ARV medication *"I don't really have to deal with everything by myself in accessing the health care services for me and my daughter, as we can ask our facilitator to sort the things out even when we have problem to get the new medication that has less side effect and more suitable for us"* (FT, 30 years). Another participant from urban area also conveyed Women living with HIV who reside outside urban areas encounter barriers to access healthcare services due to the unequal distribution of logistics and information from the Department of Health. This results in the non-provision of anti-retroviral treatment in some regions that consequently force PLWH to collect medication from referral hospitals in different districts. This has added unnecessary burdens for women by the increase of traveling time and transportation costs. One respondent mentioned that for the past 6 years she has had to pick up medication for both herself and her husband from two different hospitals due to the unavailability of ARV in Dompu hospital. *"I took the treatment right away from RSUP Mataram in 2016, because ART was not available in Dompu at that time. Therefore, we got the medicine from RSUP Mataram for two years by sending the money to the hospital and they would send the medicine to Dompu. After two years the RSUP hospital told us that we could pick up the medicine from a hospital in Bima (the neighboring district) because there is available medicine and a doctor there. So, we had to travel to Bima every month to get the medicine up until early this month,"* (NA, 32 years old).

Furthermore, women who live in remote areas in Dompu district have limited access for HIV/AIDS testing due to the poor healthcare infrastructure provided in the area. A healthcare worker who is in charge for the HIV/AIDS program in one of the community health centers in Dompu and also facilitates HIV-positive women to get HIV tests and treatment noted the structural obstacles that her patients encountered, *"One of the barriers for women to get tested and treated is influenced by the provision of services. For instance, the nearest sub-community health center that is accessible for*

the people who live in a remote sub-district area is located 50km across the island,” (NA, Health Worker in Dompu).

The existing gap of health services and provisions in Nusa Tenggara Barat could contribute to delays and barriers for HIV patients in getting their treatment. Dompu District itself has just started to provide anti-retroviral therapy in July 2022, when this study was conducted. An interview with a healthcare worker in Dompu has confirmed that one of the challenges within the healthcare system in Dompu is the poor access for ARV treatment provided in this district. This has shaped the patients' adherence to taking HIV medication, *“One of the factors that affected patients' decisions to stop taking ARV treatment is because before July 2022, HIV patients in Dompu had to travel all the way to the neighboring district to get HIV treatment. Not all the patients were willing nor able to go to that hospital, especially women who are unable to leave their houses without their husbands' support or permission. This, coupled with the costs of transportation, could pose barriers for HIV patients, and even lead to their withdrawal from treatment,”* (NA, health worker in Dompu).

4.1.6 Religious beliefs, discrimination against HIV-positive women by healthcare workers, and the questioning of HIV medicines effectiveness

Participants mentioned the impact of religious beliefs that see HIV as a consequence of husbands' sin. As a good wife and religious believer, women are expected to accept the same fate as her husband. *“I simply have to accept this situation as God gives it as a punishment due to his (her husband's) risky sexual behavior and affair outside marriage. At that time, I could not stop my husband from doing so,”* (NA, 32 years old).

Prevailing social norms in a rural region also placed traditional medicines and religious and cultural convictions as the main source of health. This was emphasized as one of the aspects that have shaped societal attitudes and perceptions towards HIV and PLWH's willingness to seek healthcare interventions. One healthcare worker told me, *“The type of people we usually encounter is those who are not cooperative with the healthcare workers. There is a strong belief that it (treatment) clashes with health regulations and is inimical for the risk population. What I found in the field were that a lot of people, including family members of HIV-positive patients, prioritized traditional herbs and went to a shaman instead of seeking medical intervention,”* (NA, a health worker in Dompu). It is reported that one of the traditional beliefs among the community in Dompu District is the propensity to define HIV as *supurasa*⁵, where consequently the person who identified as a patient of *supurasa* will be treated with a traditional and religious approach instead of medical treatment.

In addition to existing religious and societal beliefs, which are considered to be social impediments, interviews with a healthcare worker and several HIV-positive women both in Dompu and Mataram regions, reveal that stigma and discriminatory acts are still prevalent within healthcare facilities. This may lead to lack of trust and confidentiality, which eventually becomes a hindrance for patients to undergo HIV tests and treatment. *“One of the challenges for HIV patients to seeking for treatment is the distrust towards healthcare workers, whether they can maintain patient confidentiality or not and a lack of confidence whether ARV could actually prolong their life expectancy. Among healthcare workers, what I often found is that there are healthcare providers who are stigmatizing patients,”* (NA, health care worker in Dompu). One participant also recalled the stigmatized attitude she received when she visited a community health center to get the referral letter required to get ARV treatment in the hospital, which caused her to initially avoid any interaction with the healthcare workers. *“Whenever I come to community health centers and asked for referral letters to get my medication, the healthcare worker kept asking me how a housewife like me could contract the virus and it was hard for me to retell the painful story,”* (NA, 32 years old).

⁵ Supurasa is the term used to describe the disease suffered by the people in a community that cannot be cured, and it is known to be the illness innated from that village.

The participant in Dompu District also mentioned a moment when she was doubting the efficacy of ARV treatment and proceeded to halt her treatment for 3 months to see if there would be any side effects of withdrawing from the medication. *“I tried to quit ART for six months because I wanted to see how my body reacts to it. I had been taking it for 6 years so thought maybe the virus had gone. After that, I consulted with the healthcare worker at the hospital and the nurse told me that I could not do that because this illness requires me to get ART for the rest of my life,”* (NA, 32 years old). In the other hand, the participant in urban Mataram also revealed the lack of confidentiality amongst health care providers and mentioned the experiences of being discriminated against by health care workers during her visit to receive treatment for her daughter *“when I had to take my daughter who was really sick to the hospital, the treatment we received was different, they took special precautions and it was just evident that they were afraid to give my daughter proper treatment like any other patient and it was actually made other people wondering about our condition and could found out that we are HIV patient because of the differentiated action that they gave to us and it broke my heart to see them (health workers) took a distance from us whenever we came for a health check or treatment.”* (WA, 44 years).

4.2 Opportunities: Building Coping Strategy

Respondents described several opportunities they have despite being diagnosed with HIV that allowed them to develop coping strategy to deal with the negative implications of HIV-related stigma. Participants also mentioned that their experience of living with HIV could also become a source of motivation to continue living and shift away from solely accepting the stress caused by intersectional stigma to gradually reclaiming their rights and dignity. The opportunities are varied and influenced by several factors including the social locations, resources for infrastructure, and involvement of civil society. The various coping strategies and opportunities described by my respondents constitute: resilience, social network, and challenging stigma.

4.2.1 Resilience: ***“I changed my mindset and started to believe that HIV-positive woman can also live normally”*** - The construction of Motherhood

The use of resilience as a coping strategy involves the establishment of personality and attitudinal traits like optimism, perseverance, problem-solving in precarious situations, and reflecting on positive psychological outputs (Liamputtong, 2013). One of the participants talked about the process of accepting their HIV-positive status, which helped increase their sense of self-fulfillment and their will to continue their life with love and self-respect: *“As time went by, I started to think why should I continue to feel bad about myself. After a few months I decided to accept this situation and become more independent in actualizing my own happiness and prioritizing the well-being of me and my son.”* (KS, 39 years old). Other respondents, who are also mothers, expressed similar narratives of living positively to regain and maintain their motivation to continue their treatment for the sake of themselves and their children. Therefore, the status of being a ‘mother’ and the social construction of motherhood that emphasizes women’s main responsibility in taking care of their families, play a crucial role in their adherence to ARV treatment as their children became their main source of strength. A participant explained, *“After a while of consuming ARV, sometimes I felt fed up with taking the medicine but I could not discontinue my medication because I have to maintain my health for my daughters and family. Who will take care of them if I am sick? I have to be in good health so I can look after them,”* (NA, 32 years old).

Another participant conveyed how she motivated herself and reframed the negative traits associated with people living with HIV as powerless and burden to society into a positive subject through realizing her capacity as resourceful and productive being *‘Gradually as I become more grateful for my life and the help of ARV treatment to sustain it, I then believe I can be empowered too just like the people I saw on the internet and that’s how I landed myself to join online supporting group and become an active admin who relentlessly spread the awareness on HIV’* (FN, 37 years old)

4.2.2 Social Network: *“The presence of KDS (Peer-Supporting-Group) really helps me to get through this journey with HIV”*

Social networks appeared as a crucial coping resource for HIV-positive women. Joining a support group can be translated as a means to counter the shame and stigma of HIV/AIDS. Due to the issue of social acceptance and disclosure most of the WLWH I talked to tend to search for emotional support from people who have similar conditions and experiences such as PLWH rather than family or friends (Liamputtong et al., 2009). A respondent noted *“What I’m grateful for amidst this situation is the existence of Peer Supporting Group. I feel embraced and able to share my concerns with the people who are also suffering from the stigma of this illness”* (FM, 39 years). This narrative elucidates the role of supporting groups in providing emotional support for HIV-positive women to cope with interpersonal stress. Support groups were also portrayed as a way to address the feeling of isolation and considered as a safe space for WLWH in interacting with people with the same status without worrying about the issue of confidentiality and status disclosure, which was mentioned by a participant, *“At the beginning I thought why am I the only one who suffer from this illness, but then I was introduced to join this supporting group and being with the people who have similar experience to you enabled you to be yourself and not afraid of disclosing your status”* (KS, 39 years old). Support groups also provided women with more knowledge regarding the illness and how to deal with it better especially when other complex issues occur. As one participant told me, *“One of the activities of peer supporting group is constructing the knowledge regarding the illness, as I have become an older member of this community, I try to share my knowledge and story with those who are being diagnosed recently to encourage them,”* (EM, 44 years old). The peer-supporting group activity is organized by NGO INSET in Mataram city. It aims to create not only a safe space but a knowledge production site that can be useful for PLWH, *“Sometimes we conducted training or workshops regarding their treatment and how to cope with their situation during the meeting, This is also a chance for them to share the challenges they encounter in accessing treatment so that we can help them to get through it,”* (N, INSET facilitator).

Internet Social Network: *“To fill the absence of KDS (Peer Supporting Group), watching the Youtube vlogs can be the alternative”*

The limited resources and activities for HIV-positive women in Dompu have created an impetus to create a network of support for PLWH through the use of internet. Joining a support group is considered as an important coping resource, particularly in making HIV-positive women realize that they are not alone in the world living and fighting against HIV/AIDS (Liamputtong, 2013). In addition, the support group also functions as a knowledge production site that allows women living with HIV to gain more power to cope with the illness through educational information that strengthens their capacity to empower themselves. Rowlands (1997) theorizes empowerment through the use of ‘power within’ for women to perceive themselves as ‘able and entitled to act and have influence’, to create the situation of being empowered. Support groups allow women to increase their capacity to create ‘power to’ forge solidarities and reshape realities (Eyben, Kabeer and Cornwall, 2008). Whereas in the context of HIV-positive women in Dompu District, peer supporting group (KDS) is not provided in the area. To deal with this drawback healthcare workers offered different strategy in filling the gap of it through providing the knowledge and emotional support from internet videos made by PLWH with similar social identities. As noted by the health care worker, *“I often direct them (HIV-positive women) to watch Youtube videos of HIV survivors who have similar social backgrounds. For instance, one of my patients has become more adhered in taking ARV treatment after watching a lot of videos from an HIV-positive sex worker who can successfully survive with ARV”* (NA, health worker in Dompu).

4.2.3 Challenging Stigma: *“Now those people are surprised by seeing my condition and the fact that I can live longer than they have expected”*

Challenging stigma emerged as a significant coping resource for HIV-positive women well-being and empowerment, this constitutes active engagement of WLWH to struggle for equal rights and fighting against discrimination they have received including the unjust treatment against their HIV positive family members by the community. A housewife from Dompu District remarked that: *“When I came back from Mataram, I was surprised because the number of negative comments and the treatment that I got from my community were getting worse. One time, I decided to just call them out while crying out loud because I felt so sorry to my children, they were also negatively affected by this, people were avoiding them so they cannot play outside with their friends,”* (NA, 32 years old).

Many participants in urban Mataram also considered the presence of peer-supporting groups as a platform to advocate for the needs of PLWH, including to file their concerns on the negative treatments and difficulties they encounter in accessing healthcare services and the discrimination they experience from healthcare workers and representatives of hospital staff. They report these concerns to the NGO that organizes the activity of peer-supporting group. As mentioned by one participant: *“I found it really helpful because we can use this (supporting group) as a platform to speak up about the challenges we encounter in accessing health care services. For instance, one time one group member told us how she was denied to get treated at a community health center in her village and then we reported it to the facilitator and asked them for the solution. After that, we started to see improvements in the provision of healthcare services including the attitude of healthcare workers now,”* (WA, 44 years)

Moreover, in challenging the stigma, respondent in rural Dompu setting has conveyed how the socialization that was conducted by the health care worker in the mosque by incorporating the religious symbol approach has given the opportunity for tackling the stigma in her neighborhood *“There was a socialization that held in the mosque, where people were gathered together and a health worker was explaining to them the comprehensive information regarding HIV including the transmission and treatment of it. So, the people who were not aware of it could receive the correct information and knowledge that help to reduce the negative comments”* (NA, 32 years old) This community-based intervention have used to give support for PLWH instead of marginalizing them as well as challenging the negative prejudice surrounding the disease.

Chapter 5 Conclusion

This research study explored and unpacked the interdependent relationship between social identities and structural inequalities of HIV-positive women from a particular social location in Nusa Tenggara Barat and used a secondary research site in rural area to further contextualize the experiences of HIV-positive women in urban area. The research findings showed how the intersection of different social identities and social adversities signified the negative implications experienced by HIV-positive women. This has formed various challenges to access adequate sexual and reproductive health rights, including access to health care services. In this social context, the intersectional adversities comprising of gender inequality, poverty, and patriarchal construction of sexuality have interacted with different marginalized social identities. These social identities, which include women's assigned gender roles, sex workers, HIV-positive status, and marital status, have affected women's capacity to realize their rights. Most of the respondents expressed how the negative implications of these overlapping adversities have affected their adherence to accessing HIV treatment and performing their SRHR. On the other hand, the structural inequality from the limited provision of access to health care services at the macro level has significantly affected the ability of women in rural areas to receive sufficient HIV-related intervention.

As described by most participants, they have experienced different challenges in accessing adequate sexual and reproductive health intervention due to being HIV-positive patients. Married women who identify as housewives encountered difficulties in attaining ARV treatment without their husbands' support/permission. Meanwhile, divorced women often experience adversities in accessing health care services as they cannot afford health insurance, usually paid for by the breadwinner. On the other hand, participants who are former sex-workers faced intricate situations due to the ingrained stigmatization in society, which has led to the marginalization of this population.

Meanwhile, women from low-income backgrounds described the financial impediments in acquiring the proper treatment and care because of the extra cost of transportation and administration fees they have to spend, which affects their adherence in taking ARV treatment. The social locations where these women reside also affect their ability to obtain treatment and support, given the structural issue of unequal development in regions where ARV treatment and HIV tests are limited or even not equally provided. This indicates how marital status, poverty/financial capability, gender, and occupation intersected and interacted with multiple social adversities in different social locations to form challenges that limit women's capacity in acquiring health care services as well as developing coping strategy that allow women to counter negative implications of being diagnosed with HIV.

This study elucidates women's ability in reclaiming their agency and will to continue their lives and utilizing different strategies to deal with the stigma and discriminations including embracing their HIV-positive status. It is essential to understand the complexity of women's conditions who are living with HIV in order to provide the initiative to meet HIV-positive women needs, given how each social identity produces particular needs and conditions that could affect their ability to acquire sexual and reproductive health well-being. This study has explored the intricate realities of HIV-positive women that are often overlooked and treated as the adversity of being diagnosed with HIV. The government's limited responses to HIV and the lack of a positive approach to gender and sexuality within HIV interventions for women, have continued to leave the HIV-related stigma unaddressed and ignores patients' experiences of discrimination in the hands of healthcare providers and members of their communities.

The prevalence of stigmatization and discrimination has shaped the attitude of community members and health providers. Consequently, this reinforces women's challenges to actualizing their sexual and reproductive well-being amidst oppressive situations. They can still use social capital and resources to develop coping strategy and opportunities to challenge the negative implications of HIV-related stigma and discrimination, such as resilience, building a social network, and directly challenging the prejudices expressed by different societal actors.

The findings of this research highlight the importance of acknowledging and recognizing the multi-dimensional aspects of the lives of women living with HIV and the violations of women's sexual and reproductive health rights. Therefore, an integrated intervention that aims to reduce the hindrances encountered by women in multi-level social realities and the oppression of WLWH is required with the involvement of intersectoral social actors to overcome the barriers and improve the opportunity for women to access sexual and reproductive health and care services and enhance resilience and social support. It is also noteworthy that addressing stigma and discrimination in different settings, including society and service providers, is important. It can be done by providing services that accommodate the needs and adversities of diverse HIV-positive women with different social identities to promote health equity and social justice for HIV-positive women.

Moreover, it is also crucial to integrate the SRHR into HIV policies at national and local (urban-rural) levels by providing adequate social support for HIV-positive women prone to social exclusion and ensuring the equal distribution of resources and capital to the local level, including rural regions. Besides that, it is significant to strengthen community-based intervention for disseminating the right information regarding HIV and STIs. Including at the domestic level of the family to overcome the prevalent stigma and discrimination. Therefore, we can build a support system for people living with HIV at the community level.

Appendices

Appendices 1 HIV-Positive Women Demography

No.	Initials	Year of HIV Diagnosis	Occupation	Number of Children	Education level	Marital Status	Age	Notes
1.	EM	2005	Online seller/Ex-sex worker	2	Junior school high	Widow	44	Divorced from 2 nd marriage, 2 children HIV-free status, patient at RSUP Mataram
2.	KS	2005	Beverage seller/Ex-sex worker	1	Junior school high	Widow	39	Divorced from 1 st marriage, 1 child HIV positive, patient at RSUP Mataram
3.	FT	2016	Online seller/housewife	1	Junior school high	Married	30	2 nd marriage, 2 nd husband HIV negative, 1 child HIV positive, moved from Malang East Java, patient at RSUP Mataram
4.	HY	2020	Rice courier/Ex sex worker	1	Elementary school	Not married	30	1 child HIV negative with no marital status, patient at RSUP Mataram
5.	AN	2013	Beverage seller/Housewife	1	High school	Married	28	1 st marriage, Husband HIV positive and 1 child HIV negative, patient at RSUP Mataram
6.	WA	2005	Housewife/Canang Seller	2	High School	Married	44	2 nd marriage, 1 st husband HIV positive and 2 nd husband HIV negative, 1 st daughter died from HIV and second daughter HIV negative, patient at RSUP Mataram
7.	FN	2017	Online Seller/Ex-sex worker	2	High school	Widow	37	Divorced from 2 nd marriage, 2 nd ex-husband HIV negative

								and 2 daughters HIV Negative, patient at RSUP Mataram
8.	NZ	2010	Housewife; Posyandu cadre	2	High school	Widow	41	1 st marriage, ex-husband HIV positive, 1 child HIV positive, patient at RSUP Mataram
9.	PH	2020	Housewife; Cleaning Service	2	High School	Married	26	1 st marriage, husband HIV positive, 1 st child died and 1 child HIV negative, patient at RSUP Mataram
10.	YL	2022	Ex-sex worker	1	Junior school high	Widow	42	1 st marriage, 1 st child HIV negative, patient at RSUP Mataram
11.	NW	2017	Housewife	2	Junior school high	Married	30	1 st marriage, husband HIV positive, 2 children HIV negative, patient at RSUP Mataram
12.	NA	2016	Housewife; tenant farmer	2	Junior school high	Married	32	1 st marriage, husband HIV positive, 2 daughters HIV negative, patient at RSUD Dompu

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