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THE EVERYDAY LIFE OF WOMEN LIVING WITH HIV IN BANDUNG CITY

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ABSTRACT

The everyday lives of people living with HIV/AIDS are often filled with challenges stemming from physical, mental, and socio-cultural aspects. Among them, many are able to face these challenges, while some struggle to do so. Women living with HIV face even greater challenges due to their gender roles in society, whether as single women, mothers, wives, or daughters-in-law. This study describes the dynamic challenges faced by women living with HIV in Bandung City in their daily lives. These challenges go beyond biological aspects and include the ways they confront them. The research employs a phenomenological method, with data collected through in-depth interviews and participant observation involving women with HIV/AIDS who are either housewives or workers. The findings reveal that the everyday lives of women living with HIV/AIDS in Bandung are marked by issues related to their physical, mental, socio-cultural, and economic conditions. After being infected, their physical health often deteriorates, requiring them to adapt to these conditions to maintain their daily activities. They also experience mental pressure due to the need to hide their health status because of societal stigma. Some women fail to manage these challenges and experience stress, while others successfully cope with them. Remarkably, some women manage to empower themselves and live fulfilling lives.

Keywords: everyday life; women; HIV; Bandung; empowerment

INTRODUCTION

Human immunodeficiency virus (HIV) is a virus that attacks the body's immune system by targeting the body's white blood cells. The virus is spread through the bodily fluids of an infected person, including blood, breast milk, semen, and vaginal fluids. It is not spread through kissing, hugging, or sharing food, but it can be transmitted from a mother to her baby through breastfeeding. People infected with HIV are more susceptible to illnesses such as tuberculosis, infections, and certain cancers. HIV is treated with antiretroviral therapy (ART). Untreated HIV can progress to acquired immunodeficiency syndrome (AIDS), which is the most advanced stage of infection, often occurring after many years (Chapman, 2000). Today, HIV remains a major global public health issue, having claimed an estimated 42.3 million lives by 2024. Transmission continues in all countries globally (World Health Organization, 2024). In terms of sex, 44% of new HIV infections occurred among females (UNAIDS, 2024).

In Indonesia, 540,000 people were living with HIV, and 142,009 were living with AIDS by 2023. Among all provinces, West Java had the highest number of HIV cases in 2023, with 2,575 cases (Central Statistics Agency, 2024). Among regencies and cities in West Java Province, the city of Bandung recorded the highest number of cases. According to data from the Bandung City Health Office, HIV/AIDS cases from 1991 to September 2024 reached 12,170. In terms of gender, 900 of these cases were female.

Komnas Perempuan (Indonesian Women's National Commission) reported that the number of women infected with HIV has been increasing yearly (Komnas Perempuan, 2019). According to the Central Statistics Agency of West Java Province, HIV cases among women increased by 388 in 2023. Globally, women and girls accounted for 46% of all new HIV infections in 2022. The city of Bandung recorded 10,871 cases in 2022, accounting for one-third of the total cases in West Java Province. Cases of women with HIV in Bandung accounted for at least 35%, or around 7,153 cases (P2P, 2022).

Previous research has found that HIV infection in women leads to multiple burdens: biological, psychological, and socio-cultural (Jess et al., 2023). Biologically, women with HIV must take precautions to prevent transmitting the virus to their babies before, during, and after childbirth. Women with HIV are strongly advised to undergo the Prevention from Mother-to-Child Transmission (PMTCT) program to prevent the virus from being transmitted to their newborns (Imelda, 2011; Pisani, 2008).

Psychologically, women with HIV experience various mental health challenges as a result of their illness (Salami et al., 2021). They suffer from depression, stress, anxiety disorders, fear, sadness, and suicidal thoughts due to stigma and discrimination (Fauk et al., 2023, 2024).

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Socioculturally, women often bear the impact of "triple jeopardy"—as people infected with HIV, as mothers (for those with children), and as women living with HIV. Triple jeopardy refers to the layered subordination experienced across various stratifications such as gender, race, and social class (Paudel & Baral, 2015).

In Indonesia, women with HIV experience a lack of social support, which impacts their behavior change physically, mentally, and socially (Rasyiid, 2016). Gender inequality, particularly in the form of sexual subordination, also makes it difficult for women to protect themselves from sexually transmitted infections (STIs), including HIV infection (Paudel & Baral, 2015). UNICEF (United Nations Children's Fund), in a policy bulletin by Komnas Perempuan, stated that women with HIV are highly vulnerable to gender-based violence and stigma from their communities. They are also vulnerable to losing their future and their reproductive rights (Ford et al., 2018; Komnas Perempuan, 2019).

In Indonesia, where the majority of the population is Muslim, women with HIV are subjected to religious pressures. Hidayana (2028) states that women, as secondary beings, must negotiate economic difficulties and socio-cultural pressures daily. This is due to the cultural values held by most of Indonesia's Muslim population, which position women as dependent on their husbands as the head of the family.

Based on these studies, it is clear that the daily lives of women living with HIV worldwide are not easy, including in Indonesia. Meanwhile, women with HIV in Indonesia remain largely neglected by policies or programs that could improve their quality of life, let alone initiatives aimed at empowering them. Given the high prevalence of HIV among women in Bandung and the lack of government support for women with HIV, this study intends to describe the daily lives of women with HIV in Bandung and how they survive under various pressures.

In this study, the concept of everyday life refers to the daily routines, habits, activities, and social interactions that individuals engage in within their social, cultural, and physical environments. It encompasses the mundane and repetitive aspects of life, including work, leisure, relationships, and the consumption of goods and services, as well as how individuals interpret and navigate these experiences. The concept of everyday life is central to understanding how broader social structures (e.g., power, culture, and economics) influence personal and collective experiences. Everyday life can also highlight resistance and agency in how people adapt to or transform their circumstances (Fauk et al., 2022).

METHOD

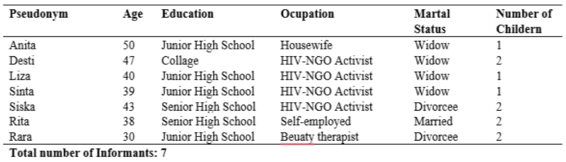
This study uses a qualitative approach, specifically phenomenological methods, to explore the daily lives of women with HIV residing in the city of Bandung. Primary data collection is conducted through in-depth interviews and observations with the informants' permission. The study involves seven women with HIV and their closest relations (children, parents, partners, and friends) who provide them with daily support. Informants are recruited using the snowball sampling technique. Secondary data collection is carried out through archival research and a review of literature on the daily lives of women with HIV. This research has received ethical clearance from the Research Ethics Commission of Padjadjaran University, as stated in letter number 571/UN6.KEP/EC/2024.

RESULTS AND DISCUSSION

Profile of Informants

Seven informants voluntarily participated in this study. All of them are HIV-positive women living in Bandung City and undergoing ARV therapy. They are married and have children. The demographic profile of the informants is shown in Table 1 below:

Table 1. Informants Profile



Pseudonym	Age	Education	Ocupation	Martal Status	Number of Childern
Anita	50	Junior High School	Housewife	Widow	1
Desti	47	Collage	HIV-NGO Activist	Widow	2
Liza	40	Junior High School	HIV-NGO Activist	Widow	1
Sinta	39	Junior High School	HIV-NGO Activist	Widow	1
Siska	43	Senior High School	HIV-NGO Activist	Divorcee	2
Rita	38	Senior High School	Self-employed	Married	2
Rara	30	Junior High School	Beuaty therapist	Divorcee	2

Total number of Informants: 7

Source: Fieldwork Data, 2024

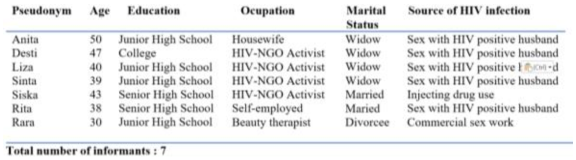
Most of the informants are middle-aged and have completed high school. Four of them work as activists for an HIV-focused NGO in Bandung. They joined the NGO soon after learning their HIV status and receiving support from the organization. Four of them are widowed after their husbands died of AIDS. All of them have children who live with them.

The informants have different histories of HIV infection, as shown in Table 2. Two informants, Rara and Siska, acknowledged engaging in activities considered high-risk for HIV infection before discovering their HIV status. Rara was formerly a female sex worker before becoming a beauty therapist, while Siska was an injecting drug user before joining the HIV NGO as an activist.

Rara discovered her HIV status when she took an HIV test while still working as a female sex worker. The brothel she was affiliated with collaborated with an HIV NGO in Bandung to conduct regular HIV testing for all female sex workers as part of a harm reduction program in the city.

Siska learned of her HIV status after taking an HIV test recommended by the doctor treating her ill child. Her child, who was only 18 months old, was diagnosed with tuberculosis and passed away shortly after the diagnosis.

Table 2. Source of HIV Infection



Pseudonym	Age	Education	Ocupation	Marital Status	Source of HIV infection
Anita	50	Junior High School	Housewife	Widow	Sex with HIV positive husband
Desti	47	College	HIV-NGO Activist	Widow	Sex with HIV positive husband
Liza	40	Junior High School	HIV-NGO Activist	Widow	Sex with HIV positive h[illegible]d
Sinta	39	Junior High School	HIV-NGO Activist	Widow	Sex with HIV positive husband
Siska	43	Senior High School	HIV-NGO Activist	Married	Injecting drug use
Rita	38	Senior High School	Self-employed	Maried	Sex with HIV positive husband
Rara	30	Junior High School	Beauty therapist	Divorcee	Commercial sex work

Total number of informants : 7

Source: Fieldwork Data, 2024

The other five informants—Sinta, Anita, Rita, Desti, and Liza—contracted HIV through regular sexual contact with their husbands, who had previously engaged in high-risk activities. Sinta's husband was involved in high-risk sexual activities outside the home, while the husbands of Anita, Rita, Liza, and Desti were injecting drug users. The process of discovering their HIV status was similar for these five informants. They only learned of their infection after undergoing an HIV test, as recommended by the doctors treating their ill husbands. Their husbands exhibited symptoms of AIDS-related complications, and subsequent HIV testing confirmed their positive status.

The everyday life of women was not an easy one. Being a woman, mother, and HIV positive person at the same time, requires them to face challenges and difficulty in their everyday life rooted in biological, psychological, as well as social and cultural aspects. Based on the data analysed in this study, there are four themes to describe the everyday life of women living with HIV in Banding City: 1) Biological challenges, 2) psychological problems, 3) socio-cultural problems, and 4) economic and financial problems. The description of each thema will be elaborated in the following sections:

Navigating Body Change and Treatment Challenges

HIV infection brings significant physical changes and necessitates treatment with antiretroviral therapy (ARV). However, not all informants immediately began ARV treatment upon diagnosis. Some struggled with acceptance and initially refused treatment. Rita and Rara, for example, exhibited no significant symptoms before their diagnoses and generally felt healthy, aside from occasional colds or coughs that lasted only a few days. These mild symptoms led them to delay ARV therapy. Desti also postponed starting ARV therapy for several months after her diagnosis, only deciding to begin treatment when HIV-related health complications significantly affected her daily life.

Three of the seven informants reported a drastic decline in immunity during the early stages of infection, experiencing frequent fatigue, high fevers, diarrhea, and oral fungal infections. These conditions eventually led them to start ARV therapy.

A significant advancement in ARV treatment has been the development of a single-dose medication that combines Tenofovir, Lamivudine, and Dolutegravir (TLD). Most informants accessed their medication through Indonesia's BPJS (National Health Insurance) program at local health centers and hospitals free of charge. Despite relatively easy access to treatment, some informants encountered healthcare professionals who provided inadequate services (Hutahaean, 2023; Kassie et al., 2023).

After starting ARV therapy, all informants reported experiencing adverse side effects. Desti experienced cognitive difficulties and slurred speech after taking a combination of Tenofovir, Lamivudine, and Efavirenz (TLE). As a result, her doctor advised her to switch to a different regimen—Tenofovir, Lamivudine, and Dolutegravir (TLD). Meanwhile, Siska, Anita, and Sinta developed swelling due to toxoplasmosis. Siska underwent two surgical interventions to treat the swelling, while Anita and Sinta relied on herbal remedies until their condition improved. Additionally, Liza suffered from asthma and gonorrhea, which caused skin rashes and prolonged scarring.

Undergoing ARV therapy was not easy. Most informants were unfamiliar with HIV management and had concerns about long-term effects. Anita, for instance, worried about the impact of ARVs on her kidney health. To address these concerns, they sought support from institutions assisting people living with HIV. Liza, Sinta, Anita, Desti, and Siska accessed medical care at hospitals. Anita was fortunate to receive additional support from Warga Peduli AIDS (AIDS Care Citizens), a volunteer-based health initiative in her neighborhood. Meanwhile, Rita, Sinta, Liza, Siska, and Desti joined the Bandung City AIDS Control Commission for further support. Rara entrusted her treatment to Mawar Clinic, an HIV clinic run by an NGO in Bandung.

ARV therapy plays a crucial role in prolonging life and improving the well-being of women living with HIV. However, strict adherence to medication schedules requires discipline and adaptation. Many women set reminders to ensure they take their medication consistently. Yet, ARV therapy also presented challenges. Liza and Rara, both career-driven women, had to adjust their daily routines to maintain consistency in their treatment. They relied on phone alarms to remind them to take their medication, often stepping away from work to do so.

Additionally, Liza and Rara faced challenges in the workplace. When their phone alarms reminded them to take their medication, colleagues often questioned what they were consuming. To avoid revealing their HIV status, they claimed to be taking supplements. The repeated questioning caused anxiety, making them fearful that their co-workers would eventually suspect their condition.

Although ARV therapy significantly increases life expectancy, it also presents emotional and social hurdles. Women living with HIV require continuous medical and social support to maintain treatment adherence. They need reliable, affordable, and accessible ARV services, including free medical consultations and healthcare professionals trained to handle the needs of people with HIV. Beyond HIV treatment, comprehensive reproductive health services are also essential. Women living with HIV need support that extends beyond managing their condition, including consultations on family planning, safe pregnancy options, and access to effective contraception. Providing these services ensures better health outcomes and improves their overall quality of life.

Embrace Psychological and Emotional Life

Living with HIV places significant psychosocial stress on those affected (Hidayanti, 2013). Many individuals remain active and unaware of their status until diagnosis. However, once they learn they have HIV, their mental and emotional well-being can become unstable, affecting their ability to work and concentrate (Chairiyah & Triratnawati, 2024). This pattern was evident among the informants in this study.

Rita, for example, admitted experiencing extreme stress and insecurity after discovering her HIV status, especially since her husband also fell ill at the same time. She had to juggle the responsibilities of being a housewife and a working mother. Liza shared a similar struggle—her diagnosis left her feeling anxious and afraid of being stigmatized. Rara, too, feared that she would suffer the same fate as her friends who had died from HIV-related illnesses in the sex industry.

Research by Nelsensius Klau Fauk in Yogyakarta (2023) highlights the profound psychological impact of HIV on women. It reveals that women with HIV often struggle with stress, anxiety, depression, fear, and sadness. Various stressors contribute to their emotional burden, including stigma, lack of social support, fear of death, and concerns about their children’s future (Fauk et al., 2023).

Desti recalled hitting her lowest point after losing her husband. She isolated herself for a year, unable to accept her diagnosis. She believed she had been a devoted wife, always obedient and caring for her family, yet she still contracted HIV. The shock left her devastated, and she avoided seeking treatment for the opportunistic infections she developed. Her refusal to accept her status led her to reject ARV therapy, causing her physical and mental health to decline further. Desti was unaware of her husband's past as a syringe drug user, which ultimately led to his AIDS-related death.

Sinta also learned about her infection only after her husband’s death from AIDS. Before he passed, doctors diagnosed him with typhoid and diarrhea. However, his condition deteriorated, and after his death, Sinta underwent counseling, where she learned her husband had been HIV-positive. She was then encouraged to take a VCT test. Her husband's sudden death was a devastating shock. Throughout their six-year marriage, Sinta had no knowledge of his behaviors that led to his infection. Worse, he unknowingly transmitted the virus to her. After testing positive, Sinta had her child tested as well. She was immensely relieved when the results showed her child was not infected.

Anita also faced overwhelming psychological distress after losing her husband and two children within 53 days. The immense grief severely affected her health, leading to toxoplasmosis-related gland swelling and partial paralysis from a stroke. Looking back, Anita regretted not being aware of HIV earlier. She wished she had taken preventive measures, such as delivering via cesarean section and avoiding breastfeeding, to protect her children.

Siska had a different experience. Although her ex-husband had no history of HIV, she suffered emotional and physical abuse in their marriage. Verbal insults and physical violence led her to leave and become a single parent. Despite being a former syringe user, Siska felt the mistreatment she endured was unjustified.

Despite the immense psychological burden of their diagnosis, these women sought ways to cope by building support networks and utilizing available resources. For instance, Sinta received an invitation from a hospital to join a WhatsApp group providing information about HIV services. At the time, she had a four-year-old child, and the doctor who had treated her husband advised her to get the child tested. The relief of knowing her child was HIV-free motivated Sinta to commit to treatment.

Her involvement in the WhatsApp group led her to connect with HIV-related organizations. She later joined Rumah Cemara, an HIV NGO in Bandung, and actively participated in its programs, interacting with others living with HIV. Eventually, she became a community organizer at the Bandung City AIDS Control Commission (KPA). This role gave her a sense of purpose and allowed her to support others facing similar struggles.

Desti, Anita, and Rita also sought support networks such as Warga Peduli AIDS (AIDS Care Citizens). They began educating themselves about HIV transmission, emotional management, and treatment adherence. Some even shared their experiences at public awareness events at the sub-district level. By giving testimonials, these women not only provided vital information to others but also developed a greater sense of self-worth and resilience.

Through these engagements, the informants found meaning in their lived experiences. Their participation in educational programs and support groups helped them cope with their diagnosis, improve their emotional well-being, and contribute positively to their communities. Ultimately, their efforts not only strengthened their own psychosocial resilience but also fostered greater awareness and empathy for those living with HIV.

Responding Stigma, Discrimination, and the Social and Cultural Pressure

HIV is not just an individual concern but also a broader social issue. Epidemics are shaped by both biological and sociocultural factors, influenced by politics and specific cultural conditions (Lindenbaum, 1998). Economic conditions, political systems, social structures, and cultural beliefs all contribute to the spread of infectious diseases, exploiting the vulnerable areas within a society. Therefore, HIV/AIDS is not solely a medical phenomenon but also a dynamic condition influenced by cultural contexts, much like emerging trends, beliefs, and practices (Butt & Eves, 2008).

Susan Sontag conceptualizes AIDS as a metaphor, symbolizing a form of punishment for behaviors deemed deviant. This perception leads to social exclusion, with many distancing themselves due to fear of infection—a fear worsened by the absence of a complete cure.

Stigma and discrimination significantly impact the lives of individuals with HIV, shaping their social identity within communities. Stigmatization alters how they are perceived, transforming them into "sick individuals" and affecting their interactions with society (Kleinman, 2020). Though stigma is often subjective, its impact on women living with HIV is well-documented, as it negatively influences their quality of life over time (Efendi et al., 2020). Despite facing stigma, many women with HIV actively seek ways to cope. They develop strategies to gain support, protect themselves, and rebuild their self-confidence (Fauk et al., 2022, 2024).

Stigma arises from differences, prompting people to isolate and avoid those who do not conform. The fear of contracting HIV perpetuates this stigma (Davis et al., 2021). Discrimination is not limited to the general public but also occurs within healthcare settings, where medical professionals may stigmatize women with HIV (Fauk et al., 2022). The burden of social rejection often outweighs the physical symptoms of the disease, leading many to hide their HIV status from friends and family.

Rara, for instance, kept her status a secret due to her employment ties. However, some women have recently begun disclosing their condition to loved ones and social circles. Those involved in HIV advocacy work have been instrumental in educating their families and communities, helping to shift perspectives on the disease.

Liza experienced discrimination from healthcare workers. She was denied a room and left untreated for two days due to a supposed lack of availability, despite suffering from an opportunistic asthma infection. Liza found this treatment unacceptable, especially from medical professionals. Fortunately, as an HIV advocate, her colleagues noticed her absence and intervened, handling hospital administration so she could receive treatment. Liza's case aligns with previous research findings, which indicate that healthcare workers often hold negative perceptions of HIV and people living with the virus. Many medical professionals lack accurate information and mistakenly equate HIV with other conditions, misunderstanding its transmission and associated risks (Senyurek et al., 2021).

Siska had a different experience. Unlike other women who faced societal stigma, she was primarily stigmatized by her husband. He subjected her to verbal abuse, repeatedly demeaning her and suggesting she would soon die from HIV. As a former syringe drug user, Siska was often blamed and cornered despite her efforts to change her life.

Stigma from intimate partners was a common issue. Husbands who were HIV-negative often treated their wives harshly, displaying intimidation and blame. In contrast, husbands who were also HIV-positive provided emotional support and acted as reliable partners. Research suggests that creating spaces for women with HIV to share their experiences is a crucial component of their healing process, helping them recover from trauma and loss (Jess et al., 2023).

Discrimination in healthcare settings remains prevalent, with some hospitals neglecting HIV-positive women seeking treatment. Many are denied rooms or proper care under the pretext of unavailability. Social stigma against women with HIV remains persistent, making them feel permanently marginalized, particularly in environments where they are unwelcome. Professional misconduct and discriminatory attitudes in healthcare institutions disrupt patient care, creating barriers to continuity and effective referral systems. Additionally, structural factors such as social pressure, public misinformation, limited access to preventive measures, and weak policy enforcement further exacerbate these challenges (Davis et al., 2021; Kassie et al., 2023; Senyurek et al., 2021).

Discrimination stems from prejudice, which is composed of beliefs, emotions, and behavioral tendencies (Handayani, 2018). This discrimination was deeply felt by Rita, who faced mistreatment from her husband's family. Unlike her sisters-in-law, she was excluded from family interactions, and her children were also neglected. During family gatherings, Rita and her children were deliberately ignored—food was offered to other children but not to hers. Despite her good intentions, Rita often faced hostility and unwelcoming attitudes from her in-laws.

Women living with HIV must navigate these complex social challenges while adapting to their new reality. Their resilience in overcoming stigma, discrimination, and economic struggles reflects their strength in rebuilding their lives despite adversity (Subramoney, 2015).

Additionally, women with HIV often face severe social stigma from their families, communities, and even within healthcare settings. Legal assistance, advocacy, and public awareness campaigns are essential to combat discrimination and promote inclusion. Given that many women with HIV live in patriarchal societies, initiatives focused on women’s empowerment and gender equality are crucial. These programs can help women gain financial independence and strengthen their roles in both the household and society (Fauk et al., 2022).

Encouraging women's participation in decision-making processes is equally important. Women should have the right to make informed choices about their health and personal lives, as well as receive the necessary support and protection. Programs like the AIDS Care Citizens initiative also empower women to educate men on the importance of protecting their families and addressing gender-based issues. In Indonesia, patriarchal norms are deeply ingrained, making it difficult for women to voice their concerns. Encouraging discussions on gender equality within communities is essential to fostering change (Herawati, 2017).

Turning Economic Pressure into Self-Empowerment

The daily lives of women living with HIV are shaped not only by physical challenges, psychological distress from the stress of their condition, and societal pressures but also by economic struggles. Each day, they work to overcome these difficulties, often experiencing repeated failures before finding effective solutions that empower them.

Financial stability remains a significant concern, even for those with partners. Various HIV programs have aimed to economically empower women with HIV in recent years, yet as of 2024, no initiative has specifically targeted their needs. Many women living with HIV have adapted by engaging in HIV-related programs and turning these activities into sustainable careers. Some, like Rita and Desti, have ventured into entrepreneurship, leveraging their hobbies and available opportunities to build businesses or join organizations advocating for HIV-related issues.

The loss of a spouse often leaves them as the primary breadwinners, necessitating swift adaptation. Research by Fauk et al. (2022) highlights that women with HIV actively seek strategies to protect themselves and regain emotional and economic stability. They turn to medical professionals and long-term HIV survivors for guidance, helping them come to terms with their condition and manage stress.

Desti faced her husband's passing with resilience, establishing a spicy noodle business from her home. She received business support in the form of cooking equipment and startup funds, which she used to develop her enterprise. Now, she employs a worker to help with sales. In addition, she sought support from the local AIDS Control Commission (KPA) and joined a community organization, which introduced her to fellow individuals living with HIV. This support network reinforced her gratitude, as she realized her circumstances were not as dire as others'.

"I refuse to die in ignorance," Desti said. "I remember my children saying, 'If we lose our mother, who do we have? Our father is already gone.'"

Her children are Desti's greatest source of strength. Despite her condition, she is determined to provide for their academic and personal needs as a single parent. She takes pride in showing the world that, even as a woman with HIV, she can raise her children to be independent and successful.

Rara, Sinta, and Rita also find motivation in their children, striving to secure a better future for them. Beyond their families, informants like Desti, Siska, Sinta, and Anita hope to support other women with HIV. They want to create spaces for emotional expression, ensuring that those affected have access to support and guidance. If they cannot provide financial aid, they offer their time, energy, and experiences to help others accept their HIV status. These efforts prove that people living with HIV can still contribute meaningfully to society. They also challenge the prevailing narrative that equates HIV with suffering.

"I don’t like being called an AIDS sufferer," Sinta said. "Our lives are not about suffering."

Finding meaning in adversity is crucial, and community support plays a vital role in HIV prevention and care. In Anita’s neighborhood, a community-based HIV care program fosters social inclusion and provides psychosocial support. The program, facilitated by the Bandung City AIDS Control Commission, collaborates with institutions to design practical support systems for those affected by HIV (Herawati, 2019). Research indicates that people living with HIV can empower themselves and others when they receive adequate community support. However, this empowerment must be reinforced by policies that address the psychosocial challenges associated with HIV (Fauk et al., 2022).

Anita, a middle-aged woman and local neighborhood leader in Bandung, is open about her HIV status yet faces no discrimination within her community. This is largely due to widespread HIV education efforts in her area. Anita remains confident, believing that HIV is not the only illness that can be fatal. Her neighborhood, an AIDS Care Citizens community, receives support from the AIDS Control Commission and engages in programs that provide social and psychological assistance to those living with HIV.

For women with advanced HIV symptoms, palliative care is crucial to maintaining their comfort and quality of life. These services include pain management and emotional support. Peer support groups also play a vital role, offering spaces where women with HIV can share their experiences and support one another, reducing feelings of isolation and fostering solidarity.

The economic difficulties that come with HIV were particularly evident in Rara’s experience. Following her divorce, she was forced to become a commercial sex worker to support her two children. However, she remained in the profession for only two years before leaving due to the emotional toll of catering to clients' demands and the pressures imposed by her employer. She transitioned into a career as a therapist, accepting a lower income in exchange for greater peace of mind and the ability to adhere to her HIV treatment without external interference.

Economic independence is another critical need. Many women with HIV struggle financially, especially when they are the sole providers for their families. Training programs in entrepreneurship, financial management, and vocational skills can help them achieve economic stability and reduce their dependence on social support systems.

Desti faced economic discrimination after her husband’s death due to AIDS. Her late husband’s family treated her as an outsider despite her continued residence in their home. Her sister-in-law, in particular, wanted to claim ownership of the house. Desti was allowed to stay temporarily, but only under the condition that she would move out once her eldest child became financially independent.

Ultimately, the fight against HIV stigma and discrimination requires a holistic approach—one that combines economic empowerment, legal protection, healthcare access, and community support. With the right policies and initiatives, women living with HIV can not only survive but thrive, proving that their condition does not define their potential or limit their contributions to society.

CONCLUSION

The everyday lives of women living with HIV in Bandung City present a complex interplay of health, psychological, socio-cultural, and economic challenges. These women face ongoing health complications requiring consistent care, psychological burdens from self-doubt and fear, and pervasive social stigma rooted in cultural norms. Despite these obstacles, their resilience stands as a testament to human strength and adaptability. Through support networks, community engagement, and self-empowerment strategies, many of these women have managed not only to survive but also to thrive. They challenge societal misconceptions, advocate for their rights, and inspire others by demonstrating the potential for personal growth and empowerment amidst adversity. This highlights the critical need for inclusive healthcare, mental health support, and societal efforts to dismantle stigma, creating an environment where women with HIV can lead fulfilling lives free from discrimination.

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