Practicum Report

Barriers and Facilitators to Long-Term Engagement in HIV Treatment Among Women Diagnosed During Pregnancy in Kazakhstan

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Introduction

An analysis of HIV in Central Asia shows the virus's continued prevalence in Kazakhstan. The data provided by the Kazakh Scientific Center of Dermatology and Infectious Diseases (2024) shows that there are approximately 43,000 individuals living with HIV in Kazakhstan. Furthermore, the percentage of people living with HIV and adhering to antiretroviral therapy (ART) in Kazakhstan in 2024 has reached 74 percent (World Bank Group, 2024). Notably, the country is also witnessing an increase in the number of HIV-positive pregnant women. Historically, the literature on HIV tended to point to an association between HIV transmission and injecting drug use, even though heterosexual transmission is also considered the leading route of HIV transmission among women (World Health Organization, 2021).

Given the increase in the number of HIV-positive pregnant women in Kazakhstan, programs for the prevention of mother-to-child transmission of HIV (PMTCT) constitute a critically important component of national efforts to combat HIV. These programs encompass antenatal care, voluntary counseling and testing, and the provision of antiretroviral therapy (ART) to pregnant women (World Health Organization, 2013). According to data from CEIC Data (2016), ART coverage among pregnant women living with HIV in Kazakhstan reached

87%, demonstrating substantial progress in expanding access to treatment within the framework of maternal health services.

Mother-to-child transmission (MTCT) of HIV remains the primary source of HIV infection among children (World Health Organization, 2021). Studies on vertical transmission – the transmission of HIV from mother to child during pregnancy, childbirth, or breastfeeding (World Health Organization, 2021) – show that this phenomenon occurs in 16% to 40% of cases of pregnancy among women living with HIV in the absence of women's adherence to ART, with breastfeeding posing an additional risk of at least 10% (World Health Organization, 2021). However, with timely and continuous treatment – specifically, adherence to ART that suppresses viral load, avoidance of breastfeeding, and cesarean section, if needed – the risk of transmission can be reduced to extremely low levels: 0–2% (World Health Organization, 2021). In Kazakhstan, the care and monitoring of pregnant women living with HIV are provided through a network of antenatal clinics and specialized AIDS centers, which ensure access to ART for pregnant women living with HIV starting as early as the 14th week of pregnancy (World Health Organization, 2013).

Specialized HIV-focused clinics provide ART programs for pregnant women living with HIV in Kazakhstan. These programs include routine HIV testing in maternity clinics and free access to ART, aimed at minimizing mother-to-child transmission (World Health Organization, 2013). In addition, regional training centers implement programs based on the WHO/CDC PMTCT Generic Training Package, adapted by the American International Health Alliance (AIHA) to align with Kazakhstan's national policies, country-specific epidemiological conditions, and established protocols for HIV prevention, care, and treatment (Sandgren et al., 2008). Training initiatives in Kazakhstan emphasize specialized curricula on PMTCT for

obstetricians and gynecologists, focusing on HIV transmission, prevention strategies, and the importance of voluntary counseling and testing, particularly for pregnant women and other women of reproductive age (Sandgren et al., 2008). These efforts aim to reduce late HIV diagnosis during pregnancy and prevent new pediatric HIV infections (Sandgren et al., 2008).

Despite the institutional advancements for the prevention and combatting of HIV, there are gaps in levels of knowledge about HIV and ART engagement among the Kazakhstani population. For example, findings from a study by Sandgren et al. (2008) conducted in Semey, Kazakhstan, indicate that women living with HIV possess limited knowledge about mother-to-child HIV transmission and its prevention. While 68% of respondents were aware that HIV can be transmitted from mother to child during pregnancy or delivery, only 46% recognized breastfeeding as a route of transmission (Sandgren et al., 2008). Since PMTCT is an important part of Kazakhstan's HIV response program, strengthening awareness of HIV transmission pathways and prevention strategies remains crucial.

HIV diagnosis during pregnancy represents a critical entry point into HIV care, but it only marks the beginning of a longer treatment trajectory (World Health Organization, 2013). This report raises a question of how structural, interpersonal, and individual factors shape the continuity of ART adherence among women living with HIV in PMTCT programs in Kazakhstan, particularly during the postpartum period. The report aims to examine the factors contributing to the decline or continuity of ART adherence in the postpartum period, with the major emphasis on the notion that adherence to ART should not be understood as being solely shaped by individual behavior, but also by social determinants of health.

Methods and Research Practicum Experience

This research practicum report is based on the analysis of qualitative data from a research project "The influence of gender and social norms on women's engagement in HIV services in Kazakhstan" (PI: Elizabeth King). During my practicum through the Center for Global Health Equity at the University of Michigan, I worked on data analysis of qualitative interviews conducted with women diagnosed with HIV during their most recent pregnancy in Almaty. The dataset consists of 15 in-depth, semi-structured interviews conducted between October and December 2024 with women living with HIV who were diagnosed during their most recent pregnancy in Almaty. Interviews were conducted in Russian and Kazakh by Professor Elizabeth J. King and partners from Kazakh National Medical University and the Almaty City AIDS Center.

Interview transcripts were reviewed in their original languages and coded using the qualitative data analysis software Dedoose. As a research intern, I was involved in the data coding process, conducted through a team-based approach to enhance validity and minimize individual bias. The data analysis employed a qualitative research design using thematic analysis to identify patterns related to postpartum ART adherence, including barriers and facilitators for treatment adherence among women living with HIV who were diagnosed during their most recent pregnancy. Themes for the qualitative data were developed with a focus on structural, interpersonal, and individual-level determinants of treatment engagement.

An important aspect of the practicum before starting the research activities was the completion of PEERRS training to ensure meeting ethical standards for human subjects research. The analysis in this report reflects the interpretation of the data, informed by a relevant literature review, with the goal of understanding social, cultural, and structural factors shaping women's adherence to antiretroviral therapy after childbirth in Almaty, Kazakhstan.

PMTCT Policy Framework

Evolution of PMTCT Strategies and the Transition to Lifelong ART

Pregnancy often represents a critical entry point into HIV care, as routine antenatal screening enables testing and identification of HIV among pregnant women and initiates the process of treatment (World Health Organization, 2013). Earlier decades of the implementation of Prevention of Mother-to-Child Transmission (PMTCT) strategies primarily relied on short-term antiretroviral protocols during pregnancy and delivery, aimed at reducing vertical transmission. However, a major shift occurred with the World Health Organization's 2010 recommendation of lifelong antiretroviral therapy (ART) for eligible individuals, followed by the introduction of Option B+ in 2013, which extended lifelong ART to all pregnant and breastfeeding women living with HIV (World Health Organization, 2013). This transition marked a fundamental change in the HIV treatment paradigm – from temporary prophylaxis of mother-to-child transmission of HIV to sustained, long-term treatment for women living with HIV – thereby placing continuity of care at the center of PMTCT programs.

The World Health Organization has proposed different PMTCT strategies:

Option A: Administration of antepartum zidovudine (AZT) during pregnancy, followed by single-dose nevirapine (NVP) during labor and a combination of zidovudine (AZT) and lamivudine (3TC) for 7 days postpartum, along with daily infant nevirapine throughout breastfeeding. This option is for women not yet eligible for lifelong ART.

Option B: Administration of triple-drug antiretroviral prophylaxis starting from 14 weeks of gestation and continued throughout pregnancy and breastfeeding.

The choice between these options depends on CD4 cell count testing to assess women's immune system status and determine their eligibility for lifelong triple-drug ART.

The HIV Care Continuum Framework

In the article *"A Paradigm Shift: Focus on the HIV Care Continuum,"* Margaret L. McNairy and Wafaa M. El-Sadr (2012) discuss the HIV care continuum framework, also known as the cascade framework. The HIV care continuum framework conceptualizes the sequential stages of HIV care – from diagnosis to viral suppression – while enabling the analysis and identification of points at which individuals disengage from care or fail to adhere to treatment (McNairy & El-Sadr, 2012).

Stage 1: HIV testing, linkage to care following diagnosis, and enrollment in an HIV clinic to initiate care.

Stage 2: Determination of antiretroviral therapy (ART) eligibility through counseling, as well as ongoing clinical and laboratory monitoring of disease progression.

Stage 3: Initiation of ART in accordance with prevailing guidelines.

Stage 4: Adherence to medication in order to achieve viral suppression. Once ART is initiated, continuous monitoring and counseling are essential to achieve and maintain viral suppression.

Attrition Across the Continuum and Its Consequences

Maintaining daily adherence to HIV treatment once it is initiated, as well as attending regular follow-up appointments with healthcare providers, is critically important for people living with HIV. Research by Gardner et al. (2011) conducted in the United States demonstrated that if each step of the HIV care continuum achieves approximately 90% retention, the proportion of viral suppression among people living with HIV could increase from 19% to 66%.

To achieve the target of reducing mother-to-child transmission of HIV to below 5%, pregnant women living with HIV must successfully progress through each stage of the continuum within prevention of mother-to-child transmission (PMTCT) programs, with overall program effectiveness reaching 90–95%. According to the World Health Organization's *PMTCT Strategic Vision Report* (2013), such programs can reduce mother-to-child transmission rates to below 5% while significantly decreasing morbidity and mortality among both mothers and children.

Completing the entire treatment process across all stages is critical to achieving optimal health outcomes, including viral load suppression for the individual, reduced mother-to-child transmission, and decreased HIV-related mortality. Furthermore, viral suppression among people living with HIV (PLWH) has been shown to reduce the risk of HIV transmission to sexual partners (World Health Organization, 2013). Despite strong evidence of the effectiveness of HIV treatment and the scale-up of treatment delivery, maintaining continuous engagement across all stages of the care continuum, including postpartum period, remains a major challenge.

Implications for Adherence in PMTCT Programs

The analysis of ART adherence among pregnant women living with HIV highlights the importance of retaining treatment across all stages of care, as well as measuring ART coverage in the long run. Given the existence of weak linkages between HIV testing and subsequent treatment, with significant drop-offs occurring between diagnosis, treatment initiation, and adherence across different settings, it is crucial to explain why women disengage from treatment, particularly after childbirth, by examining the structural determinants of sustained engagement in care.

Existing evidence suggests that the loss of patients, women living with HIV, along the HIV care continuum is not uniform, but is concentrated at specific points, where structural

constraints, social dynamics, and psychological factors intersect. Analysis of the ART adherence continuum shows that pregnant women experience loss to follow-up in treatment between specific milestones, such as the stage starting from HIV testing to ART initiation (Ferguson et al. 2012) and from ART initiation between 6 months and 3 years of treatment (Kaplan et al. 2008). Research by Ferguson et al. (2012) and Kaplan et al. (2008) demonstrates that focusing on the process of loss to follow-up among pregnant women, without a detailed analysis of the early stages of HIV care at which this phenomenon is most noticeable, reveals a lack of analysis of important trends of PMTCT. Pregnant women's adherence to healthcare services and HIV treatment may be motivated or constrained by different factors than those of non-pregnant adults and women who have already given birth. Reasons why women do not initiate treatment and fail to follow up differ among patient categories, thus requiring a more differentiated analytical approach for pregnant women and those who recently gave birth. Understanding these trends could be used to inform strategies regarding what types of targeted clinical or policy actions need to be implemented to keep women engaged in care, as well as explore how the phenomenon of loss to follow-up is shaped by the post-childbirth period and associated factors.

The Right to Health and the Social Determinants Framework: Implications for PMTCT in Kazakhstan

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WHO Constitution (1946): "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being."

The immediate treatment of existing diseases, such as HIV, is a priority in the healthcare sector. However, alongside the necessity of proper planning and organization of HIV treatment, combating the disease also requires broad socioeconomic development policies to reduce health inequalities. This report posits the importance of situating the study of HIV – specifically,

adherence to treatment regimens among pregnant women living with HIV in Kazakhstan – within the Social Determinants of Health framework as articulated by the World Health Organization. It is critical to identify and conceptualize these underlying social determinants of health that influence the treatment process and its short- and long-term outcomes. This framework is grounded in the premise that health inequities are driven by structural factors within the economic, political, and institutional context as well as related material conditions such as transportation accessibility. This analytical work highlights the importance of identifying social barriers that pregnant women living with HIV and those who have recently given birth face at every stage of treatment and of rethinking the services being implemented to increase engagement and adherence to treatment. Implemented measures aimed at overcoming barriers faced by these individuals should incorporate an evaluation of program effectiveness.

Determinants of Treatment Discontinuity in the HIV Care Continuum: The Postpartum Gap

As mentioned earlier, analyses of adherence to ART for those living with HIV also show a trend that women are more likely to interrupt ART after childbirth than during pregnancy (Myer et al., 2017). The studies by Tenthani et al. (2014) and Clouse et al. (2013), which focused on the context of ART adherence under Option B+ treatment, showed that postpartum treatment retention declines significantly within the first year after childbirth. The postpartum period, as a structurally fragile window exposing the decline in HIV retention in maternal healthcare, is characterized by a decline in clinical monitoring in general, despite elevated maternal morbidity risks remaining present (Filippi et al., 2016). It is important to consider that, for women living with HIV who have recently given birth, this decline in clinical monitoring also goes hand in hand with the need for infant care, the period of physical recovery, including recovery from

C-sections. Furthermore, the postpartum recovery can be complicated by economic difficulties, psychological adjustment, logistical burdens, mobility constraints, and healthcare system fragmentation.

The reason that loss to follow-up care before childbirth delivery is lower than after delivery may be attributed to the fact that women attend medical facilities during the antenatal period for reasons other than adherence to HIV treatment. Although there are difficulties in establishing continuity of HIV treatment between antenatal care at a clinic and delivery in a hospital, the fact that antenatal care and associated procedures take place in a single medical facility may motivate pregnant women to continue HIV treatment. In fact, HIV treatment is typically integrated into antenatal care for pregnant women – antiretroviral therapy (ART) is assessed and prescribed during these antenatal care. Furthermore, information about the pregnant woman's condition and her unique needs as an HIV-positive woman is stored in a single medical record for each patient. Interestingly, Fox and Rosen (2015) present that postpartum ART disengagement tends to occur in health systems where HIV services are vertically organized and insufficiently integrated with maternal and primary healthcare services. Therefore, the analysis of the impact of vertically organized healthcare services on ART adherence among women after childbirth prompts the need for public health experts to better understand women's specific reasons for discontinuing HIV treatment as well understand their motivations for returning to primary healthcare (PHC) after childbirth.

Framework: HIV diagnosis, treatment adherence, and postpartum engagement in care

Structural / institutional level	**Interpersonal / social level**	**Individual / psychological level**
- Multi-institutional testing and referral pathways	- Disclosure concerns - Fear of stigma	- Shock, denial, fear, anger, depression

- AIDS Center as key institution - Provider support, reminders, flexibility - Distance, transport cost, work constraints	- Peer support groups and counselors	- Routine and health beliefs - Experience of side effects

Outcome: Continuity or interruption of ART after childbirth
*Maternal concern for the child as the mediating factor between diagnosis, emotional response, and eventual adherence.

Findings During the Research Project

Gendered pathways to HIV diagnosis during pregnancy

Diagnosis during pregnancy

Most respondents shared that they learned about their HIV-positive status during pregnancy. The diagnosis typically emerged as part of routine prenatal screening when a woman registered for antenatal care, submitted standard laboratory tests, and received results indicating HIV positivity. For many, this occurred during the first or second trimester (around 12–13 weeks), though some learned much later, in the third trimester or even during childbirth. The timing of pregnancy often transformed it into a "moment of truth," revealing hidden infections previously undetected in earlier pregnancies. Several women mentioned that during previous pregnancies, they had negative HIV results, which intensified their confusion and disbelief when the new diagnosis appeared.

> Interview 5: "In 2022, I learned of my diagnosis while undergoing HIV testing during my pregnancy, at 12 to 13 weeks' gestation. This was my fifth pregnancy and my fifth child. During the screenings for my first four pregnancies, my test results were clear. It was during this pregnancy that I received the diagnosis."

Husband's HIV diagnosis during wife's pregnancy

Interviews indicated that HIV testing during pregnancy frequently triggered family-wide screening. Once women received a positive HIV result, husbands were also referred for testing,

often for the first time. In many cases, men discovered their status only because their wives were tested during pregnancy. This dynamic reveals a gendered pathway to diagnosis, where women's engagement with maternal healthcare inadvertently leads to detection within the couple. Some couples attended the AIDS Center together; others faced tensions or blame as the diagnosis became known.

> Interview 9: "So, when you found out that you had been infected, did your husband find out he was infected at that same time? – Yes. In other words, he hadn't been registered here prior to that? – Yes." "If I hadn't taken the test, he wouldn't have known about his status at all."

Reproductive decision-making and institutional influence

Pregnancy, HIV, and abortion

Interviews showed that pregnancy served not only as a testing point but also as a turning point in decision-making regarding HIV treatment and pregnancy continuation. Upon learning their diagnosis, many women faced difficult ethical questions about whether to continue the pregnancy or consider abortion. Some women reported being offered termination by healthcare providers, citing risks of vertical transmission or risks to the child's health.

Interview 3: "They asked me... 'Are you going to have an abortion?' I just looked at them and said, 'You have the abortion yourselves.' I was angry. Because this child was planned... I was supposed to give birth to a boy; I wanted to give birth... You see, I always plan my children... All my children were planned."

Interview 5: "At first, they suggested I have an abortion, telling me the child would be sick. But I refused and said I would give birth – and so I did, via C-section... Allah gave me this child. I said, 'Let's just wait and see what happens.'"

Organization of HIV testing and referral systems

Bureaucratic and multi-institutional HIV testing

Women received their HIV diagnosis in various medical settings. In the AIDS Center, which was the most common site, women were referred there from the Women's Consultation after routine testing, called by phone, invited for a visit, or even visited at home by health

workers, and disclosure in this setting typically included counseling and a detailed explanation. In the Maternity Hospital, the diagnosis was sometimes delivered during labor or immediately after birth, often in chaotic and emotionally overwhelming circumstances without prior preparation. In the Polyclinic or Women's Consultation, women might receive a phone call or be invited to a private office following routine testing, where results were shared during an appointment or through a referral to the AIDS Center.

> Interview 5: "At 11 or 12 weeks, I underwent HIV testing at the antenatal clinic... at that time, the doctor informed me that there was something wrong with my test results, and I was referred to the AIDS Center."

Institutional actors in diagnosis disclosure

Who disclosed the diagnosis

Interviews revealed that HIV status disclosure was carried out by a range of professionals, reflecting the institutional hierarchy and structure of the healthcare system. Findings indicate cases when nurses delivered results in maternity wards or during routine visits, sometimes doing so abruptly and without prior preparation. Gynecologists commonly disclosed the diagnosis in women's consultations, providing the initial information and referring pregnant women to the AIDS Center for further management. In some cases, disclosure took place before a medical council in the AIDS Center, where a group of specialists, including the gynecologist, department head, and nurses, jointly informed women of their status. Several participants recalled situations where multiple specialists were present simultaneously, creating a more formal but sometimes overwhelming disclosure environment.

> Interview 10: "When I arrived in active labor... a nurse came rushing in and said: 'You know, she tested positive for HIV.' I was in shock."

> Interview 9: "I was informed at the AIDS center when I went in for my appointment; there were several doctors there, and they explained everything and told me not to worry."

Modes and conditions of diagnosis disclosure

Format of disclosure

Interviews show that different communication styles shaped women's experiences of receiving their HIV diagnosis. The most common format was oral disclosure, delivered in person by a medical professional. In some cases, this process was accompanied by an immediate explanation of what HIV is and the next steps for treatment and care, helping women begin to process the information. In more formal settings, disclosure included showing the official laboratory test results, providing visible confirmation of the diagnosis. However, in other instances, women experienced emotionally unprepared disclosure, when, as mentioned previously, a nurse suddenly "ran in" and announced the result unexpectedly, often during childbirth or other stressful moments, leaving the woman shocked and confuse

> Interview 15: "The doctor said the result was positive and immediately referred me to the AIDS center, explaining that I needed to have my blood tested again."

> Interview 13: "Representatives from the AIDS Center came, explained what HIV is, and clarified how to undergo treatment and medical monitoring."

Timing of disclosure

The timing of diagnosis varied across interviews and shaped both the emotional response and the medical trajectory. For many women, the diagnosis occurred during pregnancy, typically following routine antenatal tests, and women experienced these moments as moments of surprise, confusion, and disbelief. Others first learned their status during labor, when disclosure happened amid contractions and intense physical pain, leaving no opportunity for psychological preparation. Some women were informed immediately after delivery, as part of postnatal testing, receiving the news in the emotionally charged period following childbirth.

> Interview 15: “I received a call from the clinic after my lab tests and was told to come in immediately. I was registered there for my pregnancy care... They told me I had tested positive for HIV. I didn't believe it; I thought it was a mistake.”
>
> Interview 14: “It wasn't until I was already at the maternity hospital – when I was about to give birth to my son... My contractions had already started... that they informed me of my status.”
>
> Interview 11: “After I gave birth, they told me that my test result was positive. I was in shock; I didn't understand what it meant.”

Procedures of diagnostic confirmation and entry into care

Confirmation of diagnosis

Most interviewed women went through multiple steps of diagnosis confirmation before fully accepting their HIV status, reflecting both medical procedure and emotional processing. Many either requested or were offered repeated blood tests to confirm the initial result, seeking reassurance and certainty. The official confirmation typically took place at the AIDS Center, where the diagnosis was verified and formally recorded. In some cases, women were additionally informed that they were in the asymptomatic stage, which helped to alleviate fear and provided reassurance that their health was currently stable and manageable under medical supervision.

> Interview 15: “She said, ‘Let’s retake the test – just in case it’s a mistake.’ They referred me to the AIDS Center for confirmation.”
>
> Interview 9: “They referred me to the AIDS Center; I gave a blood sample again there, and they provided a definitive confirmation.”

Financial, geographic, and time-related barriers to care

Logistics and distance

Some women also mentioned that commuting to the AIDS Center for regular blood tests, prescriptions, and to receive ART medication presented a barrier to adherence. For others, the financial cost of commuting to the AIDS Center was a burden:

Interview 7: “When I had financial difficulties, I couldn’t come. It’s not that I didn’t want to – I do want to. I know I need it, and I always come for the medication. But it’s expensive for me. I live very far away. Coming here... I spend a lot of time and money.”

When asked about any obstacles to visiting the AIDS Center and getting medication after giving birth, one woman responded that the AIDS Center workers actually came to her house. When asked why she did not want to go there herself, she explained:

Interview 9: “It's difficult when you have a small child. At first, I came regularly, then the child got older. But then I had a second one a year and a half later, and after that, I just didn’t have time for the AIDS center at all.”

Stigma, disclosure, and social navigation of HIV treatment

Disclosure and HIV treatment

For some women, adherence to HIV treatment was closely linked to concerns about disclosing their HIV status. Their commitment to taking medication regularly was influenced by the need to conceal their condition from others. Many women used to hide their ART bottles, putting the pills in handbags or transferring them into other containers to conceal them from acquaintances, and might sometimes forget to bring their pillbox or forget to take the medication after planning to do so discreetly. In particular, many tried to avoid taking pills in front of relatives or acquaintances to prevent questions about the medication’s purpose.

Emotional responses and challenges of diagnosis acceptance

Denial of diagnosis and lack of information

Based on the interviewees’ responses, the ultimate decision to adhere to or abstain from treatment may be linked to psychological challenges in accepting the diagnosis. Almost all participants described the moment of diagnosis as a profound shock. Many could not initially comprehend or accept the result, expressing disbelief that such a thing could happen to them. They questioned the validity of the test, insisting that there must have been a mistake. For some, especially those diagnosed unexpectedly during childbirth, the news came at a moment of physical and emotional vulnerability, heightening the sense of confusion. Women who

considered themselves faithful wives often felt that infection was incompatible with their self-image, leading to denial.

Once reality began to set in, fear quickly surfaced as the dominant emotion. This fear was twofold: fear for oneself and, more strongly, fear for the unborn or newborn child. Many women worried that their baby might be born with HIV, that they might inadvertently transmit the virus, or that the child would face stigma or hardship. Some expressed existential fears of illness, death, and social rejection. The diagnosis also provoked intense anxiety about how family, community, and medical staff might treat them if their status became known. The uncertainty surrounding their future and their child's well-being amplified this fear.

Anger emerged as a powerful reaction, especially toward male partners. Many women felt betrayed upon discovering that their husbands were the source of infection, particularly when it became clear that the men had known their status and concealed it. Feelings of resentment were intertwined with moral disappointment, as women reflected on the breach of marital trust and responsibility. In some cases, anger also turned inward, manifesting as guilt or self-blame, though others reframed the experience as something beyond personal control.

Results also showed a lack of information – about what HIV is, the repercussions of living with it, how it is diagnosed, and how it manifests – among respondents which can all contribute to the difficulty of coming to terms with the diagnosis.

One woman noted that she did her research on what HIV is and understood that non-adherence to treatment can lead to a weakening of the immune system. However, she still admitted:

> Interview 2: "Many people are afraid or don't accept their status, and because of that, they don't take the medication. To be honest, I still haven't fully accepted this status within myself. I still try to convince myself that maybe it's all just a mistake."

Meanwhile, other women's decisions to abstain from treatment are shaped by a lack of information and understanding of what HIV is and how severe its effects can be. Some believe that HIV medication is unnecessary, that it might worsen their health, or that their condition is not serious at all. As one respondent explained:

> Interview 5: "It depends on the woman herself, on how she thinks. I also had moments when I didn't want to take the pills. I thought, 'It doesn't matter anyway…' I didn't even know it was a deadly disease."

Everyday practices of ART adherence and non-adherence

Unintentional non-adherence

In analysing barriers to ART after birth, a situation was identified in which women were committed to treatment, regularly attended check-ups for viral load testing, and received medication from the relevant healthcare institutions, but may still occasionally forget to take their pills – even though they did not perceive the very act of taking them as more difficult than taking regular vitamins.

When prescribed to take pills daily at night, one woman mentioned that she occasionally forgot to take them when putting her children to sleep and unintentionally fell asleep with them. Another respondent, who worked night shifts, shared that she forgot to take her medication about once every six months or once a year due to work overload. However, she mentioned that she tried to make up for it later that night or the following morning in order to maintain a consistent intake schedule.

Another woman acknowledged that it is an individual responsibility to ensure timely pill-taking, including setting reminders. Nonetheless, she explained that abstaining from disclosing ART use to others – such as relatives – could exacerbate the risk of forgetting to take medication on time. As she noted:

> Interview 3: “The only real barrier is that you can constantly forget. It's a personal matter – whether you set a reminder or not. But on the other hand, when you live in a household where people don’t know [about your status], it becomes harder. You have to hide the medication so no one sees it. And if you hide it, it’s not in plain sight – so you’ll definitely forget.”

Physical side effects

The interviewed women mentioned experiencing physical side effects from taking ART, including an increased heart rate, nausea, dizziness, drowsiness, fainting, high temperature, and persistent fatigue, which pose distinct barriers to adherence.

Interestingly, some respondents noted that certain ART pill brands caused strong physical side effects. Some women changed their prescribed medication brand and reported that the side effects stopped after the switch. Furthermore, one respondent mentioned switching to a newly prescribed ART brand, and she was still in the process of assessing the presence or absence of potential side effects.

> Interview 3: “I didn’t take the therapy for almost a month. Now I’ve picked up the medication – well, I’ll take it and see how things go. Because with the previous medication they prescribed, I felt really unwell: drowsiness, weakness. But why would I need drowsiness and weakness if I need to be on my feet? I don’t need that, so I didn’t take them.”

Postpartum ART adherence as everyday health management

AIDS Center as the core site of care

Testing is a crucial component of adherence to HIV treatment. Women reported giving blood for CD4 counts and viral load tests as part of their adherence to ART, typically once every three or six months or once a year. Tests can be done at the antenatal clinic where a woman is registered or the AIDS Center; still, many participants expressed a preference for being tested at the AIDS Center, stating that they feel more comfortable and confident receiving care there.

Some participants noted that staff from the AIDS Center proactively called them to remind them to come in to collect their medication. In other cases, the women themselves

contacted the center when they ran out of pills and needed to schedule a visit. Many women reported attending the facility primarily to collect their ART medications, typically every three months. Once the prescribed three-month supply ran out, they were required by the AIDS Center to return for the next batch of medications. Despite also being registered at local clinics and undergoing testing there, as mentioned earlier, participants expressed a preference for the AIDS Center for medication management.

> Interview 1: "As soon as the pills run out, I come in [at the AIDS center]. They give several at once – it lasts for about three months."
> Interview 3: "It's better here [at the AIDS center] – you get tested on time and take your medications on time."

Combining medications and managing multiple conditions

Some participants reported combining their HIV medication with other treatments for common or chronic conditions, reflecting the reality of managing multiple health issues. For example, women mentioned taking ART alongside medications such as Citramon for colds, Omez for gastritis, or treatment for hepatitis.

One respondent, when asked about her experience with HIV medication, said:

> Interview 7: "It's fine. I take it like regular vitamins, every day at the same time. I used to take it at ten in the morning, but now I take it at nine because at eleven I take additional medicine to cleanse my kidneys and gallbladder. I read in the instructions that these medicines shouldn't be taken together, so I keep a two-hour interval."

This excerpt highlights the importance of integrated medical guidance to ensure safe medication use, which is crucial for adherence to HIV treatment.

Changing medication and treatment adjustments

Interviews revealed that women sometimes experience changes in their HIV medication during the course of treatment.

> For example, one respondent shared:
> Interview 1: "At first, I was given different pills. They caused headaches, so they were later changed. The other ones are fine."

Interviewed women typically reported taking ART pills either once or twice a day, depending on the prescribed brand. There were also adjustments to the medication regimen when switched to a new ART brand.

> Interview 7: "Before, I used to take two pills – one at night and one during the day – while pregnant. But now, I take only one pill. I'm not sure how these pills will work."

Facilitators of ART adherence after birth

Healthcare provider support

The presence of supportive healthcare providers is indicated as a key facilitator of ART adherence. Women described staff at the AIDS Center as responsive, encouraging, and actively engaged in their care. Interviewees indicated that providers not only answered questions and offered guidance but also emphasized the importance of regular visits and continued treatment, reinforcing a sense of shared responsibility for the patient's health. This supportive and proactive approach helped build women's trust in the healthcare system and encouraged women to remain engaged in care and adhere to treatment.

Interviews emphasized the importance of continuous care, as HIV testing rarely ends with a single blood draw. Women recounted undergoing multiple confirmatory analyses in different settings, including maternity clinics, polyclinics, the AIDS Center, and sometimes at home. Follow-up testing became part of regular medical supervision, with frequency increasing as the pregnancy progressed – from every 2–3 months initially to every 2 weeks before childbirth. Women indicated that after delivery, HIV monitoring continued, typically every six months or annually if health indicators remained stable. Infants were also tested several times after birth, reinforcing the intensive medical oversight surrounding HIV-positive pregnancies.

Women also discussed that for those who moved to another city, there were AIDS Centers there as well, and women could receive their medication. They described that the HIV center was always calling, writing, and checking on them – providers told them when to get

tested, shared updates, and informed women when to come in, whether by week or month. Even during lunch breaks, they could take their tests – if they asked, staff accommodated testing appointments.

Psychological support and counseling

Women explained that coming to terms with the diagnosis was a long process, and they received extensive support, especially from psychologists and other workers at the AIDS Center. Women also highlighted the importance of peer support groups for people living with HIV, noting that some AIDS Centers host NGO offices where peer counselors provide guidance and support. They emphasized that having structured support groups – similar to those for individuals with alcohol or drug dependence – could be especially beneficial. While some women described that they were part of general messaging groups, such as WhatsApp chats, they noted that these spaces did not always feel safe for sharing personal experiences. In contrast, dedicated support groups within a clinical or community setting could create a more comfortable environment for open communication, allowing women to share experiences, learn how others have coped with diagnosis, and receive support from individuals facing similar challenges.

Support of partners and relatives

Some women described partners or relatives support as an important facilitator of ART adherence. Some respondents' husbands actively encouraged them to take their medication and prioritize their health, often framing adherence as essential for raising their children together. In several cases, adherence became a shared responsibility within the relationship, with partners reminding each other to take medication, checking in regularly, and providing consistent emotional and practical support. This mutual care and accountability helped reinforce routine adherence and strengthen commitment to treatment. Still, it is important to note that support of a

partner might be absent in some cases due to the imposed blame and shame onto a woman due to her diagnosis, whether the virus was transmitted by a partner or not.

Conclusion & Recommendations

This report, based on the findings of a research project on engagement in HIV treatment among women diagnosed during pregnancy in Kazakhstan, underscores the critical importance of strengthening linkages between HIV testing, treatment initiation, and the maintenance of sustained treatment adherence among women during the perinatal (antenatal and postnatal) period. Indeed, the HIV care continuum remains especially fragile when pregnant women receive notification of their HIV status unexpectedly during pregnancy, at the time of labor, or immediately after delivery, making them particularly susceptible to emotional distress. Significant patient attrition occurs at various stages, spanning from diagnosis to treatment initiation and subsequent adherence, but a substantial proportion of patient losses occurs specifically during the postnatal period and can be influenced by a lack of institutional, partner, and family support, HIV-related stigma, and economic constraints. The report indicates that public health professionals should analyze both the factors motivating pregnant women to return to primary care facilities and HIV treatment services after childbirth, and the reasons for women's discontinuing antiretroviral therapy – particularly in the context of declining treatment adherence during the postnatal period.

Significant patient attrition during the perinatal period underscores the need to establish more coordinated, patient-centered systems that ensure continuity of care – from the moment of diagnosis through to long-term engagement in the treatment process. Measures aimed at ensuring the continuity of antiretroviral therapy (ART) among pregnant women are recommended to be

extended beyond a strictly biomedical approach. This report specifically highlights the urgent need for healthcare professionals in Kazakhstan to identify, understand, and address the underlying social determinants of health. This is crucial both for accurately identifying the factors influencing HIV treatment engagement among pregnant women and for implementing interventions that account for both short- and long-term health outcomes. The factors influencing HIV treatment engagement among pregnant women are not merely individual in nature – stemming from the patient herself – but are also structural, dependent on the prevailing institutional context as well as on material conditions. These factors are closely interconnected, forming multi-layered barriers that pregnant women living with HIV regularly encounter. Consequently, every stage of HIV care delivery requires a re-evaluation of existing services with the aim of enhancing patient engagement. The report emphasizes that measures designed to overcome these barriers at each stage, particularly during the postpartum period, must incorporate robust monitoring mechanisms, systematic program evaluations, and qualified specialists' recommendations for future policy development.

The postpartum period represents a critical moment of vulnerability, and declining treatment adherence following childbirth underscores the urgent need to develop and implement targeted strategies for patient retention. This report highlights that the integration of HIV prevention and treatment services with maternal health and primary healthcare systems can mitigate the process of patients' loss to follow-up. A more coordinated model of care delivery would contribute to reducing barriers to access, enhancing patient satisfaction with the quality of services, and sustaining long-term treatment adherence. Such a model includes strengthening follow-up systems, proactive patient tracking, and appointment reminders, ensuring continuity between antenatal and postnatal care. Furthermore, this report suggests the integration of flexible

service delivery, including extended medication dispensing and community-based care options, as well as formal referral pathways between antenatal clinics, maternity hospitals, and AIDS Centers.

This report also shows the need to devote particular attention to the institutionalization of psychosocial support as a key component of comprehensive HIV care, including counseling services, peer support groups, and stigma-sensitive care practices to address emotional distress, diagnosis acceptance, and HIV-related stigma. Psychological distress, stigma, and difficulties in accepting the diagnosis exert a significant influence on patient behavior. The findings confirm the crucial role of healthcare professionals in ensuring adherence to treatment. Active communication, reminder systems, flexibility in service delivery, as well as continuous monitoring and counseling – all these factors contribute to achieving and maintaining ART adherence among women. Furthermore, when implementing relevant interventions, it is essential to consider the role of interpersonal support – including that provided by partners and family members – while strictly adhering to principles of confidentiality and exercising sensitivity regarding issues related to stigma. Given favorable conditions, a supportive social environment can play a vital role in strengthening treatment adherence and improving health outcomes.

Enhancing long-term adherence to antiretroviral therapy requires broader efforts to mitigate structural inequalities through socioeconomic policies, as addressing disparities in access to healthcare, economic resources, and social protection is fundamental to improving the effectiveness of HIV treatment. As demonstrated by analyzing the findings of the research project, led by Professor Elizabeth J. King, structural factors directly impact women's ability to access treatment and maintain its continuity. Addressing these challenges necessitates integrating social support mechanisms into HIV programs, such as improving service accessibility, reducing

logistical burdens, and ensuring flexibility in the delivery of care to mitigate economic constraints.

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