14. Social and Psychological Assistance to Women with HIV in Kyrgyzstan

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Introduction

According to data of the Kyrgyz AIDS centre, the percentage of women among people living with HIV in Kyrgyzstan was 37.1% in June 2023 (Republican AIDS Centre 2023). Along with people who use drugs, women and girls living with HIV are vulnerable to violence and face widespread criminalisation and discrimination. A lack of reliable statistical data, misconceptions about how HIV is transmitted, as well as stigma and societal discrimination mean that HIV-positive women and girls face many challenges in Kyrgyzstan (Prosvet 2017).

This chapter focuses on the social and psychological needs of women living with HIV in Kyrgyzstan. The chapter first describes the general situation of women living on HIV and existing services, including the prevention of mother-to-child transmission and support services for mothers and children living with HIV. The chapter highlights the many forms of violence that women with HIV are facing and the need for mental health services and care in Kyrgyzstan.

The general situation of women living with HIV in Kyrgyzstan

Women living with HIV are highlighted in Kyrgyz national documents, strategies, plans, and policies related to the HIV response. The National HIV Programme (2023–2027) highlights women and girls living with HIV; it addresses research on gender-based violence and inequality and the impact these issues have for women in terms of gaining access to HIV services. Women living with HIV and sex workers contributed to the development of this programme and participated in the working group set up to develop the national funding request to the Global Fund.

The National HIV Clinical Protocols (2022) include sexual and reproductive health for people living with HIV, including cervical cancer pre-

vention and treatment, especially for women living with HIV. Stigma, discrimination, and the human rights of women living with HIV are also discussed in national documents. HIV and gender issues are addressed by civil society organisations, with female representatives of the community of people living with HIV representing their community and advocating and actively participating in the Country Coordinating Mechanism (CCM), which coordinates the implementation of grants from the Global Fund (EWNA 2023).

Another important coordinating and governing body in the fight against HIV/AIDS is the Coordinating Council on Public Health under the Government of the Kyrgyz Republic, which has 23 members from the public and non-public sectors. 39% of the Council is made up of representatives of key communities, namely women and men living with HIV and young people (Committee to Combat HIV/AIDS, Tuberculosis and Malaria under the Committee for Health Protection under the Government of the Kyrgyz Republic 2024). The purpose of the Council is to ensure the coordination of government agencies, as well as non-profit and public organisations in addressing HIV/AIDS issues.

Due to the criminalisation of HIV, women are particularly vulnerable to stigmatisation and discrimination. In Kyrgyzstan, HIV transmission is criminalised. The laws have a strong impact on stigma and discrimination, as they create barriers to seeking care and treatment. Women who live with HIV face many difficulties when it comes to meeting their basic needs. This has a negative impact on their quality of life. The services available to women with HIV are also not gender-specific, which often limits their access to legal, social, psychological, and medical support.

There is a lack of studies on the situation of women with HIV in Kyrgyzstan. In 2017, the NGO Prosvet conducted a study on the needs of women with HIV in Kyrgyzstan. One of the biggest issues related to accessing health services is stigma, both in society in general and by medical service providers. Other issues include the lack of peer counselling services, with a person living HIV who has received special training, as a councillor. Such a person, who understands the medical, psychological, and social aspects of HIV, can share professional knowledge and help individuals when they receive an HIV diagnosis, offer assistance with adhering to ART therapy, and provide psychosocial support. Psychological support is not always available, especially outside the capital city Bishkek. The same applies to self-help groups for women living with HIV. However, psychological care (counselling, correction, rehabilitation) is one of the most important com-

ponents in HIV prevention and treatment, which is why we focus on it later in this chapter.

The majority of women with HIV also need to be aware of their rights during the process of diagnosis and treatment and be protected from unlawful actions by employers, medical staff and others. One of the biggest fears of women with HIV is related to motherhood and losing custody of their child or children. It is not always understood, but childcare is an important motivating factor for many women with HIV, encouraging them to undergo regular health check-ups and adhere to ART treatment.

Prevention of Mother-to-Child Transmission in Kyrgyzstan

The global community has set the goal of eliminating mother-to-child (or vertical) transmission of HIV by 2030. This initiative seeks to eliminate the vertical transmission of not only HIV but also syphilis and viral hepatitis B. The actual elimination of mother-to-child transmission of HIV (EMTCT) means reducing the risk of vertical transmission of HIV to 1–2% among children who are not breastfed from birth and to 5% for breastfed children (World Health Organization [WHO] 2021).

Since 2007 in Kyrgyzstan, all pregnant women have been tested for HIV upon registering their pregnancy (The Joint United Nations Programme on HIV/AIDS [UNAIDS] 2020). The testing algorithm includes rapid HIV testing when pregnant women without prior HIV testing are admitted to maternity hospitals (WHO 2021).

Since 2020, Kyrgyzstan has also been implementing a state social contracting programme, which includes HIV prevention, diagnosis, care, and support for key populations (Ministry of Health of the Kyrgyz Republic 2020). From 2017 to 2021, the number of HIV-positive pregnant women in the country increased from 144 to 195, and the number of children with a vertical route of HIV infection increased from 16 to 24 (Republican AIDS Centre of the Kyrgyz Republic 2023). These negative trends may continue against the backdrop of existing stigma and discrimination against people living with HIV. At the end of 2022, the proportion of children diagnosed with HIV for the first time was 1.7% (two new cases out of 115 children with HIV).

The prevention of vertical transmission of HIV has been included in HIV clinical protocols, which does not prohibit a mother's choice to breastfeed. As part of a comprehensive approach to preventing the vertical transmis-

sion of HIV from mother to child (PMTCT), breastmilk substitutes are provided free of charge to women living with HIV (Eurasian Women's Network on AIDS [EWNA] 2023).

The Kyrgyz healthcare system follows international recommendations and ensures that pregnant women living with HIV continue to receive ART treatment after delivery. In the implementation of strategic directions in HIV programmes, issues related to compliance with international human rights standards remain unresolved, including issues of confidentiality and access to health services. Women living with HIV face discrimination in accessing family-planning services. According to the results of the Stigma Index 2020 survey, every tenth respondent openly reported that she had been advised to terminate her pregnancy and was pressurised to choose a specific method of childbirth and child feeding. At the same time, 25–27% of respondents refused to answer these questions. This may indicate that the topic is sensitive for women; perhaps they have faced discrimination, but do not want to discuss this experience.

Social protection of families with HIV-positive children

Families with children living with HIV are entitled to social support according to a jointly developed individual plan for working with families (SoyuzPravoInform 2015). A monthly social allowance is granted to children born to mothers living with HIV or AIDS (until they reach the age of 18 months).[1] The allowance is 8,000 soms (about 89 USD) (SoyuzPravoInform 2021).

In addition, since the beginning of 2023, Kyrgyzstan introduced a lump-sum payment of 6,300 soms (USD 71) for all mothers upon the birth of a child ("Balaga syyyunchy"). To put this into context, the average salary in Bishkek at the end of 2023 was 23,085 soms (USD 262) (Social Fund of the Kyrgyz Republic 2024). Women who have children with HIV are also entitled to an additional lump-sum payment of 4,900 soms (USD 55) until the child reaches the age of majority. The amount may be revised annually, taking into account changes in the subsistence level. In this case, financial support is provided to both the mother and the relatives who are caring for

1 The allowance is paid to children born to mothers living with HIV. In October 2021, the allowance was increased from 4,000 soms to 6,000 soms and in January 2022 from 4,000 soms to 8,000 soms.

the child. This form of support is guaranteed by the law because about 60% of the population of Kyrgyzstan are migrant workers. In many families, relatives take care of children while the parents are working abroad.

The Law of the Kyrgyz Republic "On HIV/AIDS in the Kyrgyz Republic" was amended on 17 August 2020: persons who were infected in medical institutions should be paid a compensation of at least 100,000 soms (SoyuzPravoInform 2020). From 2005 to February 2021, 403 HIV-positive children were registered with AIDS Centres who had been infected in medical institutions. Most of them became infected in 2005, in hospitals in the south of the country. This as a period when there was an outbreak of HIV cases among children, due to poor handling of medical instruments and non-compliance with infection control requirements.

It is worth mentioning that some private employers often require a medical examination for HIV, which contradicts the Law of the Kyrgyz Republic on HIV/AIDS. There are documented cases where women were denied employment or dismissed because of their HIV status. Some women will not take jobs that require a health book, which often results in them working below their skill level or in a grey zone. This is an example of stigma, and it results in people being pushed into poverty. Feelings of shame affect the self-esteem of women living with HIV/AIDS, as well as their ability to accept their status, and make them particularly vulnerable to violence, depression, and self-isolation.

Gender-based violence

A major problem in Kyrgyzstan is the criminalisation of HIV, which fuels stigma and discrimination, especially against women living with HIV. Article 143 of the Criminal Code of the Kyrgyz Republic (Infection with a venereal or incurable infectious disease), provides for a prison sentence, even in cases of unintended or negligent HIV transmission of HIV infection. The decriminalisation of HIV transmission is one of the main goals of the activist and human rights community in Kyrgyzstan. The existing criminalisation equates an HIV-positive person with a criminal, which fuels existing stigma, discrimination, and violence against people living with HIV, and women in particular.

While there are few convictions for HIV transmission, the criminalisation of HIV transmission maintains entrenched stigma against people living with HIV and is a source of structural discrimination that affects all areas

of life. In patriarchal environments, women are even more vulnerable, both economically and socially. Women with HIV face discrimination more often than men with HIV and are often afraid to start a family, find a job, access health services, and seek help for survivors of violence.

The global community states that violence is a key risk factor for HIV infection among women (UN Commission on the Status of Women 2016). Despite the existing legislation and measures aimed at overcoming gender-based violence, the country lacks sustainable programmes and mechanisms to overcome stereotypes and violence against women. In Kyrgyzstan, women face violence in their interaction with state agencies, local communities and in their direct social environment. Women from key population, including women living with HIV, are particularly vulnerable to violence. Violence against them is systemic and is also perpetrated by law enforcement officials and representatives of other state organisations whose functions include human rights protection and service delivery, regardless of HIV status, occupation, behavioural patterns, and a number of other factors.

According to national statistics, in 2022, women accounted for the vast majority (95–96%) of victims of domestic violence (Ministry of Internal Affairs of the Kyrgyz Republic 2024). According to the data of the Alternative Report submitted to the Committee on the Elimination of Discrimination against Women (CEDAW) in 2021, women living with HIV in Kyrgyzstan are subjected to various forms of domestic violence: psychological violence in the form of insults, humiliation from family members (e.g. by insisting on using separate dishes due to an unjustified fear of infection), the isolation of children; physical and economic violence. Sometimes women with HIV are kicked out of the house by the relatives of their husband or not accepted in the house by their own relatives. Sometimes women are excluded from ART or TB treatment, which has led to cases of women dying.

In 2018, the Campaign "There is no excuse for violence" conducted a study in twelve countries of Eastern Europe and Central Asia (EECA) (EWNA 2019). The study involved 36 women living with HIV from Kyrgyzstan. Seven out of ten women reported experiencing physical violence and half of them experienced sexual violence, with two thirds of the cases of physical violence and three quarters of the cases of sexual violence being related to HIV status. Psychological and economic violence was reported by four women out of five. Forms of psychological violence included insults, humiliation, separation of dishes, and the isolation of children; economic violence included the husband's relatives being kicked out of the house or the women's own relatives not being accepted in the house. Furthermore,

these women are often banned from taking ARV therapy, being treated for tuberculosis treatment, or being seen by a doctor, which has led to cases of women dying. Only one third of women sought help after facing violence during the year preceding the survey.

In interviews, Kyrgyz women reported:

> *"My mother told me not to come too often, to prevent any scandal because of me. Nobody wants my children, they [my family members] are scared that we will infect them, and they don't want their neighbours to see me come and to think that I left my husband. I have bruises everywhere, you know"* (EWNA 2019, p. 10).

> *"[He was] drunk, [he had] no job, no money. So, he lost his temper, and I was always to blame. 'Where will you go? I'll bury you and no one will find you. No one needs you; no one will look for you'"* (EWNA 2019, p. 10).

Despite the fact that Kyrgyzstan has a law on domestic violence and has developed mechanisms to enforce this law, women avoid seeking protection and resort to it only in extreme cases. Women living with HIV, being a stigmatised group, are even less likely to seek help. This situation is fuelled by widespread stereotypes that blame women for being caught up in a violent situation (victimisation). For example, one opinion leader openly accused women suffering from domestic violence of being responsible for being repeatedly battered (Kapushenko 2021). This stereotype influences the work of law enforcement officers and judges in Kyrgyzstan. In addition, women rarely receive support from relatives in cases of domestic violence; more often they face accusations from relatives. The family is often a source of stigma for women living with HIV. In such a situation, a woman is under even greater pressure and has no resources to defend herself against violence.

Kyrgyzstan lacks mechanisms for emergency interventions of specialists in cases of violence against women (e.g. to provide medical, psychological, social, or legal assistance). Protocols for HIV-related medical care do not address violence-related issues, which include screening to determine whether a woman is currently in a situation of violence, to ascertain whether there are potential threats of violence, and to provide information about organisations that can provide support in terms of counselling, legal assistance, and shelter.

Mental well-being

Mental well-being is an integral component of human health, along with physical and social well-being. The main healthcare efforts and services (including HIV prevention and treatment) are aimed at supporting physical health, while at the same time insufficiently addressing and/or ignoring problems related to mental health.

There are no available epidemiological data on depression in Kyrgyzstan, so it is impossible to see the real situation among both the general population and HIV-positive women.

In 2021, the EWNA initiated the first rapid assessment of depression screening among HIV-positive women in EECA countries, including Kyrgyzstan (EWNA n.d.). The study was designed to obtain up-to-date information on the prevalence of depression among HIV-positive women in the region and to analyse the relationship between depression and physical health problems and life circumstances. In the rapid assessment, 720 women living with HIV were screened for depression.

Factors affecting mental well-being in HIV-positive women in Kyrgyzstan

Women living with HIV often have concomitant physical health problems and find themselves in various difficult life situations, which together negatively affect both their mental health and their adherence to ARV treatment, including during and/or after pregnancy.

Depression is one of the most common mental health problems. Based on the results of a situation assessment of depression screening in women living with HIV, it was hypothesised that depression is a real problem for the mental, physical, and social well-being of HIV-positive women.

It is important to note that the problem of depression is invisible and often remains neglected for many reasons, such as due to a lack of regular screening and subsequent diagnosis of depression; women's lack of awareness of the signs and consequences of depression; and a lack of services and self-help skills.

However, the problem has not received sufficient attention. According to the first National HIV Prevention Programme in the Kyrgyz Republic of 2012, all major public health efforts and services in the area of HIV prevention and treatment were mainly focused on supporting physical health,

with insufficient focus on mental health issues (Ministry of Justice of the Kyrgyz Republic 2012).

Maternal depression

According to the World Health Organisation, depressive disorders after childbirth (maternal depression) are a serious problem for many women (WHO 2022). At present, maternal depression is an under-recognised and under-researched condition, especially in countries with a low standard of living. Increased levels of stress during pregnancy, domestic violence, and stigma due to HIV status negatively affect the psychological well-being of the mother. In the postnatal period, women often find themselves in a state of social and informational isolation, as she devotes most of her time and efforts to caring for her new-born. Factors that should be considered when discussing or attempting to diagnose maternal depression include lifestyle during pregnancy, including nutrition, the presence of nicotine, alcohol, or drug addiction, and the presence of chronic diseases. The physical condition of the woman after childbirth, including the presence of postpartum stitches, difficulty using the toilet after childbirth, and discomfort in the hospital ward, also play a significant role.

More than one third of the participants of the depression screening reported signs of moderate (15.7%) and severe (12.8%) depression. More than half of the respondents reported that they were adhering to their ARV treatment (60.2%), while the rest noted that they had missed some of their regular medication, including skipping a few days (33.7%) and skipping a few weeks (3.9%).

The emergence and development of maternal depression affects not only the health of the woman herself but also has a significant impact on the child. The interaction between mother and child is very important for the child's development. Women suffering from postpartum depression may find it difficult to interact emotionally with their baby and may negatively evaluate the baby's emotional expressions. This can lead to a disruption in the emotional bond between mother and child, and affect the development of the child's emotional regulation.

Prolonged disruption of mother–child interaction can have a negative impact on the child's future physical, mental, and emotional development. Some studies show that children whose mothers suffered from postpartum depression may experience problems with social development, anger, and

aggression and have an increased risk of developing mental disorders in the future.

It is therefore important to pay timely attention to maternal depression among women living with HIV and provide support and treatment to minimise the negative impact on both their own health and that of their child. Psychotherapy, pharmacotherapy, and extensive support from others can be effective options for treating maternal depression and promoting the healthy development and well-being of mother and child.

In the Action Plan of the Cabinet of Ministers of the Kyrgyz Republic's programme on overcoming HIV infection and viral hepatitis for 2023–2027, the strategic direction for the provision of treatment, care, and support services for people living with HIV (PLHIV) takes into account the expansion of access for people living with HIV to HIV education, psychological counselling, and mental health services (Cabinet of Ministers of the Kyrgyz Republic n.d.). Psychological counselling for women living with HIV is available at AIDS centres across the country. Some mental health care is provided for women at the Republican Centre for Narcology and Psychiatry (EWNA 2023).

The results of the rapid assessment of depression in the region suggest that depression is a real problem for the mental, physical, and social well-being of women living with HIV. In order not to ignore the impact of depression on the adherence to treatment as ART for mothers living with HIV, it is recommended to provide mothers with comprehensive services consisting of psychotherapy, pharmacotherapy, and extensive support in order to prevent and treat maternal depression in women living with HIV, and to study and research the mental health situation of HIV-positive women.

It should also be noted that both women living with HIV and their children require special attention due to the stigma and stereotyping they face from society, which may affect the women's adherence to ART (antiretroviral therapy). Therefore, training programmes for parents, which motivate them and advocate for children's rights, should be part of programmes for children and their parents. Working with and caring for women is also especially important during pregnancy, childbirth, and infant care. At this stage, adherence to educational activities should be encouraged, emphasising the importance of adherence to prevention of mother-to-child transmission of HIV (PMTCT) and the importance of viral load suppression for the health of the new-born. There may also be the issue of accommodating an HIV-positive woman and her infant following discharge from

the maternity hospital. Providing care and support during pregnancy and breastfeeding have a significant impact on the effectiveness of PMTCT and the health of the new-born baby (Ministry of Health of the Kyrgyz Republic 2018).

Thus, in light of the aforementioned issues, socio-psychological work in the field of HIV/AIDS can be seen as especially relevant and necessary. The health of future generations and the formation of moral foundations and societal values directly depend on the well-being of families and the state of maternal health. Maternal health is an important component of national policy.

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