

# New research reveals challenges faced by mothers living with HIV in Indonesia

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Living with HIV is certainly a very big deal. It has detrimental mental health impacts on people. Such impacts are even worse for mothers living with HIV whose children are also living with HIV.

Informed by the findings of [a Ph.D. project](#) of Dr. Nelsensius Fauk, supervised by Professor Paul Ward and Associate Professor Lillian Mwanri, exploring [risk factors](#) and impacts of HIV on women living with HIV, the researchers conducted further interviews with 23 [mothers](#) living with HIV who also have a child living with HIV in Yogyakarta, Indonesia.

The new research explored the [mental health challenges](#) they experienced and the [coping strategies](#) they used to manage those challenges. Two articles were published from this research, one in the *International Journal of Environmental Research and Public Health* in 2022, and another in the journal *BMC Women's Health* in April 2023.

## **Mothers' experience of HIV-related mental health issues**

Interviews suggested that mothers experienced tremendous mental health challenges after their HIV diagnosis. They psychologically struggled to accept their HIV-positive status and to find possible ways to cope with it.

The mental health burden was even heavier once they discovered that their child had also been infected with HIV, either during the birth process, or through breastfeeding.

Dealing with the [daily life](#) or social activities of their child living with HIV also caused fear and worry for these mothers about the possibility of the child's HIV status being accidentally disclosed, as well as the negative impacts the child might face afterwards.

Managing their child's health condition and treatment and repetitive complaints from the child about daily medication were stressful life situations for these mothers, in addition to the incredible effort to

maintain their own health.

Most mothers interviewed acknowledged that their [children](#) had not been informed about their HIV-positive status due to their very young age. This was another challenge that made it harder for them to encourage daily medication for the child.

In the interviews, some mothers explained that they received unsympathetic expressions and comments from friends towards themselves and their child living with HIV, which further negatively impacted their mental health. They felt sad and hurt, which for some led to friendship rifts or disconnection. Some others also felt negatively judged by their parents and families due to contracting the infection, which caused anger, guilt, and stress.

## **HIV-related coping strategies used by the mothers**

The research explored how these mothers coped with the mental health issues they faced due to their own and their children's HIV diagnosis.

It was discovered that although they experienced mental health challenges, they demonstrated positive responses and strong resilience. They tried to find positive meaning in their challenging situations through various actions.

For these mothers, their awareness of how meaningful and important they are and the sense of responsibility they have for their children and families that encouraged them to fight against fear, stress, anxiety, and depression following their own, and their child's, HIV diagnosis.

"If I don't fight this infection and stay strong then who will take care of my children," said one of the mothers interviewed.

The research revealed that this awareness and sense of responsibility also helped the mothers accept their own HIV status and the HIV status of their child. By accepting their HIV status, they stopped blaming themselves and the person who transmitted the virus to them.

Finding religious meaning through faith and prayers was also an important determinant of coping mechanisms for most mothers. This helped them calm down, think positively and provide hope for a better future.

The study revealed that these mothers tried to strengthen their relationships with their child after the child's HIV diagnosis. By providing more time and attention to the child and supporting the child's needs the burden of guilt of transmitting HIV to their child was reduced.

One of the mothers explained, "I want to give more of my time and attention to my kids, especially my son [HIV+]. I transmitted HIV to [him], and he has to carry the burden as well; he doesn't deserve this."

These mothers also shared that they tried to overcome feelings of worry and fear about the possibility of their child's HIV status being exposed, and the negative consequences their child might face.

One solution was connecting their child to other children living with HIV in groups and activities. This was considered a productive strategy and socially meaningful for their child as the child had the opportunity to build social relationships with children who were going through a similar experience. In the same way, it helped these mothers cope with the burden of overthinking and worrying about possible future difficulties and negative social impacts.

**More information:** Nelsensius Klau Fauk et al, Mental Health Challenges and the Associated Factors in Women Living with HIV Who

Have Children Living with HIV in Indonesia: A Qualitative Study, *International Journal of Environmental Research and Public Health* (2022). [DOI: 10.3390/ijerph19116879](https://doi.org/10.3390/ijerph19116879)

Nelsensius Klau Fauk et al, Understanding coping strategies of mothers living with HIV who care for children living with HIV: a qualitative study in Indonesia, *BMC Women's Health* (2023). [DOI: 10.1186/s12905-023-02299-y](https://doi.org/10.1186/s12905-023-02299-y)

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