

Social stigma obstacle to successful treatment of children with HIV in Ethiopia

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The social stigma surrounding HIV is still strong in many parts of the world. Children living with HIV in Ethiopia are at high risk of receiving inadequate treatment – or no treatment at all – on account of deeply rooted prejudice. The most considerable risk can be found among very small children, who do not receive proper treatment right away.

Ethiopia is one of the 35 countries identified by the World Health Organisation (WHO) as being in particular need of enhanced HIV prevention. More than 90 per cent of all people who were recently infected with HIV live in these 35 countries.

Over the past few years, nurse Mulatu Biru Shargie has conducted studies and collected data on how Ethiopian [children](#) with HIV are medicated through [antiretroviral therapy](#) (ART). The result is presented in his doctoral thesis "Children Diagnosed with HIV on Antiretroviral Therapy in Ethiopia: The Family Caregivers' Lived Experience and Treatment Outcome."

In his study, Mulatu Biru Shargie monitored some 300 children and the people who had undertaken the responsibility of caring for the children (caregivers). A [caregiver](#) is not necessarily the child's parent; it could be a close relative or family friend who assumes responsibility when the [biological parents](#) of a child have passed away. The children in the study were 0–14 years old, and had all faced an ART [treatment](#). Mulatu Biru Shargie followed them and their caregivers for two years.

"My goal was to help improve the care of children with HIV who receive ART treatment, by improving the knowledge and understanding of the caregivers' experiences and determining factors for the success of the children's treatment," says Mulatu Biru Shargie.

There are several obstacles to a successful medical treatment for these children. Amongst his results, Mulatu Biru Shargie wants to highlight these in particular:

The main issue when ART treatments of children are not properly implemented is the existing social stigmatisation of HIV. The caregiver may feel reluctant to be seen in healthcare contexts associated with HIV, and the prescribed medications for the child risk not being collected. Crucial follow-ups and examinations are missed.

The children who already at the beginning of the study were severely ill, suffered from anaemia or were under the age of three were the ones who experienced the most dire consequences of not receiving medication as prescribed.

Simple reminders (through mobile phones, pill dispensers, vibrating timers, etc.) make a big difference in helping the caregiver/child remember to give/take the medicine properly.

The stigma is the hardest part

Early implementation of an ART treatment, and ensuring that young children in fact receive care, is therefore of great importance. In this context, Mulatu Biru Shargie's knowledge can establish a foundation for improved healthcare planning. However, the toughest nut to crack is the stigma. Although awareness of the disease has increased over the last thirty years, and open discrimination and violence against people with HIV has somewhat decreased, prejudice and gossip, as well as being

labelled, remain common, according to Mulatu Biru Shargie.

"My studies show that the caregivers were not strong enough to stand up against society's views of people with HIV. Stigmatisation and discrimination are the main obstacles to a successful ART treatment of children and to making them feel good."

A caring and responsible society. Mentally strong and dedicated caregivers. Highly educated and compassionate healthcare staff. A well-organised healthcare system – with zero tolerance for stigmatisation and discrimination among decision-makers. According to Mulatu Biru Shargie, this is the solution for ensuring that children with HIV receive adequate treatment options.

Facts/The study in numbers:

The study included more than 300 children with HIV, as well as 21 of their caregivers. The children who participated were 0–14 years old. After 12 months, the health of 24 of the children had deteriorated due to them not having taken the prescribed medication. Six of these 24 children had died.

In cases where the caregivers themselves received treatment against HIV, there was an increased risk that the children did not receive proper medication during their first treatment week. Mulatu Biru Shargie's explanation for this is that the caregivers in these cases were often the biological parents who did not want to be seen with the child at the same healthcare institution – due to stigma and discrimination. Furthermore, the caregivers sometimes thought that the care offered was poor, which further elevated the child's risk of not receiving proper treatment and medical follow-up.

Execution of the study

The caregivers were interviewed in depth on two occasions about their experiences during the first two years after the child was diagnosed.

The caregivers were asked to report whenever they neglected to give the child medicine as prescribed. Based on this, the researcher examined the impact of this neglect on the early stages of treatment. Did the child's health deteriorate?

Retrovirus/Antiretroviral therapy

In a retrovirus, its RNA is converted to DNA. The DNA copy is inserted into the genome of the host cell. Another typical characteristic of retroviruses is their ability to always integrate the viral genome into the genome of the cell. After integration, new copies of the virus RNA are produced, as well as the proteins for which the genes of the virus encode. These are then assembled to form new virus particles. Antiretroviral drugs are used against infections of retroviruses, such as HIV. When HIV is combatted using antiretroviral drugs it also has the effect of strengthening the immune system.

More information: Shargie, M. B. (2017). Children diagnosed with HIV on antiretroviral therapy in Ethiopia: The family caregivers' lived experience and treatment outcome Lund: Lund University, Faculty of Medicine

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