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Mental Health has a major influence on HIV treatment in young people

By Bahati Kasimonje

Many young people struggle with their HIV infection and the lifetime of antiretroviral therapy that it means. They need particularly close support to ensure that their treatment continues uninterrupted. The need to understand and comprehensively address the health care needs of this key population is vital to the epidemic.

Therapy sessions are often the first time that many have talked about their HIV story. Photo: © Patrick Rohr / Ruedi Lüthy Foundation

They are falling in love for the first time, negotiating boundaries and seeking out their own path. The young people in treatment at Newlands Clinic are no exception, but for them, life is even more difficult. Not only are they HIV-positive, which is often highly stigmatized and requires a lifetime of antiretroviral therapy (ART), but in many cases, they live in very difficult circumstances. Many of them have lost their parents to AIDS and live in institutions or with relatives. Furthermore, high levels of unemployment may compromise their prospects.

At Newlands Clinic, these young people not only receive medical support, but are also treated with care and respect. In addition to their HIV medication, they are given a vitamin-rich porridge to build them up. The Clinic will also assist if they don't have the money for food or for school. The individualized care provided by the clinic team provides a secure base where hope and trust can be built and a safe space where young people can discuss their challenges and share their successes.

Some young people at Newlands Clinic's adolescent corner. Photo: © Patrick Rohr / Ruedi Lüthy Foundation

Struggling with a lifetime of treatment

This relationship of trust is especially important during the adolescent years, because that is when young people begin to understand the full implications of their HIV infection, and the fact that they have a lifetime taking ART ahead of them.

> *Responses from young people like "HIV is death, you are of no use, you are isolated and neglected, there is no longer a future" reflect the complexities of HIV.*

Treatment success is prejudiced by their fears for the future. Questions such as "will I be able to get married?", "will my children also be HIV-positive?", and "what will happen if my girlfriend or boyfriend finds out about my HIV status?" are common.

Lack of support, a loss of hope, and anxiety are principal reasons that many young people stop taking their medication regularly. This is highly dangerous, because the virus is then able to replicate rapidly, and may become resistant to treatment. If the HIV viral load shows poor control of the virus, action must be taken.

It's more than taking some pills

Simply giving out more information on ART, adherence and dispensing medication may not suffice with young people living with a chronic illness. One of the major challenges that healthcare professionals face is helping young people adhere to ART despite its well-known benefits in improving overall health and quality of life. Globally, HIV associated mortality among adolescents escalated by 50 percent between 2005 and 2012 unlike in other age groups and this is attributed largely to inadequate adherence support and poor retention in care. This position highlights the need to better understand sub-optimal adherence among young people and develop interventions that meet their needs with regards to adherence support. Such strategies are imperative in sub-Saharan African countries where an estimated 80% of the world's 2.1 million HIV-positive adolscents live. Zimbabwe is named as 1 of the 22 high burden countries for HIV and young people are a key population in which such interventions are necessary. Consequently, we developed an Enhanced Adherence Counselling Group Intervention (EACGI) at Newlands Clinic. The EACGI is grounded in a mental health approach that was utilized in young people between the ages 13-25 years old who presented with poor adherence to ART and virologic failure (VF).

Teenagers doing handicrafts. Thanks to them, they have the opportunity to earn a few dollars. Photo: © Patrick Rohr / Ruedi Lüthy Foundation

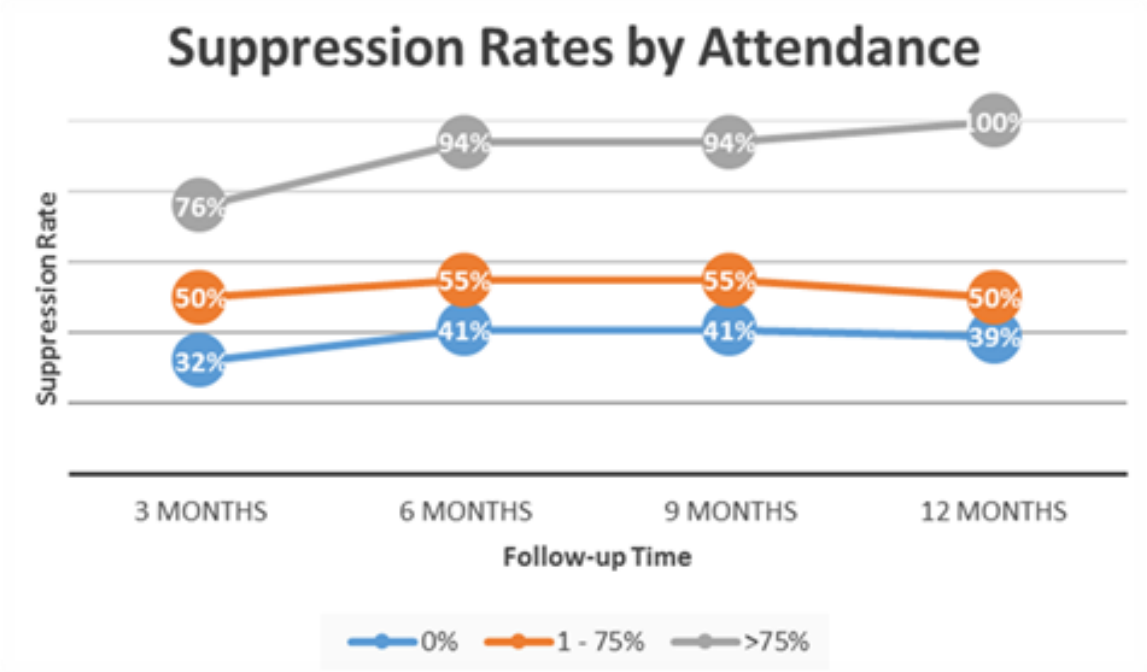
Enhanced Adherence Counselling Group Intervention

Enhanced Adherence Counselling Group Intervention (EACGI) was a 12-week curriculum of weekly, 1.5-hour sessions that accommodated 8 to 15 people per group. It was part of routine care, aimed to facilitate readiness to switch treatment to second line ART, and improve adherence through Phenomenological, Motivational Interviewing and Cognitive Behavioural Therapy principles. Each patient had a regular nurse counsellor providing ART management, and nurse counsellors referred patients deemed to require further assistance in adherence counselling and support. Viral loads were measured pre and post EACGI and at 3, 6, 9- and 12-months post switch to second line treatment to assess virological outcomes.

Results of the study

Fifty-nine patients aged 13 to 25 years were invited to EACGI and followed up for 46.8 person-years. Of these, 34 (57.6%) were female. The median duration of first line antiretroviral therapy was 6 years (IQR: 4 – 8) at the time of invitation to EACGI. Twenty-two patients (37.3%) did not attend any of the sessions, 8/22 being female and 14/22 male. The main reasons for not attending EACGI were a lack of interest on the part of the individual, school or work schedules. The main reasons for poor adherence among those who attended were hopelessness, family dysfunction, lack of illness, an aversion to a daily routine attached to

stigma, and medication side effects. Among patients who attended >75% of sessions, 76%, 94%, 94% and 100% achieved viral suppression at 3, 6, 9 and 12 months, respectively, of follow up. Compared to 50%, 55%, 55% and 50% among those who attended at least one but ≤75%. Those who did not attend any session had suppression rates of 32%, 41%, 41% and 39%, respectively.



Graphic: Complete viral suppression by participation rate.
Y-axis: Patients with complete viral suppression.
X axis: 3/6/9/12 months // after completion of group therapy

Conclusion: Innovative strategies are essential

Young people who attended >75% EACGI had better virological outcomes compared to those who attended less or none. Hopelessness, family dysfunction, a lack of illness, an aversion to a daily routine attached to stigma, and medication side effects negatively affected treatment adherence among young people failing on ART. There is more to an adolescent's life than taking daily medication.

> *HIV care and management ought not to forget the young people's narratives of grief, heightened awareness of loss of life, experiences of stigma and discrimination, sexuality and uncertainty pertaining to education and career prospects.*

There is a need for shifting perspectives regarding care. The young person living with HIV is different from the adult patient. Adolescents themselves are not a homogenous group and this needs to be reflected in their care. Given the high risk of virologic failure, disease progression, drug resistance, limited treatment options and the ultimate threat to survival posed by suboptimal adherence, implementation of innovative adherence support strategies that go beyond a traditional clinical approach is imperative.

The **Ruedi Lüthy Foundation** was set up in 2003 by Prof. Ruedi Lüthy with the goal of providing comprehensive care for HIV and Aids patients in southern Africa. The Foundation now runs Newlands Clinic, an outpatient facility in the Zimbabwean capital of Harare that provides long-term treatment for some 6,500 HIV patients, and that also has its own Training Centre and Women's Health Centre. Just over a quarter of patients are aged 25 or younger. Newlands Clinic helps them along their path to independence with school fees, group therapy, a youth group, and our vocational skills training programme. Email / www.ruedi-luethy-foundation.ch

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