



LIVING WITH STIGMA

Young voices from
the townships



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Introduction

Young people remain at the heart of the HIV epidemic, evidenced by a 30% increase of HIV-prevalence (between 2005 and 2016) among 10 to 19 year-olds worldwide. Tragically, HIV is now the leading cause of death among 10 to 24 year olds in Africa¹. Whilst the majority of infections among adolescents (70%) are acquired through vertical transmission, reducing infections continues to be a significant challenge. This is particularly concerning in the context of Africa's rapidly growing youth population, expected to reach 830 million by 2050, resulting in potential infection rates of between 270,000 - 300,000 annually by 2030². It is therefore imperative to increase efforts to effectively reach adolescents and young people to reduce infections and to save many thousands of young Africans' lives.

Stigma, adolescence and HIV

HIV stigma is one of the most damaging characteristics a person can experience. It often triggers overwhelming feelings of shame, anxiety and depression³. The challenges posed by stigma for a young person are particularly difficult, especially as adolescence is recognised as the most vulnerable period of human experience. Adolescence is the process by which a young person begins to explore their autonomous self-identity as they journey toward adult independence. This process includes puberty, initiating the formation of sexual identity, exploration, debut and intimacy. For many, this process is overwhelming, causing a heightened level of self-consciousness, together with low self-esteem⁴.

Essential to successful developmental transition is the quality of a young person's interpersonal and wider peer relationships. Forming a robust self-identity is dependent upon the consistent affirmation and acceptance received by immediate members of their belonging group. Whilst sexual identity, beliefs, moral principles and worldviews are explored during this period, the primary identities of son, daughter, sister, brother, partner and friend remain the bedrock of their core attachments and belonging⁵. It is these core attachments that are shown to influence healthy neurological development and are the principal drivers of young people's motivation⁶.

Receiving an HIV diagnosis, or sudden disclosure for the adolescent can often trigger significant disruption to their already fragile sense of self, whilst simultaneously undermining the fabric of their interpersonal relationships that are foundational to their wellbeing⁷. What is particularly damaging for a young person in this context is the destructive process of internalising stigma beliefs that generate self-damning autobiographical narratives which become embedded into their modalities of memory. Over time, these shape their recall, behaviour, emotion and perceptions of themselves within their social world⁸. Simply put, the overwhelming fear of being cast out by those they love is a terrifying experience for a young person, leaving many with feelings of internal disconnection and social isolation as they are left alone to cope with a life dominated by a harmful cycle of stigma.

These young people are among the most vulnerable in sub-Saharan societies and urgently require sustainable psychosocial support. However, due to low service provision, the majority of adolescents throughout Africa are unable to access this level of support. Consequently, many young people suffer from depression, anxiety, suicidal ideation, and in some cases suicide. These levels of psychological distress result in sub-optimal adherence, increasing both infection rates and adolescent mortality. It is within these contexts that there is an urgent need for programmes to explore innovative approaches that empower youth to harness their resourcefulness, facilitating youth-to-youth psychosocial support and adherence motivation among themselves.

1 UNICEF (2017) 'Statistical Tables'

2 Source: <http://aidsinfo.unaids.org>

3 Mbonu, N.C., van den Borne, B. & De Vries, N.K. 2009. Stigma of People with HIV/AIDS in Sub-Saharan Africa: a literature review. *Journal of Tropical Medicine*.

4 Erikson, H.E. 1980. *Identity and the Life Cycle*. London: W.W Norton & Company Ltd.

5 Hickson, 2016. An interdisciplinary study exploring how health communication can most effectively explain Antiretroviral Medication (ART) and motivate adherence among young people

6 Solomon, F.M. & Siegel, J.D. 2003. *Healing Trauma. Attachment, mind, body, and brain*. New York: W. W. Norton & Company.

7 Blas, P. 1979. *The Adolescent Passage, Developmental Issues*. New York: International Universities Press, Inc.

8 Siegel, J.D. 1999. *The Developing Mind. How relationships and the brain interact to shape who we are*. New York: The Guildford Press.

“Mostly at home, I don’t show my family that I am not feeling well, not because of the medication, but because of what’s happening in my life. I need a friend, someone I can talk to about my issues, and help me figure out some things I don’t understand”.

The Salus approach

The Salus project piloted an intervention that explored the impact of a youth-centred psychosocial model which aimed to empower adolescents and young people who are living with HIV and struggling with self-stigma to co-support one another. The pilot included a digital app to increase HIV and treatment literacy and motivate adherence to ART.

The integrative approach

The approach utilised core components from counselling and coaching practice required to create a climate of unconditional safety, trust and hopefulness about the future, necessary for positive therapeutic outcomes. These comprised:

- **Congruence**, experienced when the helper is genuinely themselves, being fully aware of their thoughts, feelings and perceptions, ensuring that relational experiences are authentic and meaningful.
- **Empathy**, defined as deep listening to the internalised life-world of the other that includes gaining a deep understanding of group members which is both intuitive and cognitive.
- **Unconditional positive regard**, experienced when the helper accepts, group members without judgement.

- **Problem-solving and goal setting** enables participants to describe their ambitions, define goals and explore how they hope to achieve them.

Methodology

The Salus team, (N=4, of whom three were living with HIV), aged 21-25 completed an introductory 'Salus approach' training programme, followed by on-going mentoring from the PI throughout the programme.

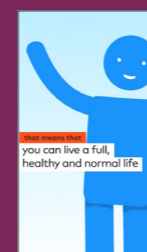
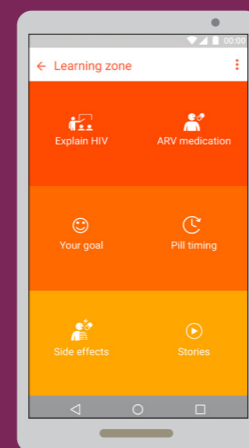
Adolescents (n=20), aged 18-26 years were included in the pilot. The group met every two weeks with bi-weekly 1-2-1 follow-up sessions conducted by Salus team members. A series of semi-structured group interviews were conducted that explored the impact of the intervention among participants. A qualitative questionnaire was also conducted examining the app's impact on participants' understanding of treatment and their motivation to adhere to it.

Thematic analysis was used to identify patterns that emerged from the data, enabling a greater understanding of the impact of the intervention.

"I used to consider committing suicide, but now I have found purpose in life, I have a child that I want to live for which I refer to as my motivation for my treatment. My mother died when I was 20 years of age and it was painful, so I don't want my child to go through the same situation that I went through, so in order for me to protect her I must take my medication."

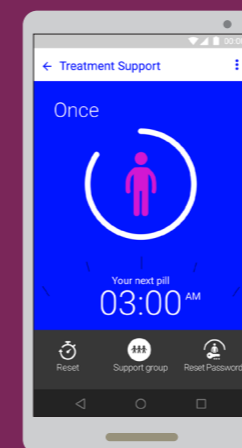
The Salus app

The Salus app was designed to encourage young people to learn about HIV and its treatment, and coach adherence to ART. Based on findings from formative research the tool was not intended to be a 'standalone' digital intervention that would work independently from interpersonal support, thus it was used as part of the overall approach.



Learning Zone

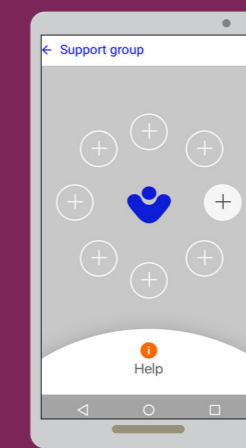
The Learning Zone comprises a series of animations that help young people to learn about HIV and treatment.



Treatment Support

This function enables a person to set their pill times so that the app can send them a series of reminders during the four hour window that supports a patient to achieve optimal adherence.

The reminder includes a visual graphic showing that the medicine is at its low peak in the body, and requires 'topping-up' to ensure continued viral suppression. A button appears at the set pill time, which when pressed fills the circle with colour, showing that the medicine required to continue viral suppression has been enabled.



Virtual Support Group

Individuals can create their own virtual support group. Each support member simply downloads the App and connects to the secure group network. Group members have the option of receiving each others (or a single person's) notification so they can remind and encourage one another.

Findings

The following five themes emerged from the data:

The need to talk and be understood

All participants spoke about their struggle with stigma and how they felt about being HIV positive, describing overwhelming feelings of depression, anxiety and social isolation:

"I don't know where to start, I try to hide it away, but sometimes I try to show people hoping that I could explain and tell them what I am going through. Mostly at home, I don't show my family that I am not feeling well, not because of the medication, but because of what's happening in my life. I need a friend, someone I can talk to about my issues, and help me figure out some things I don't understand".

These feelings were echoed by several participants who also spoke about feeling isolated and alone. Being a part of the group where they could openly share their experiences and feelings was seen as especially supportive and important:

"These support groups are effective because, in our communities, we are not accepted, nor supported. But, when we are together in this group, we find ourselves because we know we share the same pain, we have a lot in common, and we know and understand each other".

The trauma of loss and isolation

Participants talked about their historical contexts of HIV, often describing traumatic experiences that had affected their lives. These included unresolved hurt and anger towards their mothers who had not told them that they had been born with HIV. In some cases, young people discovered their status because their mother had recently died:

"You know I'm so angry, so angry because she never told me. Then she died and I was told, I have it too. I'm so angry, and that's why I don't take my pills".

Similarly, a young man described how he was also struggling with his anger towards his mum:

"I am angry with her, but I don't know what to do with my anger because I want to tell her that I am angry, but she is not here now, so how do I get rid of my anger?"

As participants began to share their stories and feelings, others in the group became confident about describing their traumatic histories that often included significant levels of loss and isolation:

"(Crying)...I know how it feels to be alone because I grew up alone. I lost my mum at the age of 5, and my dad got remarried, so my grandmother raised me, but it wasn't long before she died. So, I was left with my cousin, so every day I had to look for work. I was only eight years old when I started to work to make sure that we had something to eat at home.

There was no one to tell me about HIV, so I was afraid to go out in case I would infect someone. I was just alone, no mother, no father, and my grandmother was sick in bed, so I had to wash and take care of her".

The challenges of disclosing

Participants spoke about how difficult it was to tell their partners that they were HIV positive, mostly because they were frightened that they would be rejected, leaving them feeling unlovable and isolated:

"Disclosing to my boyfriend, that is going to leave you. No I can't."

In response, other participants described how they had chosen to tell their partners because they had prepared themselves for an adverse reaction, explaining that if their partners loved them, it would not be a problem:

"I told my boyfriend that if he loves me, he will stay with me, and if he doesn't, he can leave - it's his choice".

One participant, however, described that despite attempting to tell her boyfriend about her status, he continually refused to talk about HIV:

"My only problem now is my current boyfriend. He is very stubborn and doesn't want to hear anything about HIV. We have been dating for four years, but I still can't tell him about my status because he is very stubborn".

"These support groups are effective because, in our communities, we are not accepted, nor supported. But, when we are together in this group, we find ourselves because we know we share the same pain, we have a lot in common, and we know and understand each other."

“The films are motivating and somehow they give me self confidence to be able to talk about my status.”

Yes, I have learnt a lot about how to take treatment well, how the body reacts to the pills depending on how you take them, different lines of HIV also depending on how you take your treatment. I now see the importance of taking treatment.”

Participants also shared their fear of experiencing stigma because they had witnessed others who had been rejected by their families:

“The reason I don’t disclose my status is that there was a lady who was our neighbour and became infected from her boyfriend. She got sick and went for a test and was positive. Then after telling her family, they didn’t want anything to do with her, they didn’t even want to eat out of a spoon used by her. She ended up going to live in the Eastern Cape and died because she was not taking her treatment because of the way her family treated her”. That’s why I don’t want to disclose because I saw something with my eyes that shows how it would be like if I would disclose”.

Authentic support

Group members repeatedly spoke about how much they valued the authentic quality of their relationships with the Salus team. An important aspect that was particularly important to them was that the team members were of a similar age and were also living with HIV:

“We’ve always had support from our counsellors and other organisations, but the difference with Salus is that we are getting support from people who are the same age as us which is nice”.

Others spoke of how they felt ‘loved’ by the Salus team, describing them as encouraging, supporting and loving. The group nurse echoed these views, expressing her enthusiasm because group members were able to share their feelings in a supportive environment:

“I would like to say to the Salus team, you guys have made my job easier because the kids are now better than before. Thank you guys for your support, your care for these young people, you’ve made them better, I can see the change in them now, sharing is no longer a problem”.

The app and my adherence

All participants were introduced to the app and downloaded it onto their phones. In a few cases, this posed several issues, mostly attributed to old phone models, or having insufficient memory. In these cases, participants were given new phones.

The learning zone animations

Participants found the learning zone helpful, teaching them aspects about HIV and treatment

that they did not know before. Gaining a new understanding of the meaning of an undetectable viral load was particularly noted:

“I think the Learning zone animations are very effective in educating us, introducing us to the information that we are not exposed to as people who are living with HIV. The learning zone animations guides us to know more about what we are living with and how we can fight against it using a simple weapon which is treatment”.

“Yes, I have learnt a lot more about how to take the treatment well, how the body reacts to the pills depending on how you take them, different lines of HIV also depending on how you take your treatment. I now see the importance of taking treatment”.

Four participants said that they had not learnt anything new from the animations, although they reminded them about essential aspects of adherence.

Films:

Participants said that they found the films motivational and encouraging. The core messages of acceptance, support and gaining love from family members particularly resonated with many in the group. A number of participants spoke about how the films provided them with hope, whilst others described how the stories increased their confidence to tell others about their status:

“The films are motivating, they giving me hope and they also show that there are people out there that still cares about us”.

“The key messages that spoke to me from the film is that I must never lose hope about my future, I must always be strong and faith”.

“The films are motivating and somehow they are giving me self-confidence to be able to talk about my status. I relate a lot to Lee’s film”.

The virtual support and pill function:

Several participants found this function particularly helpful. They described how they felt motivated when they could see other people in the group had taken their medicines, motivating them to take their pills because they didn’t want to be left behind:

“ you know I saw the others had taken their pills and thought, I must take mine now; otherwise one day they will see me by my grave-looking down on me because I missed my pills”.

A young woman spoke about how she also felt motivated from seeing others who had taken their medication, describing that she wanted to “stay as beautiful as them, which is only possible if you keep well with your medicines”.

In contrast one participant described that although the app was helpful she did not take her medication because she was so angry about recently learning that she was HIV positive:

“I do have the app on my phone, but I don’t take my pills. I am still angry and depressed because I haven’t accepted my situation. The app helps, but when I’m home my anger and depression starts, and I take it out on my treatment by not eating it, I don’t know why”.

In contrast, however, others said that the virtual group was not useful for them because they were satisfied with the support received through the WhatsApp group that emerged during the pilot.

Using the app as a tool to support disclosure conversations:

Twelve participants reported that the app would be a useful tool to support them to initiate disclosure conversations. Respondents spoke about how the app helped them to accept themselves and that the films especially would be helpful to communicate to others that people can live normal lives with HIV:

“I think the app would help because it makes me feel free about my status, it makes me accept myself and my status, I now believe that I still have a lot to experience in life, this app gives me confidence that I could talk with him”.

“Yes, because the app has authentic stories from people who are living with HIV yet look healthy and strong, from their stories maybe I could be able to start a conversation with my belonging about the virus”.

Three participants said that they would not use the app to support disclosure, because they were not ready to consider disclosing their status:

“No, I hide the app because the app is for me only; it helps me not them”.

Conclusion

With the increase of HIV-prevalence and mortality among adolescents throughout Africa, there is an urgent need to explore innovative approaches that locate young people at the heart of HIV-focussed interventions. This is especially important as many top-down approaches are failing. Immediate action is required to mitigate further increases in both infection and mortality rates as Africa’s youth population is expected to grow to 830 million by 2050.

The pilot provides evidence that youth-to-youth psychosocial approach, supported by digital tools designed to teach and coach adherence are viable and have the potential for scalability. The integrative approach was shown to facilitate open spaces where participants felt that they could share their stories and feelings openly, receiving support from within the group. Follow-up sessions focussed on the coaching element, which enabled young people to discuss their hopes, goals and plans. The pilot found that the app was a useful tool that helped young people learn about HIV and treatment, and facilitated group discussion about participants’ relationship with their medicines that provided ‘adherence coaching’ opportunities during follow-up.

However, these findings need to be considered within the limitations of the study. For example, adherence was not measured due to the pilot’s limited time scale and design. Furthermore, the cost of mobile phone data limited usability of adherence support functions throughout the pilot. In response, the app would require adjustment so that these functions were simplified and operate independently from data.

Epilogue

The Salus project included a digital storytelling component that was driven by team members who were skilled filmmakers. During the project, they made several films that included the stories of community members, and from their own experiences of HIV. Towards the end of this pilot, participants wanted to view the movies, and in response became motivated to share their stories too. The main aim of doing so was to raise awareness about what it is like to experience stigma as someone who is born with HIV. The following podcast series was produced that showcases the voices of these very courageous young people who live with HIV and related stigma.



Young people talk about HIV stigma and the challenges of taking their medicines



<https://open.spotify.com/show/0sIVBn50aGvXbbjqCcQjal?si=fc0hyDxvQ62cHH7qkUf0qQ>



The mask I wear on the inside
A young man’s story about his experience of stigma.

<https://vimeo.com/425150339>

A young male participant joins the team, inspired by their vision and purpose, tells his own moving story about his experience of HIV stigma.



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This report is the result of a truly collective effort. We express our sincere gratitude to all the local community members, health care professionals and volunteers in Khayelitsha who participated in the study, especially the many young people who shared their stories and experiences. In addition, particular thanks are due to the Salus team led by Mr Aphiwe Mtendeni.