Zumbido Pulse

Deep Dive:
Empowering youth communities to transform global health research

April 2024

zumbido
HEALTH

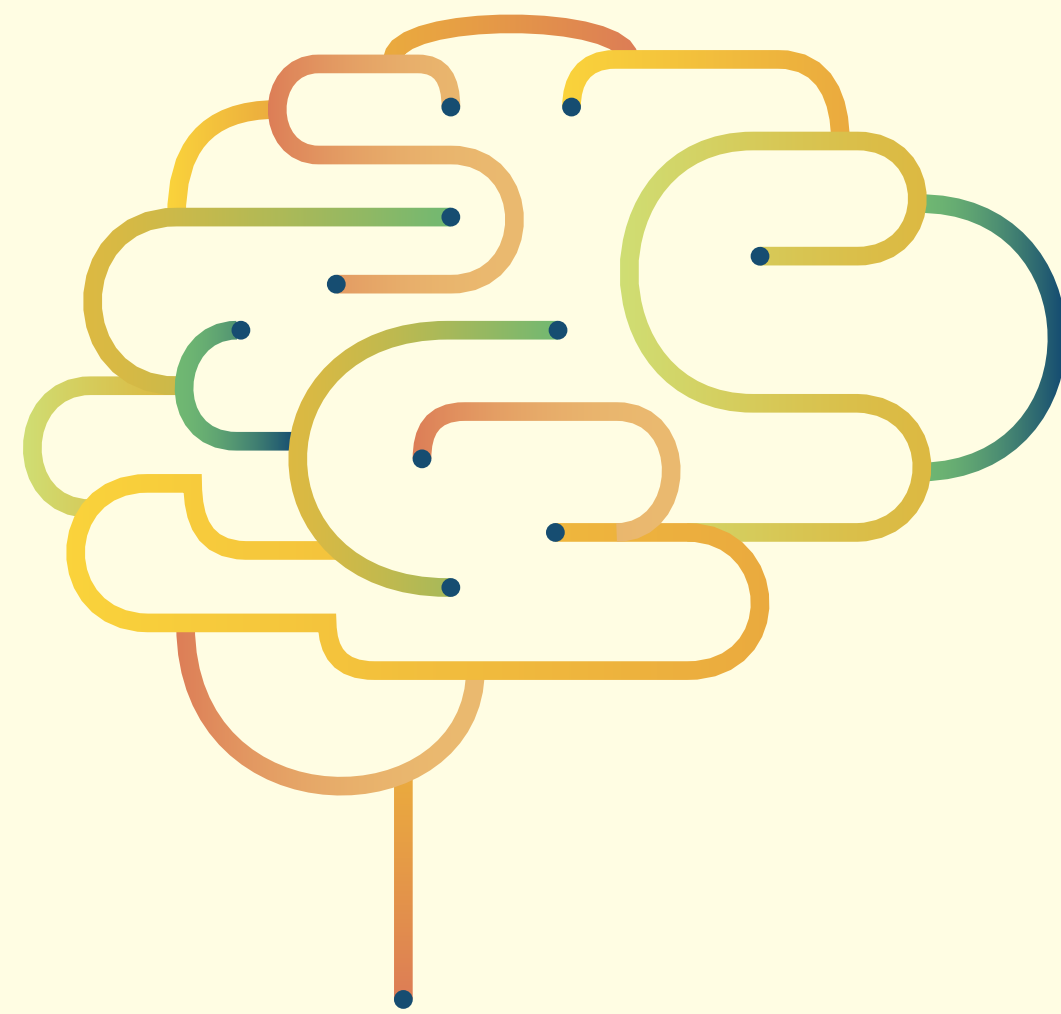This document has been designed with interactive elements.

For the best experience, open with
Adobe Acrobat Reader

Download Acrobat Reader

🔊 Click on this icon to play excerpts from interviews

Welcome to the fourth edition of Zumbido Pulse, a regular publication by the SHM Foundation in which we share insights from our Zumbido Health programme.

Zumbido works to improve the mental health and wellbeing of vulnerable, socially isolated groups of people, particularly those living with chronic or stigmatised health conditions.

The Zumbido model uses digital technology as a mechanism for overcoming those challenges by creating online communities of peer-to-peer support.

The communities that come together through Zumbido's programmes possess a unique wealth of knowledge on the issues they face. **By sharing their experiences, hearing about the experiences of others, and coming together in groups to find solutions to complex challenges, Zumbido participants become experts in tackling the mental health challenges** that often come with certain physical health conditions.

We feel it's important to share their insights, learnings, and stories with the global health community, so that more health policies, services and research might be informed by the people affected by the issues at hand.

In the previous issue of Zumbido Pulse, we demonstrated the importance of valuing experts by experience by exploring how Zumbido Health centres lived experience in the design, implementation, and adaptation of its programmes.

In this issue, you'll **learn about how young people who took part in Zumbido's South African chapter, Khuluma, became ethnographers of their own community through an academic partnership, bringing valuable insights into the factors affecting the mental health of adolescents living with HIV**.

This issue begins by detailing the different stages of the ethnographic research process as shared by the Mentors and Dr Nikita Simpson, Lecturer in Anthropology at SOAS, University of London. This is followed by the findings from the study: the challenges faced by young people living with HIV, with concrete examples focused on an individual level, in family settings, in healthcare settings and at a community level; the solutions and strategies young people are deploying to address these challenges; and what young people believe needs to change to enable them further. This edition concludes by exploring what the Mentors' experience can teach us about approaches to research in global health.

You can listen to the audio clips embedded in this article, where you'll hear them speak about their experiences, what they learned, and why this approach to research is so critical today.

The backstory:

Khuluma and the Mentor Programme

In South Africa, the Zumbido model is called Khuluma. Khuluma is an initiative working to empower young people living with HIV to lead healthy, active, and happy lives through a digital support group.

Young people who participate in Khuluma's digital support groups can join the Khuluma Mentor programme. In this programme, participants are trained to deliver peer-to-peer psychosocial support to future participants of Khuluma's digital support groups.

Currently, Khuluma has 20 Mentors. They combine their lived experience expertise with the training provided by Khuluma to ensure that young people living with HIV and facing mental health challenges receive the same life-changing support they once did. They support the running of all Khuluma groups and the replication of the Zumbido Health model in other parts of Africa.

Khuluma brokers partnerships between Mentors and academic institutions because their expertise-by-experience can help researchers design health services that put its young users at the centre. This also offers the mentors valuable educational and career opportunities.

In 2022-2023, Khuluma facilitated a partnership between six of the Mentors and Dr. Nikita Simpson, Lecturer in Anthropology at SOAS, University of London, to conduct an ethnographic study into the factors affecting the mental health of adolescents living with HIV in Pretoria, South Africa.

Before the partnership began, the Mentors already knew this much: many adolescents living with HIV face stigma, discrimination, and inadequate health provisions, leading to poor mental health outcomes. They had experienced this in their own lives, they had seen their experiences reflected in their peers in Khuluma's support groups, and they had mentored younger people facing the very same challenges.

"Before we started the research, we already knew of their lived experiences, and the kinds of challenges they experience personally as young people living with HIV in South Africa."

The Mentors wanted to find out how prevalent these issues were among adolescents living with HIV who had not taken part in Khuluma's programme. They also wanted to find the root causes behind why so many people in their age group who were living with HIV were struggling to live balanced, happy lives – and how different parts of society could come together to tackle these causes.

To do this, they needed to look beyond the Khuluma support groups, and go further out into their communities.

They needed to investigate how young people living with HIV and mental ill-health were interacting with and treated by their families, peers, support workers and healthcare facilities.

They also needed to decide how to approach this investigation in the right way: what questions to ask, to whom, and how to approach them; how to keep personal biases from clouding their judgement; how to make sure vulnerable people they interacted with were protected, and how to keep themselves safe, too.

zumbido
HEALTH

The backstory:

Khuluma and the Mentor Programme

Learning about the field of anthropology and co-designing a study

To prepare the Mentors to go into their community and conduct an ethnographic study, Khuluma organised a partnership with Dr. Nikita Simpson. Dr. Simpson has extensive experience researching, developing interventions, and providing policy advisory on mental health, care, and inequality. Her background in ethnographic research and community-based approaches to mental health care would help equip the mentors with the right skills to tackle the questions they wanted to answer.

Dr. Simpson's workshops were designed to introduce the Mentors to the field of anthropology, equip them with the skills to carry out an ethnographic study, and help them design this study themselves.

The research was highly personal and collaborative. Mentors started out by selecting topics that they felt most resonated with them, and helped one another to identify the right way to approach finding out more about their given topic.

"Our first task was coming up with a topic. Each of us had to come up with their own topic for our research. That was our starting point. "

Why ethnography?

There are many ways to conduct a study into the factors affecting the mental health of a given population.

In fact, most research in global health, particularly in HIV and mental health, is conducted using an etic, rather than emic, framework.

Emic vs. Etic?

In short, an etic framework is when ideas and concepts that already exist in a field are used as a starting point to understand a community. By contrast, an emic framework, such as the kind of ethnography the Mentors conducted, is when ideas, theories and concepts arise from communities themselves and the findings of the research.

"Usually, when you're looking at HIV and mental health, where thinking about what are the frameworks from psychology, or global health, or medicine, that can help us explain people's experiences? Whereas in anthropology, and using ethnography, we're looking at what are the concepts and ideas and theories that people themselves have of HIV and mental health?"

"I'd never done an ethnographic study before. And in terms of the methodology, especially in terms of the core designing of things, like how we're taking things step by step, it was really something new to me. It was quite interesting for me because usually with research, they have a set methodology on how things should be done, right? But with this one, we were discussing it at first. You are actually part of the process and you actually also playing a huge role in deciding on how things are going to be done."

This particular style of research was led by a simple principle:

Research Conducted By And For The Community

The complexity of ethics in community-based research
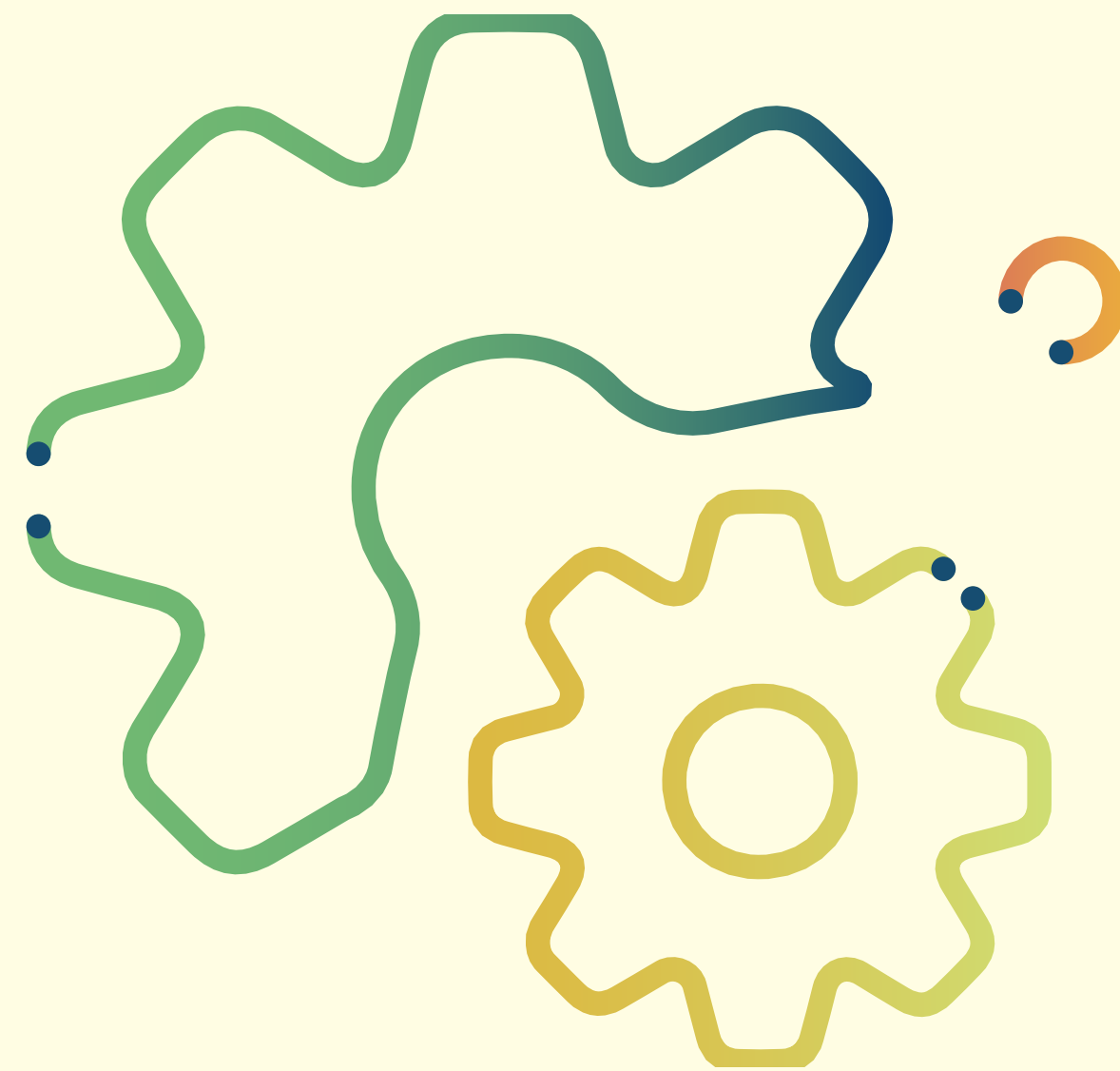
Young people living with HIV and mental ill-health are a particularly vulnerable group of people who experience high levels of stigma and often conceal their HIV status to protect their safety. This means those conducting an ethnographic study among them have to be very careful that the participants of the study are sufficiently safeguarded. Moreover, the subject matter of the research – the causes of mental distress – is particularly tough for those with lived experience to discuss, and can be triggering.

This particular ethnographic study had an added layer of complexity: the researchers were also young people living with HIV.

On the one hand, this meant that some participants felt safer disclosing their status and sharing facts about their life with the researchers. On the other hand, it meant that the researchers themselves were also at risk of being outed or triggered.

The Mentors were therefore extremely careful with how they approached ethical concerns. They spent several workshops discussing the implications of their work with each other and Dr. Simpson, and planning how they would deal with difficult situations that could arise.

"With ethics, it's not just about the participants. It's about both parties involved and protecting yourself – getting the information that you're going to get from your participant, but also *safeguarding* yourself in terms of the location, where you're going with your participant. Also, what happens to you if you get triggered? What happens if you get overwhelmed by the information that the participant shares with you?"

"One thing I was most struck by was how this group of young people were really, really careful, for example, about disclosure for both themselves and others. They went really carefully through consent form processes and things like that. And so, you know, they really learned to not only conduct research in a rigorous way, but also in an ethical way where they weren't exposing them or others to harm. And I think that's probably was the hardest bit because I think there are a lot of harms out there, and research has caused a lot of harms to the kinds of communities that they live in."

Developing skills and confidence:

'Putting our anthropological hats on'

For some of the Mentors, research was not a totally new experience. Some had completed undergraduate degrees that equipped them with certain field research skills. For others, this project was unlike anything they had ever done before. Although it seemed daunting at first, the Mentors found that leaving their comfort zones was extremely rewarding. They found that the project helped them develop life-long skills and confidence.

Some of the Mentors were conducting interviews for the very first time. Throughout the process, they learned again and again that interviewing is not just about asking questions from a script. Rather, interviewing requires a constant thinking on your feet – reading between the lines of what the participant is saying, knowing when to diverge from your prepared questions to ask a follow-up that could lead to an important discovery.

Ultimately, the skills acquired throughout this project went beyond this particular ethnography. For the Mentors, it was not just an opportunity to think about mental health and social issues in a new way, but a new way of approaching questions about the world. These skills will be invaluable as they continue to share their expertise with academic institutions and research organisations.

"This was my first research. It was quite interesting because I remember the first day they told us about research. I felt like this was beyond me… But as soon as I did the first workshop, I knew that the there would be something different coming out of it."

"I felt excited. I was so agitated to learn about how other people see see HIV and AIDS. I just wanted to learn more on how people think about about this disease. I was so, so interested in the topic."

"It was really eye opening. I think it's having to put those anthropological hats on; it gives you a different view of things. You consider different perspectives viewing the same thing. It was a great learning experience because we were able to learn that there's actually more that goes on. "

"The skills that the mentors developed that were most important were being able to step back from the flux of your daily life and to be able to take a critical analytical view of the relationships and experiences and institutions and life history that one has."

"It was also a learning experience to a lot of people. So we did not only just conduct research, but we equipped people with the skills and knowledge. So I think that's also very important. I'm thinking maybe these skills can be used elsewhere. So I think that's also a great takeaway from the work that we did."

The strengths and challenges of working in your own community

Balancing relatability and self-preservation

Because the research was being conducted by young people with lived experience of HIV and mental health challenges, participants often felt comfortable disclosing their status and sharing personal stories. On the one hand, this proximity between researchers and participants brought richer insights, as participants shared aspects of their experience which they might otherwise conceal from an interviewer they did not trust. On the other hand, this was also challenging for the Mentors, who saw that their hardships were common among their peers, and that these widespread challenges were at times difficult to overcome.

"One of the participants that I spoke to said to me, "I really enjoy doing this interview because you can relate to what I'm saying." So me being HIV positive and interviewing someone who's HIV positive was a bit easier for them, because I could understand where they're coming from. And I allowed them to speak freely about the things that they're going through. I got to sit down and tell them about my experience of being a young person living with HIV, what I went through. So they can be free. It was also easier for them to open up to me and speak freely about the things that they went through. The difference is that we understood each other."

"It was research conducted by young for young people. I think peer engagement might have aided to the openness and how raw the results are. Most of our interviewees are pupils or young people. It made it a bit easier for them to engage and to open up about really sensitive issues, right? So we were able to get results which are very raw and very honest, you know, unfiltered."

"While I was analyzing and listening to the audio, to be quite honest, it was quite difficult. Especially because I've been there. I had a [family member] who believed in supporting me financially instead of emotionality. And that also drove me to a point where I stopped taking my medication and I told myself, "You know what, it's fine, I would rather I ended it now than to live with someone who will to be treating me like this." So it was quite an emotional thing to go through, having to listen to the interviews. So, it was a bit of a challenge, but we pushed through."

The strengths and challenges of working in your own community

Expanding horizons
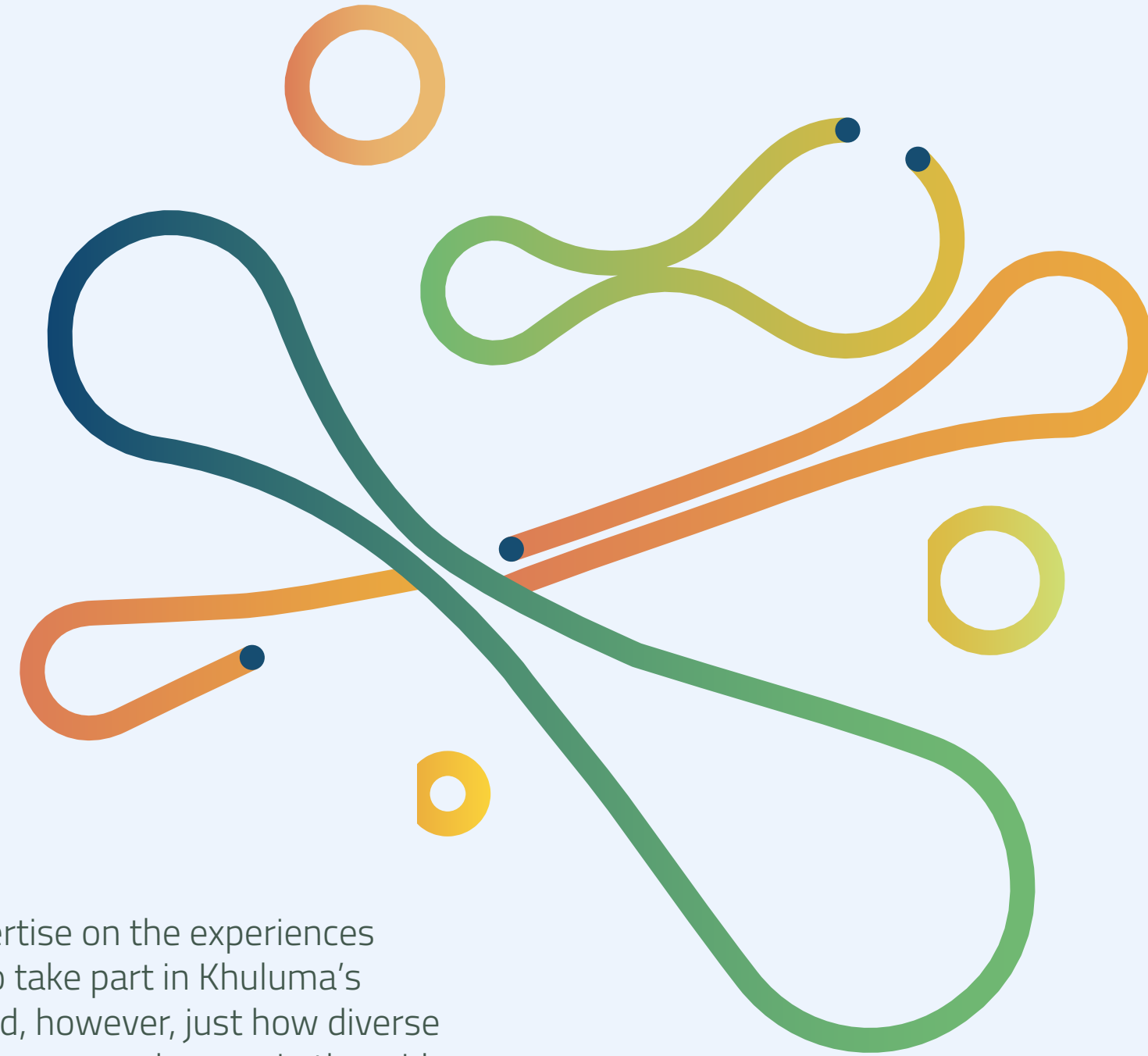
The Mentors had considerable expertise on the experiences of young people living with HIV who take part in Khuluma's support group. They had not realised, however, just how diverse perspectives on the issues facing young people were in the wider circles of the community. By working with people of varying ages and social backgrounds, they got not only a fuller picture of the factors affecting the mental health of these young people, but of the very community in which they live.

"I have learned to work with different people and different minds on a daily basis. Most of the time, I was mentoring young people. So doing the research, I've got an opportunity to question the people who are older than me. I have managed to work with different people, different minds, different genders, different ages."

"The insights you get from doing the study, I think that is somewhat a game changer. As much as we have mentors who somewhat represent [young people living with HIV], we had to really go back and hear from the ground what they felt the issues are, what change they wanted, what they are going through. Also, it proved that the needs of young people are constantly changing. We need to be on the ground and to gather updated information on those needs, on those changes."

zumbido
H E A L T H

The Findings

The challenges faced by young people living with HIV

The Mentors found that young people faced a range of intersecting challenges in different settings.

Personal

Many young people struggled to accept their HIV-positive status, making them uneasy about disclosing to others. They felt anxious about the transition to adulthood and how this might affect their experience of HIV. Mental health challenges stemming from the difficulties of living with HIV often strongly correlated with substance abuse issues.

In healthcare facilities

Young people living with HIV often experienced healthcare facilities as confusing and unfriendly. Long queues often led to uncomfortable experiences, and many found that healthcare workers appeared unempathetic, distrusting and lacking in communication. Crucially, many young people feared going to healthcare facilities for fear of their HIV status being outed to their community members.

At home

Many young people faced a lack of emotional and financial support at home. Often, cultural and religious beliefs around healthcare practices meant that adolescents were discouraged from taking the right medications for their condition.

> "I wanted to understand the kind of support that [young people] receive for home [versus] the support that they want for themselves. And it differs quite a lot. The support that they get is not the support that they want. "

In the community

Among their peers, adolescents living with HIV often felt rejected, stigmatised and stereotyped. As a result of the stigma surrounding HIV in their communities, many found it hard to disclose their status. They were also often peer-pressured to engage in dangerous behaviours such as substance abuse.

> "We were able to pinpoint things which contribute to mental health which are not only related to their HIV status. There was knowledge that if you're HIV positive, maybe your mental health is not that good. So then we came and and understood that there is other stuff which you can add on to that. And they might even have a greater impact than the stigma. You know, you might be stigmatized, but when you get home, you get the support that you need and you are able to be adherent to medication because you have all the support at home. But if you get stigmatized, then there's lack of support [at home] as well, then there isn't any support."

zumbido
HEALTH

The Findings

Solutions and strategies

Through their research, the Mentors found that young people are already developing solutions and strategies to overcome these challenges.

Young people have discovered that...

1. Support networks of lived experience provide safe spaces

2. Self-care and seeking therapy improve emotional wellbeing

3. Pursuing education about issues affecting oneself (both through independent research and asking peers about their lived experience) can reduce self-stigma

4. Treatment buddies can aid in maintaining medication adherence, as well as provide support

5. Family education can improve support available and increase wellbeing

A need for change

However, the mentors also found that there is an urgent need for change in several social spheres in order to ensure that young people's mental health needs are met.

Young people need...

1. Better safeguarding and support in hospital settings

2. More peer support groups in their communities

3. Education programmes for their family members to create safe spaces for disclosure

4. More safe spaces for LGBTQIA young people in their communities

"I want the information to be out there, especially in the hospital and with the community. How many how many other young people are there who are actually going through the same thing? Who are not emotionally supported by their parents? I wanted the information to be there so that they know how to better help other young people who are living with HIV. Also, for the hospital and for the hospital staff to know how to literally care for their patients... I want the information to be out there with the right people and make sure that it improves the lives of young people living with HIV. People would know how to better understand certain situations."

What do we mean by [safe spaces]? Not only a particular building or a structure as a safe space, but from where they come from, their households, their health care facility. That should be safe enough to allow that young person to be able to fully participate in it, just be comfortable, to be able to improve their adherence or mental health."

zumbido
HEALTH

What can the Mentors' experience teach us about approaches to research in global health?

This research challenged epistemic hierarchies by privileging the expertise of community members on their own environment. This research was conducted by young people, for young people. Rather than limiting the scope of the project, this approach only enriched the findings.

We hope to highlight to the global health community just how valuable community-led research can be.

We think the key benefits of this type of research are:

1. Participants feel comfortable sharing information with researchers with whom they feel they have shared lived experiences, bringing richer insights.

2. When researchers share lived experiences with participants, they bring new and valuable perspectives to ethics, mitigating the harm that can sometimes be caused by ethnographic research.

3. Researchers can bring lived experience into their analysis, adding a dimension to their interpretation of the qualitative data.

4. Foregoing typical frameworks of analysis allows for insights to be drawn from the information at hand, rather than imposed onto the findings.

5. Researchers who work collaboratively and offer each other peer-support avoid going into silos and generating repetitive findings.

6. Giving young people the skills to analyse the goings-on of their own community empowers them to effect change.

"So what made this research project really exciting? So the story of this research project is really, for me, one of listening and of reflection and of working together with a group of people to strive to build a set of relationships that make a certain kind of equity possible in terms of the conception of research. What made this really exciting was that I got to work and actually be led by the research interests and capacities and skills of the mentors."

Thank you for reading!

Please get in touch with any questions or comments, or if you are interested in collaborating with the SHM Foundation on a project.

You can look back at previous editions of Zumbido Pulse to understand more about our approach to co-designing social support interventions and honouring the insights of experts by experience.

You can find the 2020, 2022 and 2023 editions on our resources page.

Look out for our next edition soon!