

Zumbido Pulse

**Looking at the Zumbido Health model
in practice**

October 2021



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

Zumbido's focus is on improving the mental health and wellbeing of vulnerable, socially isolated groups of people, particularly those living with chronic or stigmatised health conditions.

The model uses mobile phones and digital technology as a mechanism for overcoming those challenges and barriers and creating peer communities of support.

Although social isolation is not just a consequence of the COVID-19 pandemic, it has made this issue more visible and urgent in our lives and communities. Finding ways to forge human connection and solace in the midst of isolation, stigma, health issues and economic and social struggles is only becoming more important.

That's why we feel it is particularly important right now to continue sharing insights, learnings and stories from our work in this field.



What's new

In the last edition we shared the origin story of Zumbido, and offered a starting point for thinking about how to design support interventions that make use of digital technology.

Our main message was that digital technologies are only ever enablers, never solutions in themselves, and that there are several important questions you need to ask yourself before reaching for them. The process of understanding the aspirations, needs, capabilities and resources of your participants is crucial to work out what kind of technology is suitable, how it should be used and modified, and what potential pitfalls to avoid.



In this edition we share some of the fruits of this process in our own work. Over the last 12 months we have implemented the Zumbido model in four different projects in three countries in Southern Africa: **Insaka** in Zambia, **Khuluma** in South Africa, and both **Zvandiri Lounge** in Zimbabwe.

The populations we've worked with in each have had varying needs and expectations, and so the resulting intervention in each context has looked different, and been incredibly varied in the kinds of engagement and connection it has produced.

We hope that this edition can shed light on the nuances of incorporating digital technologies into social support programmes - or indeed other kinds of health or development interventions - and how subtle adaptations to digitally enabled models can generate very different digital spaces.



A reminder...

The Zumbido Health model uses mobile phones to create social support groups for vulnerable, socially isolated groups. Often, these are groups of people who are living with a stigmatised health condition, such as HIV.

It is a **time-bound social support programme** wherein participants are placed in support groups of 10-15 peers who share similar experiences. These support groups are enabled by a digital platform, where participants discuss - peer to peer, at any time, via text message - a range of issues pertinent to their condition or needs, and their lives more generally.

The groups are sometimes facilitated by the **SHM Foundation's peer mentors**, a group of young people living with HIV in South Africa who have been through the Khuluma programme and received training in peer support. Other groups are facilitated by trained peer support workers from our on-the-ground partners.



The primary purpose of our model is to produce a space where participants can access peer and expert support and feel less alone.

Through open and non-judgemental discussion, participants can deal together with key issues, such as disclosure, family and caring responsibilities, experiences of stigma, domestic violence and health management. It's a space they can also offer support to others experiencing similar situations. The benefits of this experience are felt not only in the lives of participants, but have knock-on effects in the lives of those around them.



The Zumbido Health model is premised on a recognition that individualised mental health care has limitations.

This kind of mental health care serves an important purpose, but it is not the only route. We also need group spaces where we can connect with others to receive support collectively.

The following case studies give a flavour of what the collective spaces of Zumbido interventions look like in practice.



Insaka

Lusaka, Zambia

Participants

Pregnant women and new mothers living with HIV, aged 18-24.

Partners

Zambart, Imperial College London, London School of Hygiene and Tropical Medicine.

Type of project and partnership

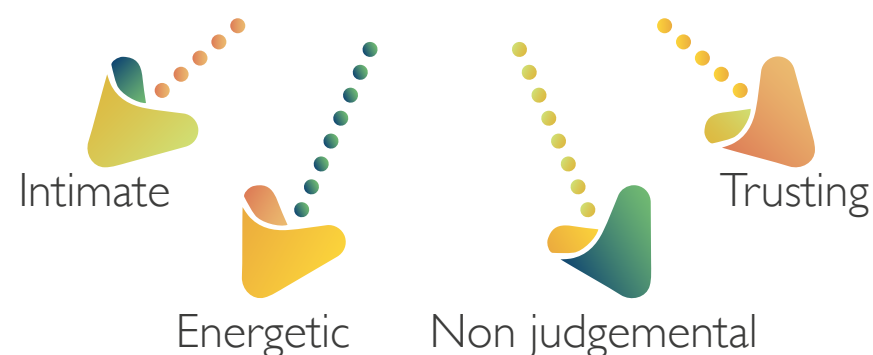
Research project: Nested study within a community-based randomised control trial (Yathu Yathu); scaled up from a pilot study conducted in 2018-19.

What was the digital space for?

Insaka means 'meeting place'. This was a distinctly women's space, facilitated by experienced peer support workers who are mothers themselves. Insaka provided a space outside of participants' domestic duties and relationships where women can seek support for their needs and those whom they care for. In times of distress like when they are disclosing their HIV status, contemplating separation or experiencing abuse, it provides women an alternate source of real-time advice and understanding.

It was used by women as a space to share intimate concerns about their relationships, and seek advice about health issues related to pregnancy, nutrition, gynaecology, family planning and children's health. It is a space where they could share insights on how to care for their husbands and children, manage finances and provide support for each other as they go through difficult experiences.

Feels like... ...a girls' night in



Prominent topics discussed

- Sex and sexuality
- Marriage, divorce and extra-marital relationships
- Women's health issues and family planning
- Gender-based and intimate partner violence
- Caring for children
- Domestic management including finances, employment, housework and cooking

How engaged were the participants?

There was an incredibly high level of engagement in these groups. The participants sent 71,415 messages and counting!

What was interesting about these groups?

These women often communicated late at night when their children and partners were asleep, and all the household chores were completed, as it was the time of day when there were the fewest demands on their time and attention.

We are conducting a rigorous evaluation of this project, including collecting viral load data to see if our work has an impact on adherence behaviour and hence viral suppression.



“Mother's...today i was at kanyama clinic and a lady came asking where GBV... she just moved in the house where she is currently staying..a woman knocked at her door pushed her child and hit her on her face ...making a big scar...the same woman thought she was beating husband's girlfriend kashi she shifted and she and's up assaulting another person..mothers what can you say this behaviour”

“Awe it's like..she was tipped by people that that is the house and door where the girl friend of your husband stays.. so after she hit her ...when neighbours came they said this is not the woman who is going with your husband..she shifted”

“Yes dear...it is really sad and to make matters worse this woman who was hit is pregnant and she looked injured mwandi”

“Is she mad? because this days even if your husband is cheating on you ,you have no power to beat your husband girl... i can't beat her course she is a woman like me i don't know if my husband lied to her that his single or maybe she knows that his married so i can't do anything course the problem here is the man”

“But dear..do you think it is a good idea to follow up your husband and beating the girlfriend”



Khuluma

Pretoria and Cape Town, South Africa

Participants

Adolescents living with HIV, aged 18-24.

Partners

Kalafong Hospital, University of Pretoria.

Type of project and partnership

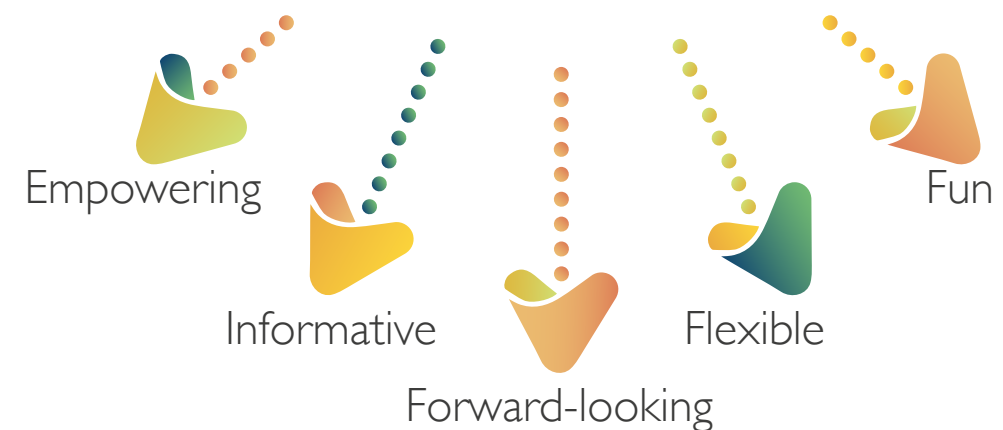
Ongoing programme that provides psychosocial support for adolescents living with HIV in South Africa.

What was the digital space for?

The purpose of the Khuluma groups is to provide adolescents living with HIV in South Africa with mental health and wellbeing support that they need to overcome social isolation and stigma.

Adolescence is a challenging time in life and living with HIV brings added complexities on top of that. Many adolescents living with HIV struggle to take medication, fearing this will lead to their status becoming known, leading to rejection by their friends and family members. For many adolescents, Khuluma is the only space where they can feel themselves and where they can talk freely. The groups provide a safe and secure place for the adolescents to talk about challenges that they face as they navigate through adolescence; talk about feelings and experiences; share funny stories; and talk about aspirations for the future. The participants can also access health advice, participate in career discussions, and talk about healthy nutrition with Khuluma guest speakers. The groups are co-facilitated by the Khuluma mentors who have taken part in the groups and who are now the champions and the driving force behind the Zumbido Health program.

Feels like... ...a youth club



Prominent topics discussed

- Relationships and dating
- Family relationships
- Challenges related to disclosing HIV status
- Adherence to ART
- Hobbies and entertainment
- School work and employment
- Future aspirations

How engaged were the participants?

This set of groups saw a moderate level of engagement, varying over the time period. It tends to go down around school exams, so we try to avoid these periods.

What was interesting about these groups?

For many adolescents that we've worked with, Khuluma groups, was the only place where they could be themselves and express their true feelings. Many of them told us that they had never been asked about their feelings before and had to simply accept their status and treatment. Khuluma provided for them a space where they could question things and where they could express their opinions while being able to access advice and support from others.



“U 2 enjoy your day”

“Love you later then my transport is hear enjoy u day”

“thanks Lebza”

“DID YOU TAKE YOU MEDICINES BE FOR YOU GO”

“They were making me vomit so i stopped but now I drink them. I didn't take them for 2 months after I was admitted to hospital. I spoke to the dr ... I drink them with a yogurt now”



Zvandiri

Harare and surrounding areas, Zimbabwe

Participants

Adolescents living with HIV who are peer supporters.

Partners

Africaid Zvandiri.

Type of project and partnership

This project addresses the mental health needs and skills gaps of Community Adolescent Treatment Supporters (CATS) and aims to provide them with adequate mental health and professional support.

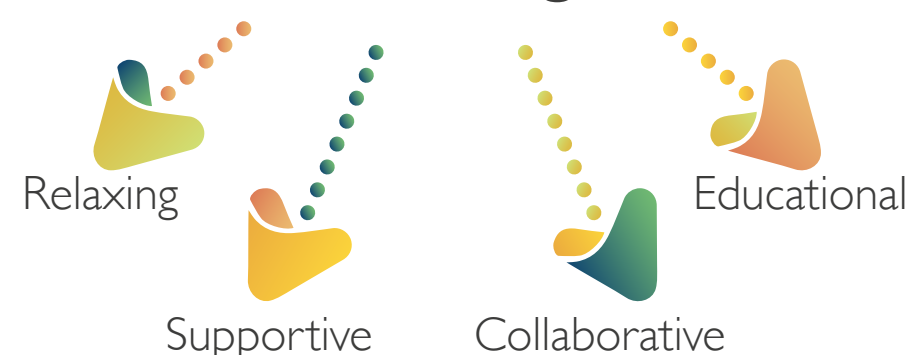
What was the digital space for?

In collaboration with the Zvandiri CATS, we designed the model for their ideal support system as a 'lounge' where they could access peer and professional support informally anytime, anywhere, anonymously.

The CATS were able to communicate amongst each other and access peer support. This project demonstrates how important it is to provide support for supporters so that they can thrive and support others sustainably, and avoid burn-out.

The CATS discussed a wide range of subjects from home visits and supporting others through dealing with stigma and social isolation to future career and aspirations, including fear.

Feels like... ...a lounge



Prominent topics discussed

- Disclosure
- Stigma
- Social support
- Relationships and sex
- Physical and mental health
- The future

How engaged were the participants?

There was a high level of uptake and engagement in these groups, with 88% of participants taking an active part in discussions, and 2195 messages sent in total.

What was interesting about these groups?

It was the first project of the SHM Foundation which was focused on addressing the challenge of how best to build accessible and effective support mechanism for peer supporters so that peer-to-peer models can continue to grow.



“I haven’t disclosed yet to all the girls I had. how do I do it”

“do you have any suggestions to help @Transporter with disclosure to his girlfriend? Disclosure is a process and it’s your choice. We can think about the pros and cons.”

“Yaaa it’s true it’s a choice and u have to know that either she is going to accept you or not put this in your mind... And if you’re not ready to do that don’t force”

“I suggest you have to talk to yo girlfriend privately and face to face. Then tell her yo status ..and see the next reaction ...”

“Ok thanks guys for the advice. I will definitely try it”

Discussion

What we hope to highlight through these case studies is that by combining simple digital technology with a human approach, you can create very different kinds of virtual spaces - whether it's the dynamics of a youth club, a lounge, or a girl's night in.

Creating these kinds of spaces requires an in-depth understanding of the preferences of the people who will use those spaces, and a commitment to putting those preferences front and centre in the design process.

Within Zumbido, we gain this understanding by taking a creative, participatory approach with the people who are going to take part in our interventions. We work with the participants through a series of workshops and conversations, often using methods that involve arts and drama, and then design how the groups will work around their needs and ideas.

The process centres their voices and perspectives. It also requires thinking imaginatively, sometimes through metaphors, to translate dynamics and feelings of "real-world" settings into digital contexts.



It's not rocket science - it's being human.



You can look back at the first Zumbido Pulse to read about the kinds of questions to consider when thinking through this process.

In our next edition of Zumbido Pulse, we will delve further into our participatory approach for co-designing mental health interventions.

