CHAPTER
35

Youth contribution

The Khuluma Mentor programme: Young people's experiences of running a digital peer-led psychosocial support intervention in South Africa

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Khuluma Mentors is a flagship programme of the SHM Foundation in Pretoria, South Africa. The programme aims to provide psychosocial support to adolescents and young people aged 13–24 who are living with HIV, a stigmatised condition that evidence shows can have a detrimental impact on mental health. It does this in two ways: first through peer-led digital support groups, and second, through a mentorship programme that provides mental health and employment support.

DOI: 10.4324/9781003341666-40

At the heart of the programme is young people's participation in co-design, recruitment, delivery and monitoring of impact. In this piece, a group of mentors who have been with the programme for up to nine years reflect on the programme and the ways it has been effective in centring the voice and agency of adolescents and young people who are living with HIV.

Khuluma Mentors are young people in their late teens and early 20s who have tested positive for HIV. Many of us have also previously participated in the peer-led digital support groups. As part of becoming mentors, we receive training using a curriculum that covers various topics related to HIV/AIDS and psychosocial peer support. We are then supported to facilitate peer support groups with training on how to broach challenging topics, help young people feel comfortable discussing HIV and other issues, and offering support as needed.

The peer-led digital support programme works in collaboration with departments in the local hospital which offer HIV testing for both under-18 year olds and older youth aged 18–24. Mentors attend face-to-face support groups offered to adolescents and youth who have tested positive for HIV and introduce themselves and the programme. We explain that the purpose of the programme is to provide a digital social support and information system which adolescents and young people will be able to access for a period of three months.

Upon joining, young people answer a questionnaire co-designed by the mentors, which assesses what sorts of information and support would be the most useful to them. We mentors analyse this information and then use it to adapt and structure the curriculum on HIV/AIDS and psychosocial support to the young people's priorities and interests.

The new participants are then given a phone which is pre-loaded with a messaging app. Usernames are created for each young person to provide anonymity. A group is then created in the app, with ten participants per group. The groups are organised by age rather than gender, based on the preferences expressed by young people, so generally there are groups of 13–17 year olds and of 18–24 year olds.

Two mentors of any gender are then allocated to each group of ten. We keep an eye on the conversations in the app every day, checking in on participants by instigating conversations, encouraging them to share their thoughts and feelings, and offering psychosocial support to the young people in the group.

The app has a referral system in place for issues that may be beyond the capacity of the mentors to handle. Red flags are attached to certain words so that if a word such as 'rape' is mentioned, then an external monitor which has access to the real identity of the young participants will get an email to say they've mentioned this. The monitors have the personal details of the person and will call and check on them to see if they need more support, whilst at the same time, the mentor of the group will make extra effort to include them in discussions and check on them virtually. If young people in the groups express an interest in learning more about a certain topic or issue, mentors can organise a guest speaker who will join the group for a certain amount of time and they can ask them questions anonymously.

After the three months have passed, we hold a focus group discussion to assess whether the group has been useful for the participants in improving their mental well-being and self-efficacy, especially in relation to coping with stigma. Through a post-assessment questionnaire, we also check if there are other ways that young people would prefer to engage, and we monitor how young people are doing over time.

This information is also used to improve practices more widely within the hospitals, as this is a key part of ensuring change beyond the individual level. Because all these activities are done by the mentors, information sharing remains focused on service providers; stigma around HIV within the wider community could put mentors at risk if they had to disclose their status and activities more widely.

Young people who have completed the three months in the group and have been active participants in the discussions are invited to undergo training to join the programme as new mentors if they wish. Participants who are not selected to be part of the mentorship programme are invited to join a network through which they continue to participate in activities and events.

As well as providing psychosocial support in the digital groups, mentors are also part of a wider supportive team that fosters our own well-being – being part of the programme is like picking one's own family. Because the Foundation found that young people were interested in employment skills, and a major component of empowerment that would extend beyond the programme is job readiness, there is a lot of emphasis on this dimension of agency. Mentors receive training in skills such as research, analysis, digital innovation and other areas related to the peer-led support programme, and then work in various roles relating to its design and implementation, for example the research team and app development team. This work is paid with a stipend.

Being a peer mentor puts an obligation on one to lead by example. We want to motivate and positively influence others, which means looking after ourselves and each other. This has built character in us, increased adherence to HIV treatment protocols and improved our overall well-being. Because of the stigma of HIV, being able to not only speak openly about our experiences but also to access genuine opportunities to help others and ourselves and to tackle the barriers that remain in our way is a deeply empowering experience.

We are experts of experience, Experts in our own right

FIGURE 35.1
Artwork designed by Khuluma Mentors to promote the programme.