

# REACHING ONE ANOTHER

Harnessing storytelling to empower  
community-based HIV communication  
in the Eastern Cape



This project was initiated and conducted by  
Mr **Aphiwe Mtendeni** and the community members who courageously  
told their stories.

# Introduction

The Eastern Cape province in South Africa suffers one of the highest HIV burdens in the world. The 2017 National HIV Prevalence Survey identified the Eastern Cape as having the third-highest burden of HIV (25.2%) after Kwazulu-Natal (27.0%) and Free State (25.5%). During the preceding years, the region has experienced the highest rise in HIV infection in the country.<sup>1</sup> According to UNAIDS, a lack of knowledge of HIV and sexual health is a crucial barrier to reducing HIV infections among young people. However, within South Africa, only 43% of young people are reported to have sufficient knowledge about HIV prevention.<sup>2</sup> More recently, a study published in 2019 found that only 11% of young people reported having 100% accurate knowledge of HIV, while 25% had 75% knowledge accuracy. Young people who were unemployed or living in rural locations, such as the Eastern Cape, were least likely to be knowledgeable about HIV, while those who were sexually active had better HIV knowledge than those who were not.<sup>3</sup> A recent Salus pilot conducted in a school, based in the Eastern Cape found that a lack of HIV knowledge is a significant barrier that prevents young people from attending clinics for an HIV test, connecting to healthcare, and adequately adhering to treatment.<sup>4</sup> It is also one of the main determinants of stigma, often causing people to fear and discriminate against those who are infected because they do not understand the disease, how the treatment works, and how to prevent infection.<sup>5</sup>

Stigma is an insidious phenomenon that pollutes all levels of society, often causing people to adopt the belief that 'others' have violated a distorted idea of normality.<sup>6</sup> One of the central drives of stigma is the complex forms of destructive communication that permeate individuals' thinking, families, peer groups, institutions and broader communities.<sup>7</sup> What is particularly damaging about stigma is how it generates acute levels of fear of becoming its victim, resulting in deeply embedded feelings of shame, driving communities to the most harmful form of communication – silence. As a result, the dominant stigma narrative remains discriminatory.<sup>8</sup>

Breaking the cycle of stigma requires an intervention that disrupts the intricate weave of the destructive narratives described above. Essentially, stigma is a social construct. An effective strategy, therefore, will need to empower communities themselves to reconstruct alternate counter-narratives that become embedded at the personal, interpersonal and community levels. Central to success is enabling people, especially adolescents, to simply begin to talk about what they find so difficult to talk about – themselves and HIV. Whether infected or not, both are equally important. Message content and how it is communicated are recognised as the critical enablers to health communication success.

However, recent research has shown that conventional understanding of the content formation and delivery needs to shift to a new paradigm that places people as both the message and messenger.<sup>9</sup>

## The Salus project

The Salus project is an evidence-based HIV communication intervention which centres around adolescents and young people in its design and implementation, empowering youth to be the communicators within their communities. The Salus approach is informed by over a decade of research that focussed on how communication can effectively support young people's understanding and motivation to prevent infection and adhere to ART.<sup>10</sup> Findings showed that communication must engage all actors who are part of a young person's interactions, including their families, peers, and broader community. Furthermore, it should aim to increase treatment knowledge and encourage acceptance and support as a proactive response to HIV discrimination and stigma. The importance of belonging in the context of young people's wellbeing should be an integral component of HIV communication, especially if it is to shift destructive beliefs and attitudes to narratives that focus on self-compassion and unconditional acceptance.

1 Hansoti, B., Mwinnyaa, G., Hahn, E., Rao, A., Black, J., Chen, V., Clark, K., Clarke, W., Eisenberg, A.L., Fernandez, R. and Iruedo, J., 2019. Targeting the HIV Epidemic in South Africa: The Need for Testing and Linkage to Care in Emergency Departments. *EClinicalMedicine*, 15, pp.14-22.

2 Source: <http://aidsinfo.unaids.org> (Accessed in May 2020)

3 De Wet, N et al. (2019) 'How Much Do They Know? An Analysis of the Accuracy of HIV Knowledge among Youth Affected by HIV in South Africa', *Journal of the International Association of Providers of AIDS Care*, Volume 18.

4 Hickson, W and Mntendeni, A. (2020). Breaking the silence of stigma. Becoming communicators in our community. <http://www.thesalusproject.org>.

5 Lifson, A. R., Demissie, W., Tadesse, A., Ketema, K., May, R., Yakob, B., ... & Shenie, T. (2012). HIV/AIDS stigma-associated attitudes in a rural Ethiopian community: characteristics, correlation with HIV knowledge and other factors, and implications for community intervention. *BMC International Health and Human Rights*, 12(1), 6.

6 Scambler, G. 2004. Re-framing stigma: felt and enacted stigma and challenges to the sociology of chronic and disabling conditions. *Social Theory & Health*. 2(1):29-46.

7 Mburu, G., Ram, M., Oxenham, D., Haamujompa, C., Iorpenda, K., & Ferguson, L. (2014). Responding to adolescents living with HIV in Zambia: a social-ecological approach. *Children and Youth Services Review*, 45, 9-17.

8 Genberg, B. L., Hlavka, Z., Konda, K. A., Maman, S., Chariyalertsak, S., Chingono, A., ... & Celentano, D. D. (2009). A comparison of HIV/AIDS-related stigma in four countries: Negative attitudes and perceived acts of discrimination towards people living with HIV/AIDS. *Social science & medicine*, 68(12), 2279-2287.

9-10 Hickson, 2016. An interdisciplinary study exploring how health communication can most effectively explain Antiretroviral Medication (ART) and motivate adherence



***“The pastor told my son that he could be healed of HIV if he is saved, and to believe in his healing he must stop his medicine. Just before he died in hospital, he had a breakdown because God did not come. The pastors can pray, but they must stop telling people not to take their medicine. I miss my son”.***

<https://vimeo.com/386508315>



The Salus project began in 2016 as part of an HIV communication pilot (funded by ViiV Health). Using a participatory communication approach, a team of young people (mixed status) were empowered to take ownership of communication to reconstruct social meanings related to stigma and HIV. From the very beginning, the team worked together with other young community members to co-design the Salus vision, strategy, and its implementation. Harnessing their creativity, they explored how digital media can be utilised to reframe the HIV narrative, encouraging acceptance and support among their peers, families and community. Their aim was to break the silence of stigma, socialise knowledge about HIV and treatment, and generate solidarity and the motivation to test, adhere to treatment, and stay well. Inspired and motivated, they used their media to challenge and disrupt the dominant discourse of HIV and stigma, breaking the cycle of stigma among many hundreds of other young people.

One of the outcomes of the project was how Aphiwe Mtendeni, a filmmaker from the community, became inspired to initiate a storytelling project in his community, based in Tsolo in the Eastern Cape. The project resulted

in him making thirty films of people from his community who are living with HIV. Once the films had been completed, Aphiwe travelled back to the Eastern Cape to meet with the storytellers to show a sample (twelve) of the films and discuss how participants would like to use them. Participants decided that they wanted to use their film story to show family/clan members and community members to encourage acceptance and support and increase HIV knowledge. This approach empowered them to “own” and tell their story, rather than having it ‘taken’ from them, or being ‘told’ on their behalf. This part of the project was then included in a study.

### **The Salus film narratives study**

The purpose of this study was to explore the uses of a series of films that tell the stories of people’s experience of living with HIV, along with a series of HIV literacy animations that explain HIV infection and ART adherence. The study investigated how the films could be used by people living with HIV to generate empathetic communication, resulting in them receiving acceptance and support from family/clan members.

*“I heard that my son was making a film about his story. So, I went to the Salus team and told them that he has never told me that he is HIV positive, although I know, and that him not telling me eats at me.*

*The next day he came to me, saying ‘mum, I didn’t want to tell you because all of your other children have died of AIDS, and I am the only one left, so I didn’t want you to worry.*

*We cried together, and now we are one again.”*

### **Methodology**

This is a qualitative case series that will explore how 12 people’s (aged 18-45) own storytelling films, supported by health literacy animations, can be used as a communicative tool that empowers them to talk to family and clan members about their status, and facilitates a conversation about acceptance and support.

### **Research procedures**

The study was conducted over two months. Each participant organised his or her viewing event(s) that occurred in the first month. Each film was provided on a memory stick for viewing on a television via a digital box. A tablet was provided to participants who do not own a

smartphone or TV to show the films/animations. The co-investigator (Aphiwe Mtendeni), meet each participant and ask them how they used their films/animations, and who they showed them to. A semi-structured interview was conducted to examine the viewer’s responses about acceptance and support and what may have been learnt from the health literacy animations. Qualitative data from the interviews were captured using a digital tape recorder. Thematic analysis was used to identify, analyse and report patterns that emerged from the data, resulting in a greater understanding of how the films were used to facilitate empathetic conversations within participants’ belonging groups, and the quality of these conversations.

# Findings

The following five themes emerged from the data:

## Staying together – acceptance and support

Participants described how excited and motivated they were to have received their films. They were eager to share their stories because they wanted others to learn that they can live a healthy life with HIV, evidenced by their own lives. This, in turn, would encourage family members and friends to support and motivate them to take their medicines regularly.

*P3: "I feel happy, I feel really happy because at the end of the day I want other people to learn about this thing [HIV], and I want them to hear it coming out of my mouth".*

*P11: "I would like others to see that I am strong though I am HIV-positive. I would also like to get support from my family that would help with my adherence. For example, they will remind and motivate me to take my pills when I have forgotten or just not taking them".*

*P12: "I want to watch it with them because they give me support and to keep motivating me on taking my treatment consistently".*

One of the main barriers to receiving acceptance and support from family and friends was their disbelief in the validity of their disclosure. This was associated with the common belief that people who are infected with HIV appear thin and emaciated; to look healthy and well meant that you were not HIV-positive. Members of the project felt confident that people would now believe their status because they had been courageous enough to make a film and then show it on TV to others:

*P4: "I am really happy about this film because some of my family members still don't believe that I am positive judging from my health and physical appearance they don't believe what comes out of my mouth so this film is going to confirm everything and I will receive more support from my family. So, this film is going to confirm everything, and I will receive more support from my family, but like I said it will be good to watch with those that don't believe that I am really HIV-positive so that they can be convinced and stop judging me from my physical appearance."*

*P3: "I would like my family and friends to support me about my status, especially my best friends that I will invite to come and watch the film with us. It is going to help me in motivating others especially those who doesn't know about their status, they will finally see that this thing is real and not be deceived by my physical appearance thinking HIV is only for people who are thin. They will see that I'm healthy yet HIV-positive, so they might get motivated to out and get tested because they might realise that they might be looking fat and strong. Still, there are chances that they could also be positive because HIV is not determined by your physical appearance".*

Participants described how they wanted to use the film's stories as a tool to facilitate disclosure to family members and friends. The purpose of their disclosure was to receive acceptance and support and provide hope to their loved ones because they are living normal and healthy lives and are no different from those who are non-infected:

*P2: "There are some of my family members that I would like them to see the film so that they can know about my status and not doubt me. I am*

***"I feel happy, I feel really happy because at the end of the day I want other people to learn about this thing [HIV], and I want them to hear it coming out of my mouth".***

*going to watch it today and invite my friend over. I want to watch it with my family with even those that don't know both friends and relative. I'll watch and invite them today. I am hoping that those will be watching the film, positive or not, will be motivated when watching the film, give them hope to see that even if one is positive, it is not the end of the world. There is still life after testing positive".*

*P7: "I am going to watch the film with my family. Though they all know about my status, I would still like them to see my film. It is my friends that don't know about my status that I would invite them over to watch the film with me. I want people to see that people living with HIV also have a life; HIV does not mean death. HIV does not mean you are less of a person, or you are different from others, no".*

*"I was raped and I went to the clinic to get tested. That's when I found that I am HIV positive. I was really hurt, but as soon as I got home and spoke about it to my brothers and sister, because I have no parents, I felt better. They encouraged me that it is not the end of life.*

*I would encourage people and tell them that this is not the end of life. Life goes on."*

<https://vimeo.com/424803550>





Participants also spoke about how they wanted to use their film stories to provide an open and safe space for others to disclose their status, knowing that they would be there to support them. This was particularly evident to parents and aunts of children who they knew or suspected were positive as described by two mothers:

P5: *"I am happy about the films because I can see that my daughter is sick with HIV, but she is not ready to talk about it yet. So, I am happy that the film is here because there is a possibility that she is not the only one sick. It could be possible that my sister's children too might be going through the same thing but are afraid to talk."*

P4: *"I'll watch the film with my daughter who's recently diagnosed with HIV and very sick because she is in denial, also with my sister and cousin for them to be encouraged and see that I have accepted it even for them if it might happen that*

*"I'll watch the film with my daughter who's recently diagnosed with HIV and very sick because she is in denial, also with my sister and cousin for them to be encouraged and see that I have accepted it even for them if it might happen that they test HIV-positive they could watch, learn and get motivation from it"*

*they test HIV-positive they could watch, learn and get motivation from it. I'd also invite my other relative because I keep hearing that he is infected but scared to disclose"*

#### **The misinformed will be informed**

A core motivation to sharing their films was to inform and educate their family members, friends, and broader community members to attend the clinics for a test. They wanted people to feel motivated by them, living a healthy and full life with HIV, made possible by treatment:

P2: *"I am hoping that those will be watching the film, positive or not, will be motivated when watching the film, give them hope to see that even if one is positive it is not the end of the world. There is still life after testing positive. The misinformed will be informed, and they will see that this is someone we know that is living with HIV, and they will get extra motivation"*

P1 *"My aim to watch it with them is to give them the knowledge and educate them about my virus. I want them to be encouraged by my story. The reason I want to watch it with them is for them to be educated and get knowledge about HIV"*

P: *There are a lot of people that I would watch it with because most people are scared to go to the clinic to get tested for HIV, so I would like them to get motivated to tests, so they can know their status, knowing that HIV does not kill as long as you take your treatment"*

*"I disclosed my status to my mother and she disclosed it to my siblings on my behalf. She also advised me that this is not the end of it, life goes on. The only thing I need to do is to take my medication so that I can be healthy.*

*I advise people to follow the instructions given at the clinic and also to use protection when it comes to sex.*

*The support to me is amazing, my family still treats me the same"*

However, as described above, many young people believe that looking healthy and well meant that you were not infected by HIV, resulting in them not attending clinics for a test because they are not presenting with any of the visible signs that they believed were necessary to indicate HIV infection. Participants were eager to challenge this myth by educating young people that physical appearance was not an indicator of disease and that they should always attend the clinics for a test:

P3: *"It is going to help me in motivating others especially those who doesn't know about their status, they will finally see that this thing is real and not be deceived by my physical appearance thinking HIV is only for people who are thin. They will see that I'm healthy, yet HIV-positive, so they might get motivated to out and get tested because they might realise that they might be looking fat and strong but there are chances that they could also be positive, because HIV is not determined by your physical appearance"*

P7: *"I want people to see that people living with HIV also have a life. HIV does not mean death. HIV*

*does not mean you are less of a person, or you are different from others, no. Other people don't believe when I say I am HIV-positive because they say I look nothing like someone who is HIV-positive. So, with my film, people will finally see that HIV is not seen through physical appearance"*

#### **Responses - stories that empower**

All except one participant, who had been unable to organise a group, watched the films with family members and friends. Many respondents were motivated by the film stories, asking questions about HIV and treatment, learning that they could live a normal and healthy life if they were ever to test positive. As a result, stories emerged about young people saying that they would go for a test because they would also be supported and accepted by their family members who attended the group event:

P4: *Yes, I watched it. I was with my daughter and son. He asked questions about HIV and STIs. I encouraged him to test, and they said they were fearless. They'll also go for testing. He said that he*

was scared to go for testing, but he is encouraged because it may be the case that his HIV-positive, he wouldn't be alone in the family.

P5: "The whole family came to watch it. It was exciting as I was sharing my story live in front of them. They were pleased about it and the message I was sharing. I think they got informed and motivated because everyone promised to go for a test, and also they learned about the importance of treatment and support".

The films facilitated a number of conversations to group members disclosing their status to family members and friends. Several participants described how they received praise and encouragement from family members and friends after they had seen the film because they had been able to talk about their status, rather than remain silent. Silence was acknowledged as a reason why people in their communities die of HIV/AIDS. They were particularly encouraged by the way their families were keen to continue to support them so that they would remain well and healthy:

P2: "They were happy that I disclosed and opened up about my status because a lot of people die of silence, so they support me and encourage me to take care of my health".

P3: "I have watched my film with my brother and his family and my family too. My family has been waiting for my film, and they were happy and proud when they finally saw it. They said that they were pleased that I've accepted my status and free to talk about it because many people out there don't talk about their status, they die with it".

Several participants described how people didn't initially believe their stories because of the belief that infected people look thin and unwell, as described above. The films facilitated discussion about the effectiveness of treatment, which enabled participants to challenge this myth and encourage them to go for a test, even when they looked healthy themselves:

P11: "Yes, there was someone new when he saw my film. He was surprised, and said you are trying to lie to us that you are you really HIV-positive or you are trying to sell your film?" I had to show him my pills to convince him that I am HIV-positive because he thought it was just a joke. Some people don't believe what they see on TV anymore because they think people do things on TV for money, and they are just acting. I had to show him my pills for him to believe and he was like "I've never seen someone living with HIV looking so beautiful" I told him that

people living with HIV are beautiful. They are not different as long as they are taking good care of themselves and taking their treatment they can still live a normal life. I told him if he thinks people living with HIV are ugly, he most likely used to see those who are not taking good care of themselves and not taking their treatment. He suddenly understood and said: "People should get tested"; and I told him that was important, that is what we want, we want people to know their status, and he was interested that he would also go get tested for HIV".

One participant spoke about how they used the film to encourage her daughter, who she suspected was recently diagnosed with HIV to disclose so that she could support her:

P4: I am happy about the films because I can see that my daughter is sick with HIV, but she is not ready to talk about it yet. I encouraged my child, and she disclosed to me. I said I'm here as your mum. I'll coach you and told her how to protect herself and take your treatment. I was happy that she disclosed, I could even see that she's happy".

*"Yes, I watched it. I was with my daughter and son. He asked questions about HIV and STIs. I encouraged him to test, and they said they were fearless. They'll also go for testing. He said that he was scared to go for testing, but he is encouraged because it may be the case that his HIV-positive, he wouldn't be alone in the family".*

### **Empowerment through solidarity – a desire to change communities through stories.**

Participants were encouraged by the impact they had achieved from showing their stories. Feeling empowered, they became motivated for the project to grow and expand so that they could reach many other young people in their community, increasing HIV knowledge and motivating them to test and take treatment. They had discussed among themselves a strategy that included showing their films at schools, taverns and other local spaces:

P3: "Going forward with the project I think it would also work if we could go around our community talking about HIV and motivating people, also visiting schools around to talk with the youth and creating awareness".

*"In 2010 my wife started taking treatment for high blood pressure. In 2012 my brother got sick and told me that he was HIV positive and showed me his medication. As soon as I saw his medication I was shocked because it was the same as what my wife was taking for blood pressure.*

*I stayed with my brother and helped him with his medication, but he gave up and passed away. After we buried him I went home and asked my wife what her medication was for, and why was she lying. Why are you hiding from me?*

*I got scared and decided to get tested. I was HIV positive. When I told her she was shocked, and I told her that she nearly killed me.*

*I forgave her and we supported each other until she died of AIDS."*

<https://vimeo.com/424806578>



*“Yes, they will have an impact in this community, because they will help educate and motivate others to get tested and know their status. It will also help those living with HIV to be confident and accept themselves and get inspired seeing other people they know to speak with confidence about their status because what scares people to death sometimes is that they hide their status”. thinking they are the only people living with the virus”.*

*P4: “We plan to educate our children at local schools, at taverns educating them on how to protect and to live a healthy lifestyle if they have the virus themselves”.*

*P6: “Through these films, people will realise that we are true when we say that we are HIV-positive as they will be seeing us on television sharing our stories with the whole world that is when some people will get motivated to get up and go to the clinic”.*

*P7: “The impact that I want in our community is for people to see that HIV is not something to be ashamed of. You shouldn’t be embarrassed. HIV is just a virus like any other virus out there; it does not make you different. You can live a normal life like other people, while HIV is just a word. Yes, they will have an impact in this community, because they will help educate and motivate others to get tested and know their status. It will also help those living with HIV to be confident and accept themselves and get inspired seeing other people they know to speak with confidence about their status because what scares people to death sometimes is that they hide their status thinking they are the only people living with the virus”.*

Using their films as tools to impact youth was exemplified by one participant who had taken his tablet to the main street in his town to show young men his story so he could encourage them to go for a test, telling them that if they were to test positive, they could come to him for support:

*P6: “I came across six young men when I was carrying the tablet, we watched the films together, and they were emotionally touched to hear and see my story and had some few questions about HIV. They said that they didn’t know much about HIV and the pain that HIV people suffer when*

*they discriminate them. They were motivated to change their attitude towards HIV and to stop the stigma against HIV, and realised the importance of knowing their status. They said they would go for a test while there are no symptoms of HIV, and if they tested positive, they know who to come to for advice and support, I could guide them”.*

## Conclusion

The Eastern Cape continues to suffer from the impact of the HIV epidemic, resulting in high levels of infection, mortality and stigmatisation among its communities. While treatment is readily available, many young people do not attend the clinics for a test, and linkage to care and adherence to treatment remains a challenge. One of the significant gaps that currently exist that remains within this region, and more broadly, is effective HIV communication. It is readily acknowledged that top-down approaches most commonly used within these contexts have been ineffective, mainly because they adopt Euro-centric health behavioural models in their design, and that they focus on increasing peoples understanding of disease risk versus treatment benefits only. While these modalities have relative success in message dissemination, they have mostly proven ineffective in behavioural health change throughout the southern hemisphere, in particular sub-Saharan Africa. Northern hemisphere communication approaches are primarily aimed at individuals, locating behavioural change as a cognitive response based upon them gaining a binary understanding between risk versus benefit. The problem with this approach is it does not recognise how stigma negatively impacts communication, causing people to simply not talk about HIV to one another. Hence, these approaches do not focus on facilitation of dialogue – it is about telling and instruction only.

This approach also assumes that baseline levels of health and functional literacy are sufficient throughout a population to engage with public health messages properly. In the context of South Africa, however many people do not complete their education, resulting in varying levels of both functional and health literacy. Secondly, the approach assumes that the way sub-Saharan indigenous peoples form understanding is based upon northern hemisphere epistemological models. These assumptions are wrong and often contribute to confusion, and sometimes the loss of people’s lives.

Central to sub-Saharan communication culture is the oral tradition of storytelling, that is located in a deeply embedded cultural belief about what it means to belong to a community, defined as Ubuntu. Ubuntu frames a person as inseparable from their community who carefully considers their actions in the context of others. In many ways, the notion of Ubuntu can be understood as a ‘social contract’, which impacts an individual’s choice and action which may, or may not be constrained by the wider community’s pursuit of shared aims. It is within this context that knowledge is ‘shaped’ and ‘formed’ by community members through the process of sharing and discussion, shaping understanding into what makes sense for them, their families, and broader communities.

This pilot provides evidence that a youth-led HIV community-based communication project that harnesses local people to tell their stories provides high levels of impact, generating dialogue and participation throughout communities, breaking the cycle of stigma, and increasing HIV knowledge. Findings show that localised storytelling empowers family members and friends to develop their communication strategies and plans that provide safe spaces for family members and friends to disclose and discuss HIV at an interpersonal level

that encourages testing and supports adherence. An essential element to effectiveness were the following guiding principles to community-based communication for social change:

- To facilitate co-empowerment through generating solidarity, drawing together collective agency to co-support one another using young filmmakers’ creativity that harnesses local community members desire to share their stories with others.
- To empower community members to become dynamic actors who control and drive the process of HIV communication that increases knowledge and the importance of belonging, empowering youth to test and treat, and communities to embrace acceptance and support narratives and behaviours.
- To enable community-members to harness their creativity, facilitating family-level communication and community-based media that focus on generating dialogue and participation throughout their communities to break the cycle of stigma and increase HIV knowledge.



Aphiwe together with participants of the film making project



Published by the Salus Project  
[www.thesalusproject.org](http://www.thesalusproject.org)

Report written by Warren Hickson (PhD) 2020

© Warren Hickson  
[warren@thesalusproject.org](mailto:warren@thesalusproject.org)



This report is the result of a truly collective effort. We express our sincere gratitude to all the local community members, who participated in the study, especially the community members who shared their stories and experiences. In addition, particular thanks are due to Mr Aphiwe Mtendeni who initiated and led this project.