



**COMMUNICATING
ART ADHERENCE
TO YOUNG PEOPLE:
MOTIVATION AND
UNDERSTANDING**

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The research aim

The aim of the research was to explore ways to improve communications about HIV and antiretroviral treatment (ART).

Currently an estimated 6.8 million people in South Africa are living with HIV, making it the country with the largest HIV epidemic in the world¹. Antiretroviral treatment is the only effective treatment for HIV and is one of the most demanding medicine regimes in existence, requiring a 90% compliance rate.

However various studies have documented worryingly poor levels of adherence to the regime, especially amongst adolescents and young adults in South Africa, and because of this, mortality rates remain high.

Effective communication that clearly explains how to take medicines for life-long chronic diseases such as HIV has been shown to improve treatment adherence rates significantly.

“Effective communication will be critical to the successful implementation of the National Strategic Plan.”

(South African National AIDS Council, SANAC)³.

Effective communication has also been identified as one of four core strategic enablers for the South African National Strategic Plan for HIV, STIs and TB². Therefore we need to find new ways to communicate with young people in order to improve their adherence to the treatment regime, and ultimately,

their chances of survival. The research aimed to address this need and to inform future strategies for communications about HIV and treatment adherence.

1. UNAIDS (Joint United Nations Programme on HIV/AIDS), 2013. Global report: UNAIDS report on the global AIDS epidemic 2013. P. 22.
2. SANAC, 2011. The National Strategic Plan on HIV, STIs and TB 2012-2016. Summary. www.sanac.org.za.
3. Op.cit. p. 24.



The research methodology

Research was carried out in Khayelitsha, a peri-urban township on the edge of Cape Town. Data collection took place during a total of eight months' fieldwork, between 2011 and 2013, and the principal methods used were focus groups, semi-structured interviews and participant observation. A short visit to Khayelitsha was also made in 2016 in order to update the findings.

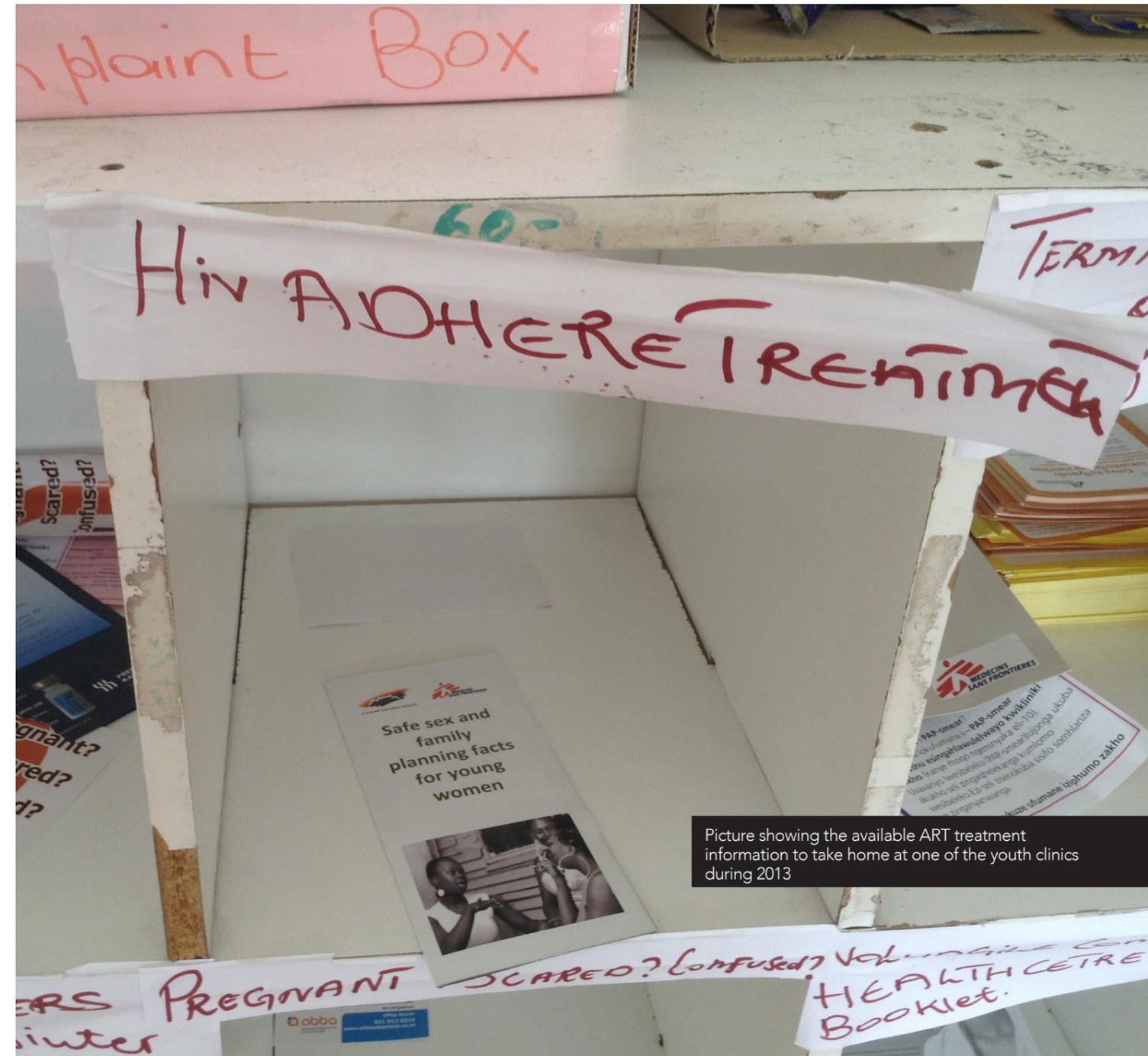
The research focused on young people from Khayelitsha and the health care professionals and volunteers who are involved in informing them about HIV and antiretroviral treatment:

- Counsellors play an important role in HIV testing and in starting young people on antiretroviral treatment.
- Doctors, nurses and pharmacists who work in the HIV treatment clinics in Khayelitsha also inform young people about treatment.
- Voluntary treatment support educators, who are members of the Treatment Action Campaign (TAC), also play a role

in educating young people about HIV and treatment. They work with groups of people in waiting room areas and also on a one-to-one basis.

In order to make sure that local people's perspectives were the main focus of the research, a grounded theory approach was used. In line with this approach, periods of data collection were interspersed with periods for data processing and analysis, each of which then informed the detailed research design for subsequent stages.

Grounded theory research: a research methodology in which the researcher starts from an open-ended position and builds understanding stage by stage, based on ongoing qualitative analysis of what people say. Data analysis uses a standardised set of tools to ensure rigour. There are no pre-defined hypotheses; instead, theories emerge as the study progresses. In this way, emerging theories are described as grounded in the data.



Picture showing the available ART treatment information to take home at one of the youth clinics during 2013

Key findings

The study found that current communications about treatment were limited in their effectiveness and rates of treatment adherence remained poor. This was partly because many young people did not understand what they were told about treatment and the importance of following the treatment regime. However it was also linked to deeper issues of motivation, which were related to the trauma of diagnosis and a loss of hope. Therefore in order to improve communication effectiveness, it will be important to address motivational issues as well as issues of understanding.

● The trauma of diagnosis

"You cannot really process any information at the clinic, it could have helped to take some more information home once you've calmed down."
Young woman living with HIV

When young people were first diagnosed as HIV-positive, they were too traumatized to take in what clinicians said to them. Then as the initial shock died down, many young people still failed to become motivated to learn about treatment because they had lost all hope of a normal life. Many of them had lost parents or other family members to AIDS, and they had an overwhelming fear of becoming sick and suffering an early death. Often, they had an even greater fear that they would be rejected by their family and friends because of the stigma connected to HIV.

Motivation: regaining hope

Restoring hope was recognised by clinicians as a vital factor in helping people move towards successful treatment.

"The key message I want them to know, to remember, even if they forget everything else, is to know that there is hope." Doctor

However, regaining hope and motivation was not only dependent on understanding that there was an effective treatment available. Young people also talked about the importance of being able to reconnect with at least one person to whom they were close, especially a family member, who accepted and supported them in spite of their new diagnosis. Reconnecting with someone in this way affirmed their identity - as a son, a daughter, a cousin or a close friend. This in turn gave them hope and made them motivated to learn more about the treatment regime and adhere to it.

Pages 10-11 for a new communication model for motivation for ART adherence among youth.

Current communications: The choice of language and images

Once people had become motivated to learn about treatment and treatment adherence, they still faced challenges in understanding the information given to them. Some specific barriers were identified that limited the effectiveness of current communications:

- Low literacy and education levels were an obvious barrier to understanding of written materials.
- Rumours in the community about treatment caused confusion among young people.
- Complex concepts such as the relationship between infection, CD4 count, and undetectable viral load, and why it is so important to take antiretroviral treatment every day within a narrow window of time, were particularly difficult for young people to understand.
- In face to face situations, some clinicians used complex medical terms to describe these factors without sufficient explanation. Often, there simply wasn't enough time to explain things thoroughly.
- Metaphors were also used by some clinicians as a way to simplify the information. However, data analysis suggested that the use of metaphors created further confusion. This has also been documented in other places.
- The inconsistency in the language and images used across the care pathway was in itself a further source of confusion.
- All these factors led to misinterpretation and, in some cases, failure to follow the treatment regime.



A young man who lives with HIV using the animation that was developed during this study, designed to explain ART adherence, during the pilot study at the youth clinic.

New visual communication tools:

In direct response to requests from young people, two new visual communication tools were developed towards the end of the study: a film and an animation.

A film that communicates hope: Coming to terms with HIV

To help support them through the trauma of diagnosis and give them hope, young people had said that they wanted to listen to other young people's stories of how they had moved forward. Accordingly, a film was made presenting the story of one young person who overcame his initial diagnosis shock and, through the acceptance and support of his family, learned to live a normal life with HIV.

The animation: Explaining the medical basis for antiretroviral treatment

Young people said that an animation might help them to better understand the medical basis for antiretroviral treatment and the treatment regime. Accordingly, an animation was produced explaining the concepts of viral load and CD4 count. Rather than using metaphors, it used isotype⁴ as the central visual language. Other details of the visual representation were developed in consultation with clinicians and young people.

The pilot animation was presented to groups of young people at one of the clinics by a young man who himself was living with HIV. He presented it in colloquial language without using unnecessary technical terms. Initial feedback suggested that it was effective in instilling understanding.

Communication contexts: creating spaces for sharing and learning

During presentations of the pilot animation young people talked passionately about their own experiences, including the loss of family members, friends and community members to HIV in the past. Many of them had not done so before and found it very helpful. They also asked many questions about HIV and treatment, and a dialogue developed. This kind of exchange was valued greatly by them. It is probable that communication will be more effective in settings that provide a space for sharing and learning of this kind than in conventional one-way transmission of information.

- **Message targeting: increasing acceptance and understanding in the community**

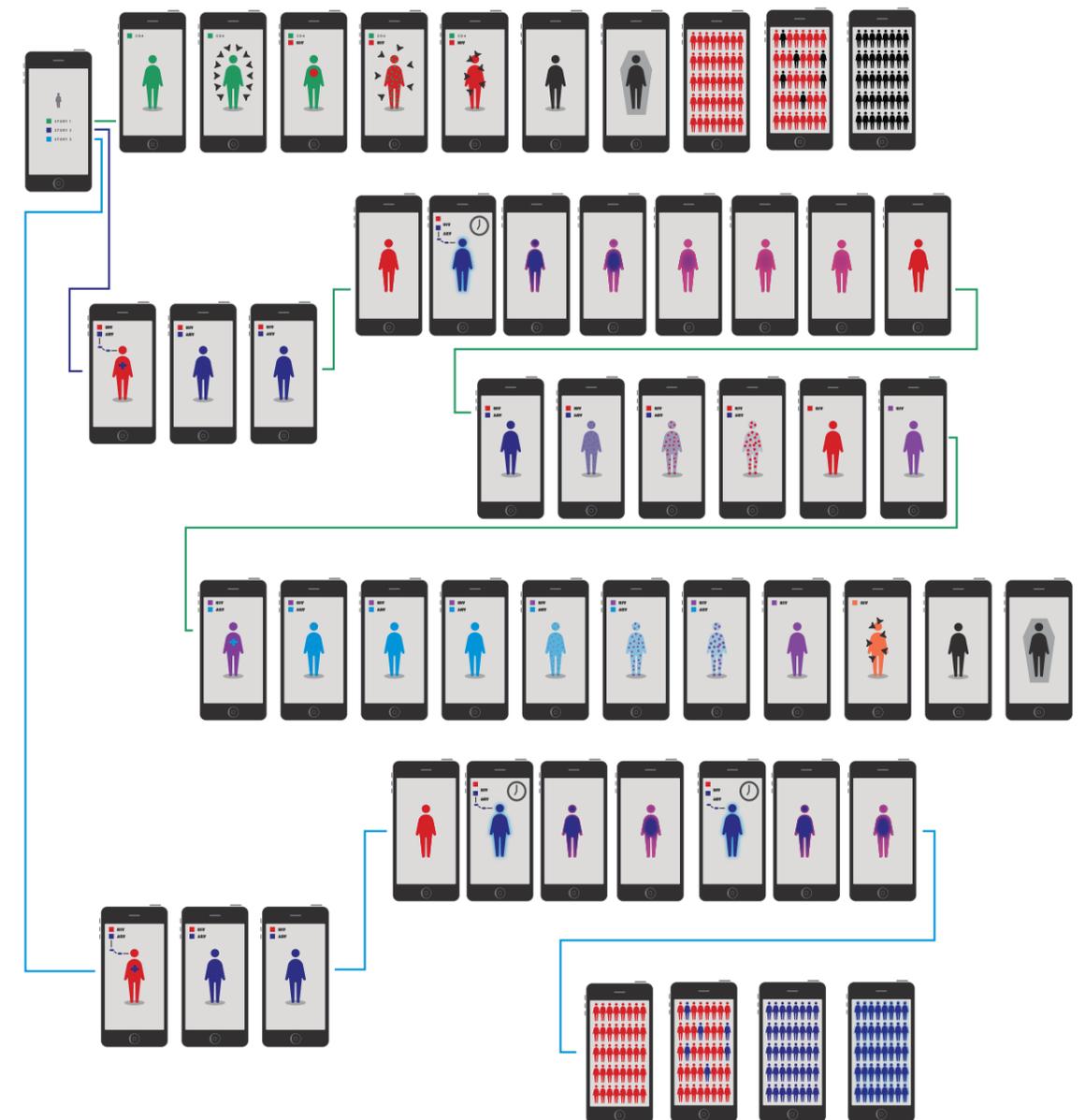
A finding that emerged strongly from the data was that it is not only people living with HIV who wish to gain a better understanding of antiretroviral treatment:

- Many young people who visited the clinics said that they wanted to learn about treatment irrespective of their test result, so that they could support friends and family members who lived with HIV. It would also make them better prepared if they were to become infected themselves.

4. Extensive research shows that Isotype (International System of Typographic Picture Education) is the most effective visual language used to communicate medicine instructions, especially to low-literate populations.



- The family members of several young people in this study wanted to learn more about treatment so that they could better support their HIV-positive relative.
- Many young people also wanted to be able to share information about HIV and treatment with a wider circle of people, so that the stigma in the community as a whole would be reduced.

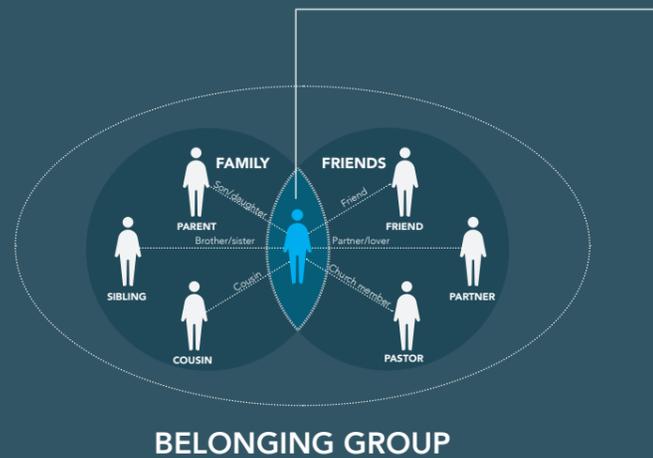


"It can make people pay attention to it, 'cause the thing is we don't understand how this thing [antiretroviral treatment] all works you see"
Young man, after watching the animation

One of the storyboards developed during the animation prototype

A COMMUNICATION MODEL FOR ART ADHERENCE AMONG YOUNG PEOPLE

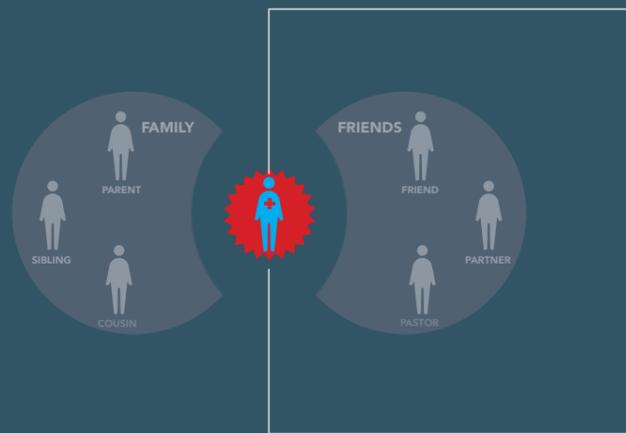
1 THE CONTEXT OF YOUNG PEOPLES MOTIVATION



Belonging is the context in which young peoples identities are defined, through recognition and validation from those with whom they most often interact within their social worlds

Identities are meanings that a person assigns to them self (and others assign to them) within the social context of belonging, and are the source of young peoples motivation.

2 THE IMPACT OF AN HIV POSITIVE DIAGNOSIS



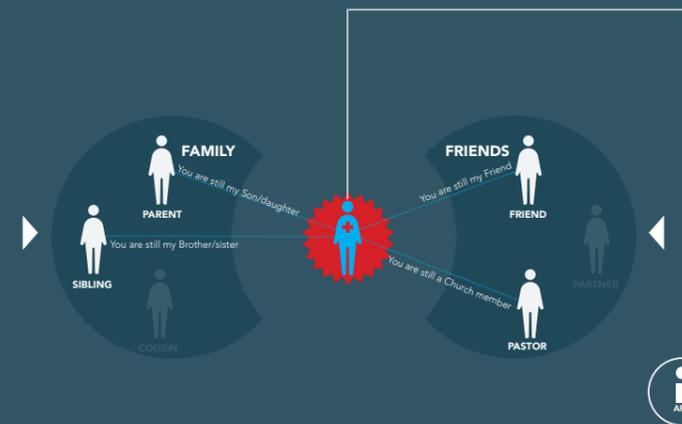
For the young people who participated in this study, the definition of diagnosis included the overwhelming fear of becoming sick and suffering an early death, as well as being rejected by those to whom they belonged, which would result in the terrifying possibility being socially isolated.



Because young people felt so traumatised by their diagnosis they said that they could not hear the messages that clinicians spoke to them. At this juncture treatment information was not their priority.

To help support them at this difficult moment, participants said that they wanted to listen to other young people's stories of how they had re-connected and had moved beyond the trauma of diagnosis to living normal full lives.

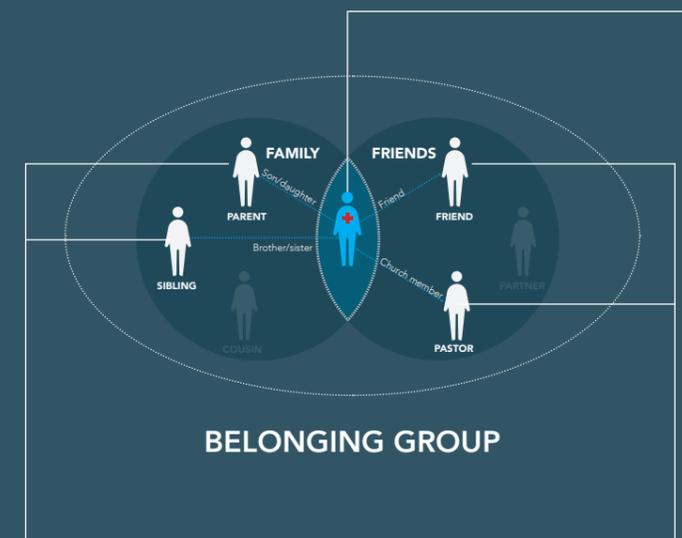
3 RECONNECTING TO BELONGING



This study showed that immediately after young people received a diagnosis they wanted to feel accepted and supported by a significant other. Support was described as loving and empathetic, reassuring them that they would not get sick or die or be rejected. Acceptance and support affirmed their belonging identity of son, daughter, sister, brother, cousin or close friend, which enabled them to reclaim hope for their present and future lives.

As young people reclaim hope they become motivated to learn about ART and adhere to it.

4 AFFIRMED BELONGING = RENEWED MOTIVATION TO LIVE =



For young people, motivation to adherence was an outcome of re-connecting to one or more significant other(s) who through acceptance and support affirmed their belonging identity, which enabled them to reclaim hope for their present and future lives.

As an active act of acceptance and support family members and friends want to learn about ART adherence so that they can properly support their loved one.

Key

- Young person
- Interpersonal communication
- Affirming messages through acceptance and support



It was during the testing of the prototype animation that it became evident that the best way to minimize misinterpretation and misunderstanding was to use the animation as a teaching aid. This offered young people the opportunity to learn about ART adherence during an interactive session, rather than as a standalone visual communication designed for independent use only.

RECOMMENDATIONS

The findings of this study have a number of implications for policy, practice and education that are aligned to the South African National Strategic Plan's core objectives. The following recommendations are specific to Khayelitsha and other peri-urban locations within South Africa, although aspects may be transferable to other contexts:

Policy

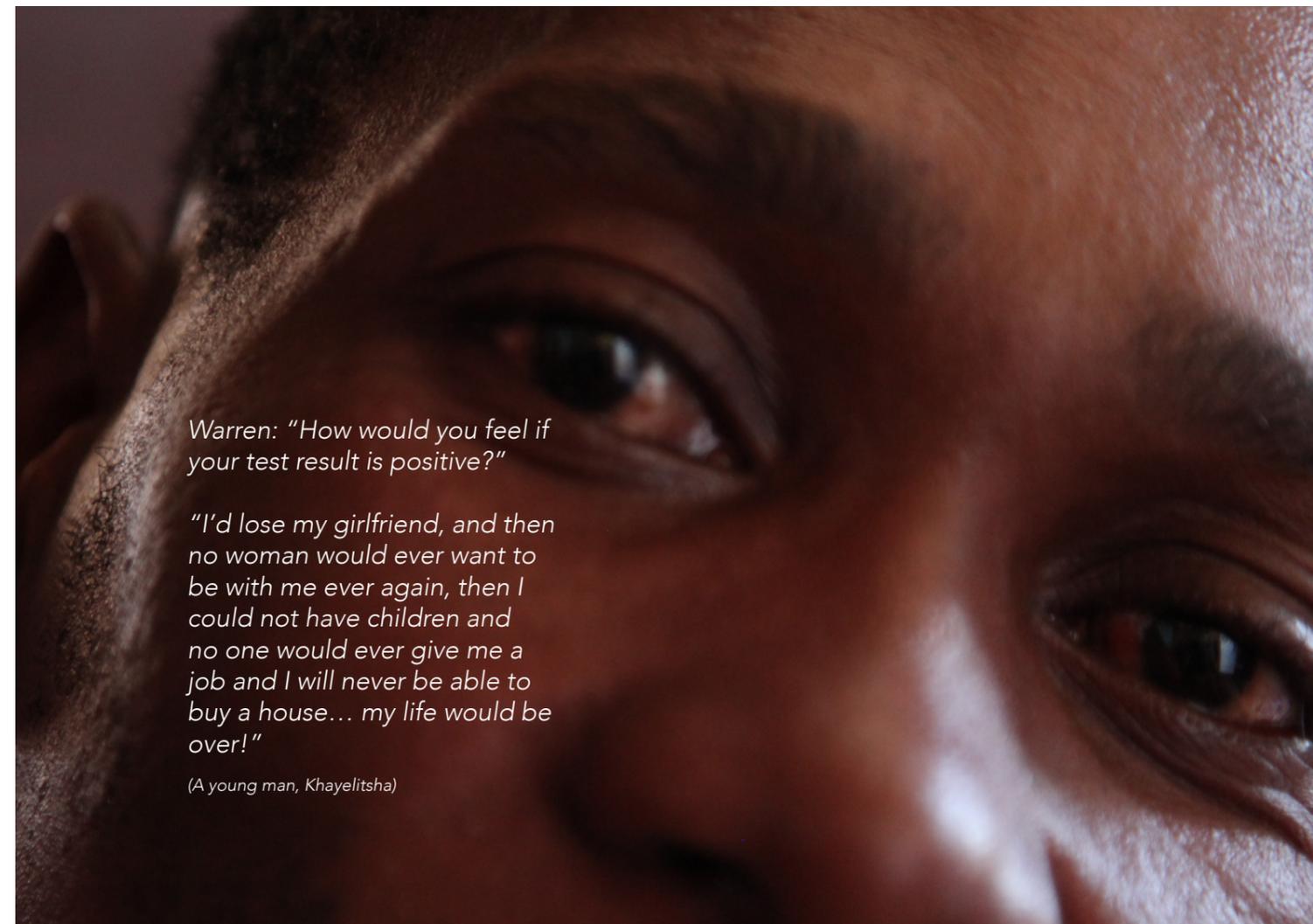
Multiple messages are currently communicated within the healthcare system across Khayelitsha, creating mixed messaging that causes confusion and misinterpretations among young people. To address and overcome this structural barrier, clear guidelines on messaging should be developed and issued as a matter of urgency. At the South African Department of Health, a clear policy could be considered that provides a framework to support all agencies working in the field to align ART adherence communication strategies and message content throughout the health care pathway.

Practice

- Communication strategies should include measures to alleviate the initial shock of diagnosis and to give people hope and reassurance for the future. One approach to doing this is to share stories of others who have managed to continue living their lives successfully with HIV.

- A key factor in becoming motivated to follow the treatment regime is to gain acceptance and support from at least one other person - usually a close family member or trusted friend. However the process of revealing an HIV-positive diagnosis to others is upsetting and risky. Communication strategies could include elements to help people to manage this process, and to decide how much to disclose and to whom.
- Communication strategies should take into account the value of spaces for sharing experiences and group sharing, learning and discussion.
- The use of technical scientific language should be kept to a minimum. Where some technical language is necessary, it is important to allow time for adequate explanation.
- Metaphors should be avoided. They do not translate well across cultures and in Khayelitsha they were frequently misunderstood.
- Language and images should be standardised across the treatment pathway, as inconsistencies were causing confusion. A health communication training programme could be considered that would provide clinicians with additional training to improve and standardise their communications.

- Communication about HIV and treatment regimes is likely to be most effective if information is available through a variety of different media. These could include visual tools such as film and animation as well as the current one-to-one sessions and printed materials.
- Communications should be targeted not only at HIV-positive individuals, but also at groups of young people who attend clinics together and at the families and friends of those living with HIV.
- Ultimately, communications need to target the wider youth community. Youth clinics offer one possible space where this could be done, and the use of mobile technology should also be considered for this purpose. It offers a powerful means to reach large numbers of people, but also bears significant risks. This is a point that needs further research.

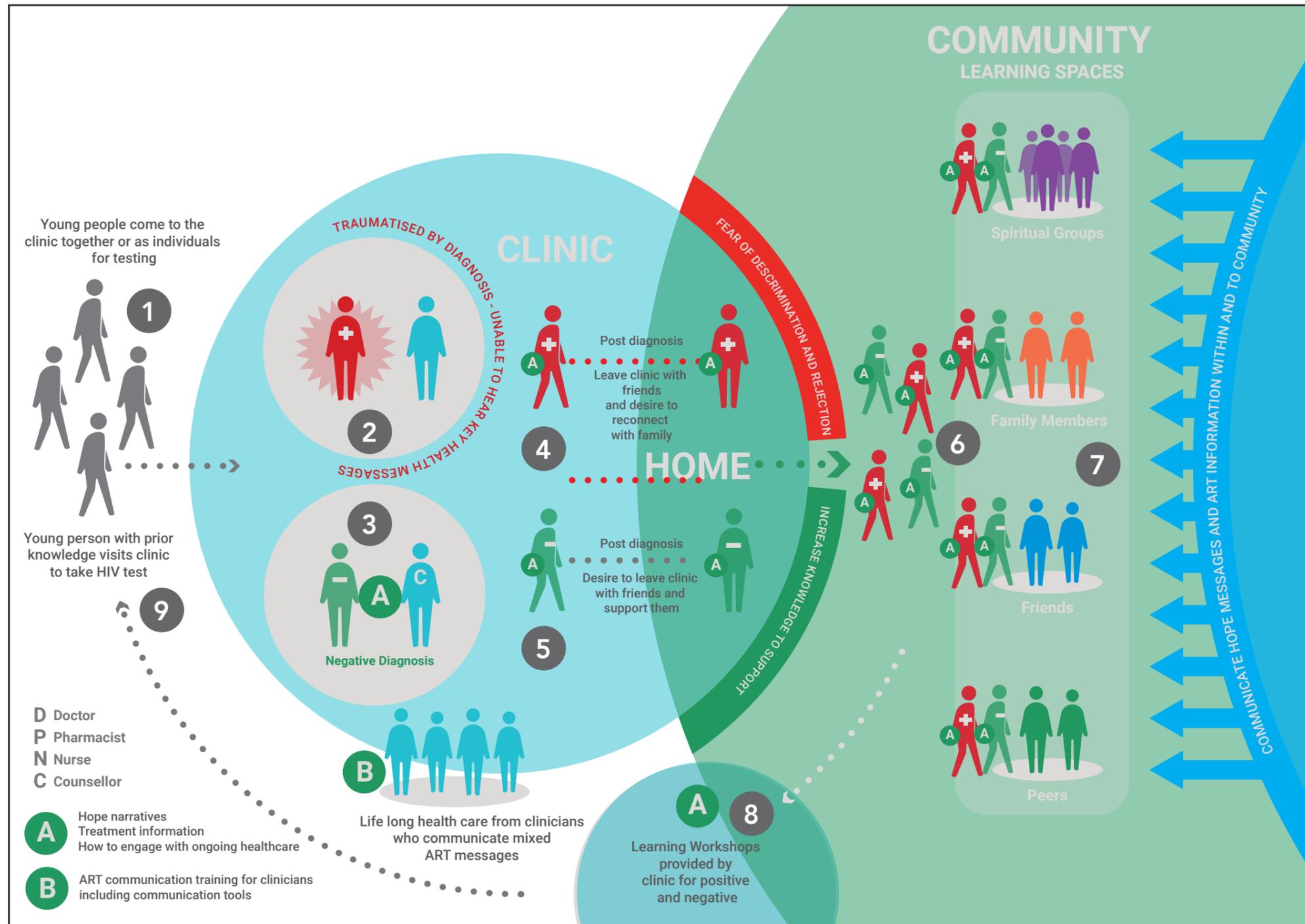


Warren: "How would you feel if your test result is positive?"

"I'd lose my girlfriend, and then no woman would ever want to be with me ever again, then I could not have children and no one would ever give me a job and I will never be able to buy a house... my life would be over!"

(A young man, Khayelitsha)

AN ECOLOGY OF ART ADHERENCE COMMUNICATION



- 1** Young people come together or as individuals to the clinic for a HIV test
- 2** Young person tests positive and cannot hear messages of hope, ART treatment instructions and what to do next because of diagnosis trauma. They are given toolkit to take home
- 3** Or young person tests negative
- 4** Young people want to leave together to support one - another and decide what they want to do next - use toolkit together and as individuals
- 5**
- 6** Young people engage with family members/ trusted friends if appropriate
- 7** Community members who engage with toolkit improve their understanding about HIV/ART and are encouraged to accept and support
- 8** Some young people and community members want to learn more about HIV/ART in workshops organised by the clinics
- 9** Young people who have increased knowledge about HIV/ART are better equipped to cope with positive diagnosis

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