



POLICY

BRIEF

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[www.chp.ac.za](http://www.chp.ac.za) | 011 717 7420 | Further information: Please contact Jana Fried at [jana.fried@coventry.ac.uk](mailto:jana.fried@coventry.ac.uk)

# Beyond supplying HIV and TB treatment: improved access to acceptable care in South Africa by engaging with patients' health contexts, experiences and illness perceptions

## Introduction

HIV/AIDS and TB are much more than chronic *diseases* requiring medical treatment. As *illnesses*, they entail more than physical discomforts or difficulties. Instead they are deeply affecting how patients perceive their own emotional well-being, self-worth, and bodies – and how others in society perceive and interact with patients.

Such perceptions, beliefs and experiences are central to patients' lives because they frame the options available to them, affect relationships within families and communities, and influence their decisions and actions. Crucially, these factors fundamentally impact on the treatment pathways that patients decide on and the acceptability of the care that the health system provides.

Access to acceptable care, however, is not only about the perceptions and circumstances of each patient, but transcends the individual to encompass the broader social context or "healthworld"; the socially shared,

## Conclusions and policy implications

- The health system's provision of free HIV and TB treatment is necessary, but not sufficient, for achieving widespread access to services. In addition to factors such as services' locations and affordability, access is also determined by the demand for services, particularly their acceptability to patients.
- To improve the acceptability of treatments and services it is important for policy-makers and health system managers to appreciate patients' understandings of their illnesses, how services are provided, and how different healthworlds can shape perceptions and care pathway decisions.
- Understandings that foreground fear and futility can, to patients' detriment, delay or disrupt their care pathways, while fostering feelings of worth, hope, and life returning to normal can make treatment adherence more acceptable.
- Policy-makers and health system managers must acknowledge that patients' experiences and understandings, and thus the acceptability of care, are influenced by how treatment is provided. Treatment is more likely to be successful if providers actively engage with patients in a respectful way. Conversely, a health system or provider that projects patronizing or unsympathetic values can create mistrust, thereby reducing services' acceptability and use.
- While health contexts or healthworlds can certainly support HIV and TB testing, diagnosis, treatment initiation and adherence, they can also complicate, delay or disrupt any of these steps in the pathway of care, especially where potentially competing religious, traditional and biomedical spheres intersect. Acknowledging traditional medicine, appropriately including traditional healers in education and counseling, and where possible accommodating different healthworlds can support the acceptability of care.
- Current South African policy initiatives to re-engineer primary healthcare provision and pilot a national health insurance system offer an opportunity to reconsider how treatment is provided and how providers can connect with the contexts and healthworlds of patients to revisit and reinvigorate the patient-centered approach that has, albeit implemented with difficulty, long been on the agenda of post-apartheid South Africa.

collective ways in which societies pursue health and well-being. This brief explores how HIV and TB patients in South Africa construct their illnesses through their beliefs, experiences and perceptions and how these constructions and patients' healthworlds influence their access to care, in particular, the acceptability of that care.

Understanding acceptability and access is crucial as South Africa, a country with a history of polarizing debates around HIV, has experienced the world's fastest growing HIV/AIDS epidemic, is the country with the highest number of people living with HIV, has seen TB become the leading cause of death, manages what is now the world's largest anti-retroviral (ART) programme, and is challenged to deliver uninterrupted ART and TB treatment.

## Methods

In-depth interviews were conducted with 29 patients who accessed ART and TB treatment from public health facilities in rural Bushbuckridge (Mpumalanga) and the urban settings of Cape Town (Western Cape) and Johannesburg (Gauteng).



Nine patients were HIV-positive, 12 suffered from TB, and a further 8 had been diagnosed with both HIV and TB. About half were “successfully” accessing care, while the rest were “unsuccessful” as they had not always collected or taken their treatment.

The interviews, which were conducted in 2009/10, sought to illuminate the patients' life circumstances, key health events in their lives, treatment pathways and care-seeking strategies, and the contexts within which these experiences and the perceptions around them played out to impact on the acceptability of care. The availability and affordability dimensions of access were not the main foci of the work.

## Findings

### *The nature of treatment pathways and acceptability*

Ideally, HIV and TB patients will progress along a pathway that starts with testing and diagnosis, moves through treatment initiation and adherence, and ends in symptom control or healing. However, this research highlights how the (un)acceptability of services and treatment, influenced by patients' illness constructions and healthworlds, can delay or disrupt steps in this pathway.

Acceptability, therefore, is not a static characteristic to be found at one point in the care pathway, but can in fact change over time as a patient moves through different stages of that pathway; it has to be negotiated and achieved repeatedly. The dynamic and changing nature of acceptability is illustrated by the cases of two patients from Johannesburg and Cape Town.

### Patient from Johannesburg

- She learnt her HIV-positive status during an antenatal care visit, without prior counselling or consent. This devastating news shattered her trust in the health system and left her bewildered.
- Despite the violation of her rights by the insensitive health worker behaviour, the patient was very concerned about her own HIV-literacy and whether she would infect her unborn child.
- The patient began to build her expertise on HIV and taking care of herself, eventually becoming an HIV counselor.
- Thus, she actively worked to make the available services more acceptable to herself and others, restoring some of the lost trust.

### Patient from Cape Town

- This man, who had TB before, went to a clinic where nurses conducted sputum tests. The tests were negative and he was told to return eight weeks later to be re-tested.
- Based on his prior experience of TB, the patient sought to persuade the nurses that he was too sick to wait, reiterating his pain and shortness of breath.
- Making no headway – a nurse patronizingly asked “Do you want to have TB?” – and not meeting his expectations of acceptability, the patient bypassed the clinic to go to a doctor at a hospital, who diagnosed him with TB again and referred him back to the clinic for the correct treatment.
- Testing was therefore not simply followed by correct diagnosis and treatment. Acceptability was only achieved over time as the patient navigated the care pathway.

#### ***Fear and acceptability***

Fear and futility in patients' constructions of illness can influence patients to delay steps in their care pathways in relation to testing, diagnosis and treatment initiation.

This was the case for a man from Bushbuckridge who, before ART was publicly available, delayed his HIV test for a long time. The acceptability of the service was challenged by the fear of a negative outcome and the futility associated with knowing how people were dying from the disease. Similarly, the abovementioned patient from Johannesburg initially refused to start ART treatment out of fear that the treatment itself would kill her and because of linking the death of two close friends to the treatment itself. She eventually relented after concerted efforts from her doctor and family.

In both cases, the fear was also related to the patients' broader healthworlds and contexts, not just their individual approaches and circumstances. The Bushbuckridge man's friends were also afraid of getting tested, while

the fear of the woman from Johannesburg was perhaps also linked to the concerns that the President and Minister of Health at the time expressed about the safety of ART.

#### ***Disillusionment and acceptability***

In addition to delays caused by perceptions of fear, treatment experiences and perceptions can also disrupt care pathways by prompting patients to abandon their treatment.

Experiencing side-effects or a lack of pain relief can, for example, create perceptions that the treatment is not working or that life is not getting back to normal, while patients can also become concerned about drug dependency. Such experiences and perceptions can cause disillusionment as they challenge health beliefs and unsettle healthworlds, potentially undermining the acceptability of services and leading to treatment default.

#### ***Shared and competing healthworlds***

Different healthworlds, where among other things the influences of family and culture loom

large in how illnesses are understood and socially constructed, can influence the care pathways that HIV and TB patients embark on and the acceptability of the services offered by the health system.

Especially in rural Bushbuckridge, patients mentioned the traditional illness *mafularha*, with essentially identical symptoms to TB, which leads to care pathways that are in line with traditional beliefs and healing, but may conflict with the biomedical healthworld. The case of an HIV and TB patient illustrates the intersection of the traditional and biomedical healthworlds in testing, diagnosis and treatment:

*“Yes, [my family] gave me traditional medicine and I took it for a while. And others came with the suggestion that it is better to send me to the hospital first to have a better idea of what I was suffering from. And it would be easy for them to give me traditional medicine after knowing my illness.”*

Problems in the biomedical healthworld of the public health system, for example incorrect diagnoses, can undermine the acceptability of services and push patients towards self-care or traditional diagnosis and healing.

However, as illustrated by a female HIV and TB patient from Cape Town, trust with the health system can be rebuilt and the biomedical and traditional healthworlds can co-exist or work

together to support holistic person-centred care.

After an incorrect TB diagnosis and a mistake with her ART, this patient’s family supported her in seeking out a traditional healer, who “exorcised” her and prescribed traditional medication. She abandoned her ART and TB treatment. Shortly after, nurses reached out to her, persuaded her to return to the clinic and agreed that she could take the ART and TB treatment alongside the traditional medicine as long as she did not display symptoms such as diarrhoea or vomiting. The nurses’ willingness to engage with the patient’s healthworld was therefore crucial to the acceptance of the biomedical treatment.

While healthworlds can complicate or undermine care pathways and the acceptability of services, they can also have positive impacts, for example on patients’ adherence to treatment over time. This was the case for an ART patient from Bushbuckridge, whose healthworld was shaped by her mother’s suffering and death without ART, her sister’s survival because of ART, and her own positive response to the treatment. In addition, finding resonance for her healthworld through positive interactions with providers at the clinic also contributed to the acceptability of the services and her accessing it over time. Such resonance and respectful provider treatment was also crucial to service acceptability for an HIV and TB patient from Cape Town:

*“I started to know [the nurses] that helped me and I started to talk with them...And they were very helpful, they helped me. [The DOTS coordinator] was my pillar here. She was making me happy. She always smiled and she encouraged me to say that it was worth it to live. It was a pleasure to come to this clinic till I finished.”*

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