POLICY BRIEF

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Endurance, resistance and resilience: lessons from patients and healthcare providers in a constrained South African health system

Introduction

Despite positive developments in recent years such as better leadership and an improved response to the major challenge of HIV/AIDS and tuberculosis (TB), providers and patients alike often experience South Africa's health system as a very constrained environment.

The issues that weigh on providers include strained relationships with their managers, too few staff, high workloads, resource shortages, dissatisfaction with how the system works, and wanting to do more to increase its responsiveness. Patients face challenges such as poor quality care, services and treatments that are unacceptable for cultural or other reasons, and negative staff attitudes.

Indeed, suspicion, blame and mistrust in the provider-patient relationships significantly constrain the functioning of the health system and make it all the more challenging to deliver the caring, efficient, effective and equitable services that so many desperately need (Figure 1).

Although there are many examples of positive provider-patient relationships, mistrust, when it occurs, can lead to negative outcomes that include a tense working environment in health facilities, as well as patients interrupting their treatment, withholding information about side effects or treatment complications, and experiencing feelings of being unwanted and less than human.

Against the backdrop of a challenged system, this brief highlights selected strategies that providers and patients use to cope with their circumstances in order to access services and provide care in a meaningful way.

Conclusions and policy implications

- In the constrained South African health system, patients and providers cope through endurance, resistance and resilience.
- Some coping strategies have negative outcomes such as breaking provider-patient trust and risking patients' health. Others have positive effects such as increasing patients' and providers' resilience, e.g. when providers treat patients with respect or when patients appreciate providers' work.
- Patients can improve their coping ability in their own contexts, e.g. by building their social networks, and providers can do the same, e.g. by connecting with colleagues. However, the welfare of these two groups remains inextricably linked as they interact positively or negatively with each other to co-produce care.
- It is thus crucial to build patient-provider trust and mitigate behaviours that cause mistrust. Limited and uncaring service can lead patients to mistrust providers and the health system. Similarly, the expectations of providers, who are under pressure to provide care and use resources efficiently, may be left unmet by the combination of a constraining system and patients who do not always behave as expected.
- Trust-building can be achieved through transparent decision-making that involves all stakeholders, including citizens, and through which the needs, wants and motivations of patients and providers can be interrogated in order to work towards more respectful relationships and better quality of care.
- Trust is key to the more capable state envisioned in government policy, which will see better management, stronger manager-administrator linkages and transformed service delivery for citizens. It cannot, however, be achieved in a top-down way without engaging patients and citizens.
- Patients' and providers' coping behaviours highlight the need to build trust. A better knowledge of these behaviours also helps policy-makers and managers as they develop new initiatives to transform the South African health system.
- Patients' and providers' experiences indicate behaviours and resilience resources to be nurtured, but also problems to be addressed to improve care, and so that both groups can make more positive coping decisions in the contexts of their illnesses, life circumstances and work settings. Organizations will not change unless individuals within them act and communicate with trust and compassion.

Figure 1:
Suspicion, blame and mistrust from the perspective of patients and providers

Disrespect: rudeness, neglecting responsibility for care

"She [the nurse] talked to me in an impolite manner in front of her staff. She told me where to get off because I was late...because I am late she said I should come back on Wednesday, but I thought 'clinics operate until 4PM' [designated closure time]..."

Disrespect: disregard for patients' time

"...they told me she will be here at 3 o'clock and I went there at 3 o'clock and they told me 'no, after 6'. And I came back to the clinic because I did not get my pills. I had to wait for strength to come here...I got an answer that she will be here at 7 o'clock..."

Disrespect: dereliction of duty

"...some of the nurses are very hard, when you talk to them they just ignore...patients...It is like when you find that the complainant is bed-ridden and tries to call the nurse...and the nurse just leaves without attending to that patient..."

Disrespect: belittling the patient

"...And when I was lying with my legs opened to her, because I didn't know how to lie, she was yelling at me and told me how can I lie in that position because she was not going to look there. And she was laughing with the other nurse..."

Insensitive to life circumstances: access to grants

"Q: Nobody at the clinic told you that the TB patients can get a grant?
A: No
Q: And you never asked?
A: No I did not know about the grant and if I can get it or not."

Insensitive to life circumstances: treatment regimentation

"...they say I must take my pills...then they will give me tomorrow's pills. I just told them straight 'I can't come tomorrow...I can't walk every day so far and back'. [The nurses said]...I must make a way to come to the clinic. I must just come, there is nothing they can say..."

Providers felt they were doing their jobs diligently in the face of high workloads and resource shortages, but that ungrateful, demanding and abusive patients were exhausting them.
Echoing some patients' talking points, they complained about patients presenting at the clinic on the "wrong" days and times and were often sceptical of patients who claimed to have lost their medication.
Providers often interpreted such occurrences as ignorance of the system and demanding, disorganised and dishonest patient behaviour, rather than as reflecting a service entitlement or patients' trying life circumstances.
Providers also often regarded patients as ignorant: "You have been aware that you are not working, both, but you've decided not to go to family planning. That's a bit on the stupid side because if your boyfriend, my girlfriend's not working, really, I should think for myself that 'why must I fall pregnant?'".

Methods

We interviewed 45 patients and 63 providers from rural Bushbuckridge (Mpumalanga) and the urban settings of Cape Town (Western Cape) and Johannesburg (Gauteng).

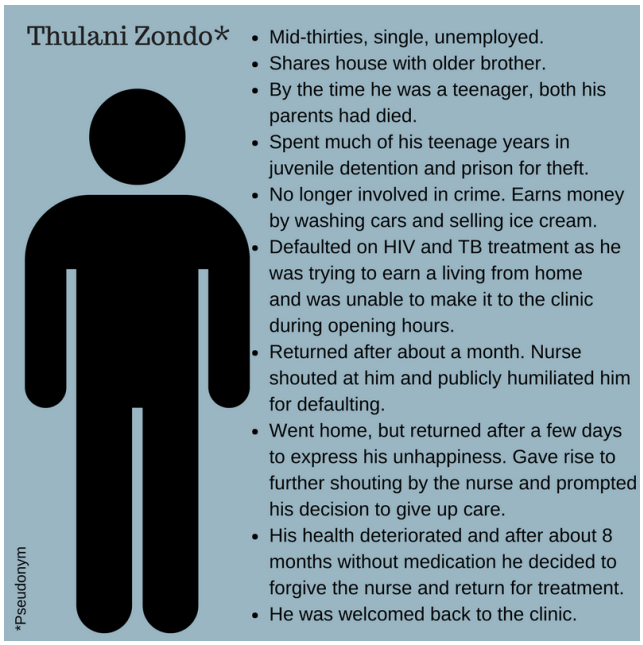
Sixteen patients accessed maternal health services, while 29 received TB and HIV/AIDS treatment. Twenty of the providers delivered TB services, while 21 provided anti-retroviral treatment and 22 worked in maternity services.

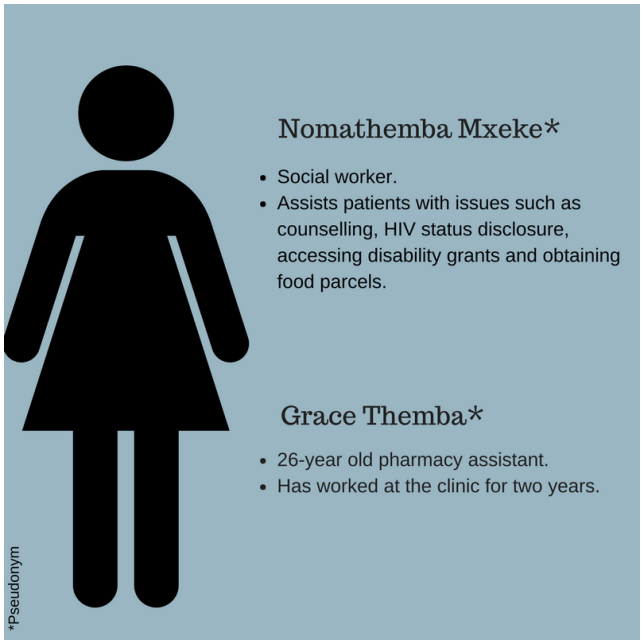
To capture diverse access experiences, the patients were a mixture of those who had managed to access care successfully, for example by being adherent to their TB treatment, or unsuccessfully, for example by giving birth at home or on the way to a health facility.

The interviews, conducted in 2009/10, encouraged patients to talk about their illnesses or pregnancies and their experiences with care. The providers were interviewed about their careers and understandings of patients and their lives. These factors still resonate with today's health system, despite recent policy and practice changes.

Findings

We use the narratives of four people – two patients and two providers – to highlight different ways in which patients and providers cope with the entrenched challenges of a constrained health system.





Resources

Connections to others

We found that, even in very limiting environments, people draw on resources to cope with difficult life and work circumstances, and interactions with the health system.

One key resource is a connection to sympathetic others. For Sthembiso and her sisters, neighbours provided emotional support and material help in the form of food, while Thulani was able to open up about his illnesses to a neighbour and fellow churchgoer, both of whom faced similar health problems. Despite their positive potential, social connections can also undermine the ability to cope, for example when they are used to spread gossip and stigma.

Nomathemba and Grace, the providers, relied on support from colleagues and team members and used regular meetings to discuss challenges and potential ways of dealing with them. Going beyond their colleagues, the providers also clearly drew strength from patients' acknowledgment of the services provided.

Positive framing

Another resource that supports coping is the ability, even in the direst of situations, to maintain a strong sense of self and stay positive about one's circumstances or actions, thereby resisting a passive sense of victimhood or despair. Thulani, for example, only opened up to his neighbour after setting aside feelings of depression and hurt relating to the HIV and TB diagnosis and early treatment, telling himself "…I have to be positive. I am still a human being like everybody". Optimism was also one of the ingredients helping Nomathemba to deal with the challenges of being a social worker and the poverty and adversity affecting her patients.

Patients: Coping strategies

We found that provider behaviour such as rudeness, expressing negative value judgements, and regimenting care - behaviours that cause mistrust (Figure 1) - can lead to acts of resistance by patients which, in turn, can have severe consequences for their access to services and health.

In addition to the regimented routines that caused her to abandon facility delivery, Sthembiso also resisted seeking care because

she expected to be judged by providers for having sex at a young age. This expectation was largely grounded in others' stories, not first-hand experience:

"You know, the reason why I didn't go is that I was scared that when I go there, they will judge me and shout at me on top of that. The other thing was that I thought they would tell me that I'm still young and I'm having sex already. You know, people have a tendency to judge without understanding what led you to doing what you did…It was from the stories I heard from people, somebody will tell you about their experience at the clinic when they were told that they are young but sleeping with men. So I thought that maybe with me it was going to be worse."

Sthembiso therefore coped through resistance (by withdrawing from a system perceived as uncaring) and endurance (of an unwanted pregnancy without support from the health system or others). Her coping was facilitated by thoughts of self-encouragement ("…this [birth pain] is just a temporary pain and it will pass"). However, it was only once the baby was born, and she was warmly welcomed by providers for post-natal care (to her surprise) that her coping showed resilience in the positive ways she framed the baby's birth and life thereafter, including that she had already dealt with bigger problems, she hoped to continue her schooling, and having her own child would not be particularly burdensome.

Thulani's story of abandoning treatment was also typified by resistance and the protracted endurance of his illnesses with little support. In returning to the clinic and getting medication again, Thulani significantly increased his meagre resources and thereby his resilience: the treatment improved his health, enabling him to better respond to the adversities related to his illness and life circumstances.

Providers: Coping strategies

Resources such as supportive collegial relationships, patient appreciation, and a positive outlook on their work were crucial to maintaining Nomathemba's and Grace's resilience.

Providers need this resilience because they have to endure and act in difficult contexts characterised by systemic challenges such as patients' difficult life circumstances, discrimination against patients living with HIV/AIDS, patient denial and ignorance about illnesses, and patients not adhering to treatment and heeding advice.

An interesting feature of Nomathemba's and Grace's practice was their resistance to aspects of health system functioning for the benefit of their patients, not themselves. In part, this resistance entailed verbal criticisms of system functioning and advocating for better patient experiences. Grace, for example, argued that the system had too many managers and insufficient oversight over resource use and lamented the lack of consideration for patients who have to wait in long queues and suffer a lack of privacy when consulting with providers.

Additionally, they acted as a buffer between the health system and their patients in an attempt to boost the latter's resilience and make the system more responsive.

Nomathemba sometimes paid patients' transport costs or transported them herself when she thought their difficulty in getting around might affect their treatment adherence. She helped them to write appeals against decisions not to award them disability grants, and referred patients to support groups where they could access food. Grace spoke about consulting with patients and returning their files to the doctors to highlight problems that patients were afraid of sharing with the doctors.

This "positive" resistance contrasts starkly to other, well-documented forms of provider resistance such as criticising the Patients' Rights Charter, blaming patients, and arguing that providers have too few rights compared to patients.

Sources: Eyles J, Harris B, Fried J, Govender V, Penn-Kekana L. (2015). Suspicious minds: apportioning and avoiding blame for distrustful relationships and deferring medical treatment in South Africa. Sociology Mind, 5, 188-199 // Eyles J, Harris B, Fried J, Govender V, Munyewende P. (2015). Endurance, resistance and resilience in the South African healthcare system: case studies to demonstrate mechanisms of coping within a constrained system. BMC Health Services Research, 15, 432. **Funding:** Teasdale-Corti Fund of the International Development Research Centre of Canada // Global Health Research Initiative, a partnership of the Canadian Institutes of Health Research, Canadian International Development Agency, Health Canada, the International Development Research Centre and the Public Health Agency of Canada. JE acknowledges the support of the South African Research Chairs Initiative (SARChI) programme (Department of Science and Technology, National Research Foundation). **CHP Policy Briefs:** The briefs aim to make CHP's research accessible to key stakeholders by summarising the work and presenting key policy implications and recommendations.