

and the City and a lack of understanding on how specific City processes and services work. These included, not knowing what they should report where; how to follow up when problems are not fixed; and when the City is or is not responsible for particular issues. Although the researchers recommend that more consistent work is needed to sustain change, in the evaluation workshop discussions, participants expressed how the project helped them in at least three important ways. It increased City officials' awareness of local realities and challenges around participation and service provision as well as citizens' understanding of City processes and structures. It also strengthened collaboration between officials and the community to improve the provision and maintenance of services.

More collaboration needed

The researchers found that service delivery challenges (and protests) often emanate from communication failures. Therefore, more collaborative spaces are needed to improve provision of basic services and understanding of each other's (the City's and the citizens') realities, needs and resources. Improving communication and active participation processes for residents to provide ideas and communicate constructively with the City, is key.

An infrastructure overload

It was also found that service provision to backyarders is a major challenge for the City, mainly as a result of infrastructure overloading and restricted access for maintenance. This creates unfair conditions for citizens living in these conditions, who are often at the mercy of landlords and can't access benefits such as electricity subsidies.

Private contractors who provide services on behalf of the City play an important role in the service delivery matrix. Therefore, the researchers recommend that monitoring needs to be strengthened to improve quality of the provision and to safeguard the relationship between residents and the City.

The researchers found that City officials are often overworked and under-resourced, particularly for community engagement. Especially junior officials need more support to engage with the community in a meaningful and mindful way.

Value of new research methods

The collaborative approach and outcomes of this frontline service delivery study serve to highlight the potential of using participatory and action research tools and adapting and mixing methodologies to promote not only better understandings of service delivery, but to promote actual change. This experience should be useful to policy makers, activists and academics interested in social research approaches aimed at enhancing local agency to build collaborations to support transformation around service delivery and citizen engagement practices.

Collaboration between officials, residents, politicians, researchers and NGOs is not easy, as it requires time, resources and flexibility to align each other's understandings and needs. However, if we want to improve service delivery and community engagement practices, particularly in marginalised contexts, multi-stakeholder collaboration and applying the principles of participatory action research are essential.

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HIV-POSITIVE MOTHERS supported to disclose their status: A potential benefit to their children

Research shows nearly one in four HIV-infected people with children have not had the courage to tell them. Yet, children of HIV-positive parents face significant developmental, health and psychological challenges, particularly in communities where the stigma is high. The HSRC's Dr Tamsen RoCHAT and a team of researchers from the African Health Research Institute in KwaZulu-Natal led the Amagugu intervention, which successfully increased the levels of disclosure among a group of mothers with young children in KwaZulu-Natal. These findings were published in the medical journal *The Lancet HIV* in August.

The World Health Organisation recommends that parents disclose their HIV status to children under the age of twelve, but there is little guidance on how to approach this with children. Studies show that mothers benefit from disclosing their status. It reduces stigma and improves adherence to HIV treatment, their parent-child and family relationships and their mental health. Their children also benefit from improved mental health, but also because mothers who disclose tend to plan better for custody and care of their children in periods of illness.

The Amagugu intervention

The Amagugu intervention took place at the Africa Health Research Institute in a rural, HIV-endemic region of KwaZulu-Natal where HIV treatment coverage is good. A total of 428 HIV-positive women on antiretroviral treatment with HIV-uninfected children aged 6-9 years completed the trial.

RoCHAT and her team wanted to address maternal avoidant coping.

These mothers cope with HIV by distancing themselves from the problem, and by avoiding communication about it within their family and close relationships. They try to forget or avoid the day-to-day stressors of being HIV infected. However, open communication with children about parental chronic or terminal illness is important. Although parents want to protect their children from a painful truth, the realities of living with HIV often mean that children become aware that things have changed for their parent. They notice signs, symptoms and medication, and can worry more if they are not reassured. Avoiding open communication can affect the quality of the parent-child relationship and create more stress in the parenting role, affecting the child negatively.

Shifting to active coping

The Amagugu intervention aimed to shift maternal parenting behaviour to an active coping style, by disclosing their HIV status to the child and by addressing issues linked to the

children's well-being, such as health education and custody planning. The aim of the study was to compare the efficacy of the Amagugu intervention with that of a single counselling session at a primary healthcare facility, the standard-of-care group that represented the status quo for women who seek healthcare in that community. The participants were randomly assigned to the Amagugu intervention or the single session.

Home-based counselling

The Amagugu intervention included six home-based counselling sessions conducted by trained lay counsellors over a period of 8-12 weeks. The counsellors provided printed material and activities to support age-appropriate disclosure and to prepare the mothers for their children's emotional reactions and questions after disclosure.

The mothers were able to choose whether they wanted to partially disclose (using the word virus) or fully disclose (using the term HIV) or not at all.



Rochat explains, “There is no way to make HIV disclosure to a younger child easy for parents, but the Amagugu intervention focused on making it manageable and on providing the parent with tools to ensure a good outcome for the child. Amagugu participants were supported with user-friendly age-appropriate materials to approach the topic in a way a child would understand. Parents had a chance to prepare for the disclosure, which resulted in it going better than if it was unplanned, or came as a result of something stressful like illness or hospitalisation.”

The results

The results of the study show that 92% of the Amagugu intervention group disclosed their HIV status to their children and only 57% of the group who received the standard-of-care group. In the Amagugu group, 68% of mothers fully disclosed using the term HIV, versus 44% in the standard-of-care group.

Both groups showed improvements in maternal and child mental health, family functioning, health-related quality of life, and overall parenting stress. However, dysfunctional relationship scores between parents and children in the Amagugu intervention group were significantly lower than in the other group.

HIV-infected parents have multiple stressors, including strained family relationships, which complicate care planning for children. When HIV disclosure does not occur, or if it occurs during periods of maternal illness, children are more likely to have emotional and behavioural difficulties and risk of neglect. Timely maternal disclosure of HIV status, with planning before illness, might mitigate some of the

effects of maternal HIV-illness on children.

A key aspect of the Amagugu intervention was that primary school children had the opportunity to learn about HIV and become familiar with their local healthcare clinic with mothers being more likely to take them along on clinic visits.

Improved custody planning by mothers in this group can decrease the likelihood of children being moved between households, separated from siblings or placed in foster care when they fall ill or die.

The outcome of the trial suggests that without an intervention that actively encourages parents to deal with communication about HIV, health education and care planning, the rates of these actions remain low, which is concerning since the absence of these actions confer risks.

Child-friendly tools

A key component that makes Amagugu successful is the materials and tools, says Rochat. “The research has confirmed that providing colorful, branded, child-friendly materials helped mothers have the confidence to address a difficult issue. It was important to community stakeholders and participants that the researchers used illustrations that reflected South African culture and portrayed families in a positive way.”

One community stakeholder explained, “...to have something that looks like you, not like a cartoon with black coloured skin or those stupid things you know, but that really looks like you, your culture, the colours, your hair, the way people dress, you just don't see things like that... and then you say,

A key component that makes Amagugu successful is the materials and tools

‘Hey look at this – this is really cool. I’m a Zulu guy and this looks like me, this looks like my family’ ... it’s really positive and it counts for a lot, and it says something about who you are and how you want to help and respect people in this community.”

Similarly, mothers said,

“I cannot believe that somebody made something so beautiful to help me.”

“When we started, I was not caring much to do it, now I am really looking forward to doing all these steps with the child.”

“I was so nervous about the telling, saying the words, but now I see how the body map works, I can just show the child and take myself there easy.”

The trial, funded by the National Institutes of Health through the Eunice Kennedy Shriver National Institute of Child Health and Human Development, signals an important milestone for South African-led psychological research aimed at addressing the challenges faced by HIV-infected parents raising HIV-uninfected children. This is the first trial testing a parental HIV disclosure intervention to show positive outcomes on the African continent.

Rochat says, “Amagugu is a great example of how South African researchers can innovate and lead on much-needed psychological research aimed at improving the outcomes of HIV-infected parents living on treatment. In addition, providing HIV prevention education

to young children is crucial in the South African context where their risk is high of becoming HIV-infected as they reach adolescence. The epidemic is evolving, parents are living longer on treatment, and given the success of HIV prevention programmes in pregnancy these parents are raising predominantly HIV-uninfected children. We need to address and respond to the parenting needs of this rapidly growing population. Supporting them to communicate with their children about HIV is central to that.”

Rochat also believes that in resource-constrained settings, it is critical to invest resources where you know they can have impact. “Our health system functions under immense pressure given our large HIV treatment programme. Often, the most rural and poorest do not have access to the additional support needed to live positively with HIV. Amagugu addresses this by empowering lay health workers in their communities and by transferring skills to parents that will help them in the longer term. While the question remains whether Amagugu will show effectiveness at a larger scale, the national Department of Health now has robust evidence to support this additional investment in children and families, with a very good chance of success.”

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