

Study examines public understanding of drug rationing amid AIDS epidemic

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Moureen, a young mother of two children, is part of generation in Malawi that has grown up amid an HIV-AIDS epidemic in the east African nation. Credit: Gregory Collins

In Balaka, Malawi, HIV-AIDS has been an epidemic for so long that young adults have never known any other reality. Anti-retroviral drugs,

which keep infected people healthy, are available, but there aren't enough to treat everyone who needs them. So policymakers in the east African nation must prioritize.

Rationing is complicated, and priorities have shifted many times over the years. Young adults in Balaka are often unaware about what the current distribution strategies actually are, despite the fact that their lives, and the lives of their family members, hang in the balance. People often end up confused and suspicious of a system of rationing that has not been clearly communicated, while having clear ideas about who should get the drugs first.

Researchers in a new study find the ideas among community members are surprisingly quite similar to what actually happens. The research was published recently in the *Journal of the International AIDS Society*.

Co-authors Jenny Trinitapoli, associate professor of sociology at University of Chicago, and Sara Yeatman, associate professor of health and behavioral sciences at the University of Colorado, Denver, examined what [young adults](#) think about how [anti-retroviral drugs](#) are distributed. Their findings suggest that decision makers who allocate anti-HIV drugs should make their policies—and the rationale behind them—clear to the publics they serve, in part because such steps would help ensure people continue to come to health clinics.

"The priority of policymakers has not always been on communicating their priorities to the average people." Trinitapoli said. "But questions of access to anti-retroviral drugs and fairness in allocating them have consequences for how people will engage with the health care system broadly. We are trying to see opportunities for improving relationships between people who are affected by policy and the people who are carrying it out."

The new findings are part of a long-term project begun by Trinitapoli and Yeatman in 2009. They have been following a group of 1,500 women and 600 men through a period of their lives in which most people form relationships and have children—also the time of life when most new HIV infections occur. Respondents have been interviewed at four-month intervals to try to shed light on how young people deal with reproduction in an AIDS epidemic.

"In a generalized epidemic where as many as 20 percent of people in communities are infected, HIV is really part of the context," Trinitapoli said. "The question of whether someone is infected or not has become secondary to the fact that everyone is trying to make decisions, forge relationships and start their families with a backdrop of a deadly condition swirling around them. It makes for very complex interactions for young adults, especially as they navigate relationships and decisions about childbearing."

In the most recent study, Yeatman and Trinitapoli wanted to find out what people understood about a new government policy that shifted priority access to drugs from the sickest people to pregnant women who are HIV positive, regardless of their health.

Most Balakans are semi-literate, so the researchers used pictures to probe what people think happens in the clinics under the new allocation system. Participants were given six drawings—a healthy-looking pregnant woman and a sick-looking one; a healthy woman who was not pregnant and a sick one; a healthy man and a sick one. They were asked to arrange them according to who they thought was likely to get anti-retroviral drugs and who wasn't. Then the researchers asked the study participants to re-arrange the drawings according to what they thought would be the fairest way to distribute the drugs.

Only about a third of women and 20 percent of their male partners

showed that they understood how the drugs were being distributed. But when those who didn't understand moved the cards to show what they thought would be more fair, they illustrated the policy that is actually in place.

"A lot of people moved the healthy-looking pregnant woman up, to show that she should be prioritized," Trinitapoli said. "So the sensibilities around fairness are highly consistent with the policy. But the policy hasn't been communicated to a general audience. And that gap between what people think is happening and what people think is fair is pretty unnecessary."

In the next phase of their research, Trinitapoli and Yeatman plan to look at how HIV-AIDS reduces trust between partners and de-stabilizes relationships, creating an environment in which the disease can spread more quickly. And they want to look at how understandings of the disease are changing as more people gain access to treatment and live long, normal lives.

"In a place like Malawi, where the GDP is one of the lowest in the world and most people live as subsistence farmers, can it really happen that HIV will become a chronic, manageable condition like it is in the United States?" Trinitapoli asked.

More information: Sara Yeatman et al. Awareness and perceived fairness of option B+ in Malawi: a population-level perspective, *Journal of the International AIDS Society* (2017). [DOI: 10.7448/IAS.20.1.21467](https://doi.org/10.7448/IAS.20.1.21467)

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