Shame and fear: Lessons to learn as COVID-19 collides with a growing HIV epidemic in Indonesia

27 August 2020, by Keerti Gedela, Evi Sukmaningrum and Irwanto

The nation with the world’s fourth-largest population, Indonesia, has become a target of criticism for its poor COVID-19 mitigation response that "does not value policy advice from external experts". This has contributed to the country having the highest recorded COVID-19 death toll in Southeast Asia.

A failure to handle stigma associated with COVID-19 has also contributed to the surge in cases in Indonesia. The number of cases is the second highest in Southeast Asia.

Globally, we are witnessing how stigma is taking its toll on affected communities, including in Indonesia, and how fear is preventing COVID-19 testing.

Stigma and discrimination have historically accompanied many infectious disease epidemics.

Similarly to what has been observed with the HIV epidemic, we are seeing how shame and fear resulting from stigma and discrimination can drive increased transmission of COVID-19 and prevent vital public health control.

**Shame and fear help disease spread**

AIDS-related deaths fell in most countries, including in the developing world, following widespread improved access to anti-retroviral treatment by the early 2000s.

However, AIDS-related deaths have never fallen in Indonesia. The toll has increased by 60% since 2010.

Among many challenges that Indonesia has to deal with in its HIV epidemic, stigma and discrimination are the greatest barriers. The COVID-19 pandemic in Indonesia presents similar challenges.

Shame, a negative emotion of unworthiness and inferiority linked to one’s core identity, is a specific consequence of stigma.

Shame leads people to behave in ways that may be against their best interests. It can lead people to seek belonging in riskier environments and communities.

Regardless of the method of transmission and major differences in the viruses, HIV and COVID-19 are both potentially fatal. However, the threat of shame can feel worse than the threat of death itself. Public health responses to infectious diseases must also tackle and prevent shame.

Fear of persecution and negative outcomes, such as violence, abandonment and relationship breakdowns, due to the stigma associated with HIV lead people to avoid getting tested or treated.
Similarly, if people know that a positive COVID-19 diagnosis for themselves or a family member negatively impacts or isolates them from their community or prevents them from making a living, this fear can prevent them from getting tested.

Residents in Penjaringan, North Jakarta, "shut themselves in when COVID-19 swab tests were being administered in the neighborhood's community hall". They did this for fear of being stigmatized and losing opportunities to make a living.

Social stigma has worsened HIV rates among men who have sex with men and other marginalized groups. The stigma has pushed risk underground. This then further increases HIV risk and vulnerability in these groups.

Back in April, it was reported that a patient diagnosed with coronavirus in Indonesia was subjected to cruel innuendo suggesting she contracted it through sex work.

Public fear often creates stigma against those infected as a protective mechanism. Beliefs that put the blame and responsibility on those infected, however unfounded, can enable people to feel better off and negate their own risk.

Similar impacts have been observed for populations affected by tuberculosis, leprosy and Ebola, for example.

**Misinformation makes it worse**

Myth and misinformation and the spread of fake news compound these issues.

A Global Fund report highlighted that in Surabaya, East Java, patients presenting for HIV tests have been asked to seek forgiveness by health workers because of perceived sins before they will be seen. Many people living with HIV are asked to wait for hours for treatment, implying they are not worthy of health care.

In one study of public understanding and misinformation about COVID-19 in Indonesia, 28% of 530 respondents believed COVID-19 is a deliberately created biological weapon and 20% believed gargling salt water or vinegar could kill the virus.

Indonesian government ministers have themselves suggested unconventional and non-evidence-based methods, such as prayer, to beat COVID-19.

Government leadership guides such public understanding; an understanding that prayer protects one from COVID-19 can translate to a belief that those infected are not abiding by religious teaching, undermining their worth in society.

Governments and institutions that encourage blame or false beliefs about an infectious disease drive stigma.

This cycle of stigma prevents affected individuals and communities from thriving and drives poor physical and mental health.

Public health strategies that perpetuate stigma are not successful in controlling any infectious disease epidemic. Structural power and mechanisms should be used to educate people and generate positive behavioral change.

**Public health strategies**

We can learn from strategies that have reduced HIV-related stigma to manage COVID-19.

Countries that have strategically reduced institutional stigma have observed better HIV testing and treatment rates and engagement in care. As a result, new HIV infections are reduced.

These trends have been observed, for example, in neighboring Southeast Asian countries Thailand and Vietnam.

Thailand has been a pioneer in reducing HIV-related stigma and discrimination in health-care settings through an innovative health system-wide response.

This involved a strategy to reduce stigma and discrimination based on global measuring tools.
The strategy includes a permanent monitoring system, evidence-informed actions at health facilities and instructed community engagement at all levels.

Thailand has also had greater success than most Southeast Asian countries in averting COVID-19 deaths and cases by adopting a "whole-of-society" approach. This enables understanding and appropriate responses to the needs of vulnerable populations.

To counter growing COVID-19 infection rates, public health endeavors must aim to understand the needs, priorities and fears of populations and prevent stigma. The most vulnerable populations must not be left behind.

The Indonesian government should learn from the impact its policies have had in fuelling HIV-related stigma so as to avoid perpetuating stigma during the COVID-19 pandemic.

It is vital that governing bodies and policymakers discourage misinformation and follow robust local and international data. They must also translate the data for public understanding to minimise fear and promote compliance with public health interventions.

This should include risk communication strategies to fill knowledge gaps in the general population and prevent the spread of "fake news."

Government public health endeavors should provide clear, robust, evidence-based information; promote equitable health strategies; reduce stigma and encourage community cohesion. By building public trust and confidence, these measures will have far better success.

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