

The Impacts of Covid-19 on Health and Human Rights Among Women Living with HIV in Nepal: A Rapid Assessment from a Community-Led, Participatory Study

EXECUTIVE SUMMARY

The global evidence-base on Covid-19 has been rapidly populated by clinical studies and epidemiological models. But there is a critical lack of data about the impacts of the pandemic on the health and human rights of people living with HIV, particularly within resource-constrained settings in the global south. Informed by advancements in HIV treatment and prevention, UNAIDS and its partners (including national governments, bilateral agencies, advocacy coalitions and community-based organisations) had committed to the ambitious '90-90-90' targets, to be met by the year 2020 (UNAIDS 2014). The Covid-19 pandemic threatened to defer or even reverse the gains made in meeting these targets, undermining critical progress in the global HIV response.

In June 2020, the International Treatment Preparedness Coalition (ITPC) launched a new project to map the impacts of Covid-19 on people living with HIV, and to support and strengthen community-based monitoring of essential health services and human rights in specific locations around the globe. From June – July 2020, ITPC worked together with Dristi Nepal (an advocacy organisation of women living with HIV and who use drugs), to source, analyse and disseminate meticulous, first-hand accounts of the effects of the Covid-19 pandemic on women living with HIV and using drugs in Nepal, particularly in Kathmandu and surrounding valleys.

Collaborative Methodology

A participatory research tool was developed collaboratively by Dristi Nepal and ITPC to capture and assess the impacts of Covid-19, combining and adapting the formats of a 'Citizen's report card', a 'Community assessment', and a qualitative survey (Baptiste et al. 2020). The tool used images and emoticons to encourage participants, regardless of literacy, to relate their experiences of healthcare services as people living with HIV, and to rank their government's actions on health provisions and human rights both prior to and during the Covid-19 pandemic. Every component of the tool's development and implementation was collaborative, from the formulation of indicators, to its inclusive design and analysis of findings.

The tool included eight indicators:

- 1. HIV testing**
- 2. Antiretroviral Therapy (ART)”**
- 3. Integrated care (sexual and reproductive health and harm reduction)**
- 4. Employment and income (economic vulnerabilities and impacts)**
- 5. Food security**
- 6. Safe place to live**
- 7. Violence and stigma**
- 8. Government accountability**

While structured according to these indicators, narrative response fields were blank, encouraging women to relate whatever they determined to be relevant and meaningful. Two response fields for each indicator elicited information about users’ experiences both prior to and during the Covid-19 pandemic. The last section of the tool encouraged users to convey strengths and weaknesses in the public health and social support systems, and to articulate their most urgent needs for health and social services now and in the near future.

The tool focused primarily on the HIV treatment cascade, providing community-based organisations — in this case Dristi Nepal — with detailed, context-specific information about HIV testing, ART access, and viral load suppression. Data analysis demonstrated the negative effects of the Covid-19 pandemic on each step in the HIV treatment cascade.

Findings

Collaboration between government, international agencies and local advocacy groups was critical in shaping and implementing Nepal's Covid-19 response.

Nepal's lockdown, instituted on 24 March 2020, closed all public and private facilities, except those providing 'essential services'. Some public health services that were essential to sexual and reproductive health, such as family planning clinics and HIV treatment centres, were also closed or furloughed (Cousins, 2020). Yet, government ministries, bilateral agencies and community-based organisations also worked closely to plan the emergency response, including through arranging clinic referrals, increasing 'take-home' doses of medicines, and conducting visits at people's homes during the lockdown.

Nepal's lockdown severely restricted people's movements.

Despite the efforts of a government and civil society networks to provide support to people living with HIV, the lockdown had profound consequences for women living with HIV and on ART. Leaving home during lockdown aroused the suspicion of families, neighbours and landlords, who questioned women's reasons for going out or seeking healthcare. Without public transport (which was prohibited or severely restricted during the lockdown), women had to walk lengthy distances to healthcare facilities, taking along their children who were also on ART. Due to changes in location and restrictions on movement, many women could not continue to access ART from the facilities in which they had initiated treatment or were previously retained in care.

Within some healthcare facilities, staff were fearful of Covid-19 transmission, and treated women with HIV with rudeness and disdain.

Numerous respondents reported that healthcare workers were annoyed by their presence and served them abruptly and unwillingly. Anticipating that their facilities would be overrun by Covid-19 patients, and perhaps hoping to delay or to avoid this, healthcare workers seemed to be discouraging patients requiring chronic care from continuing to burden the health service in the midst of more urgent threats to public health: Covid-19. The continued provision of medicines for chronic care patients was deprioritised, as attention shifted, and fears were directed, to Covid-19.

Women themselves were afraid to seek ART and other healthcare services. They worried that their transferral to ART facilities that

were closer to where they were living during lockdown, might lead to breaches in patient confidentiality as new healthcare staff learnt their HIV status. They also worried that their families and neighbours would discover that they were HIV-positive, and that they would face stigma or even expulsion from their homes (as some women had in the past).

Women described the stigma and discrimination endured after disclosing their HIV-positive status to their spouses, families or communities, prior to Covid-19.

This was evidence of the ongoing stigma and violence that women living with HIV confront in Nepal, with findings from the rapid assessment suggesting that living with HIV may deepen economic and social vulnerabilities in the Covid-19 era, as access to public services are restricted and as chronic care patients was deprioritised.

Findings from the rapid assessment revealed that the difficulties that women faced in monitoring the efficacy of their own ART regimens have been exacerbated by the Covid-19 pandemic.

Prohibitive difficulties in procuring a viral load (VL) test had a direct and negative impact on many people living with HIV in Nepal, as the switch to dolutegravir as the first-line ART regimen coincided for many with the outbreak of Covid-19. The requirement for VL testing prior to the switch delayed or complexified the ART regimen change for many, and exacted a direct cost for users. Women reported that they were required to pay for VL tests in the public sector, and struggled to access these tests due to the limited number of VL machines (believed to be 3 machines in the whole of Nepal, with only two functional in July 2020). Women worried that, with the growing burden of Covid-19 on the health sector, ART would no longer be free to access publicly.

Data from the rapid assessment tool also revealed the real-world economic toll of the Covid-19-pandemic on an already marginalised and precarious population.

Nepal's lockdown suspended economic activity, with casual ('daily-paid') workers among the hardest hit. Most of the women in Dristi's Nepal's community of care had lost their jobs during the lockdown. As a result, they were unable to pay their rent or provide enough nutritious food for their families. One woman explained that she ate only enough to fill 'half of her stomach' with each meal, to ensure that her children did not go hungry.

During lockdown, as their incomes evaporated, women and their families faced greater hunger and insecurity.

Women went on daily searches for menial work such as 'household chores' (domestic work) to bring in an income, however small. They were often unsuccessful. As a result, these women and their families faced the threat of losing housing due to rent shortages looming larger with each passing week. The cash payouts promised by the government to support and sustain families were insufficient (RS 1000 per child), and were difficult or impossible to procure. When women succeeded in accessing cash grants, the amounts they received were significantly smaller than what had been publicly promised.

The rapid assessment highlighted the strengths of civil society in collaborating with government partners to face a novel public health crisis.

Through long-established relationships and coalitions, activists worked to secure the necessary permits to visit extremely vulnerable women, to provide emergency health services and food aid, and to prevent people from getting ill or, indeed, starving. In many contexts, the community-based response to the Covid-19 pandemic has been led by organisations that have coalesced around HIV treatment access, women's rights, and 'grassroots', civil society monitoring of state policies and expenditure. The work of Dristi Nepal – and the aspirations of the women it supports – convey the strengths of civil society in providing vital support to their communities of care and, moreover, in helping citizens to articulate their needs, priorities or indeed demands for improved service delivery, particularly in the realms of health and social support.

Conclusion

This project has demonstrated the vast potential for grassroots advocacy organisations to gather and analyse detailed, context-specific data about the impacts of the Covid-19 pandemic on their communities of care.

Using visual, participatory tools, these organisations can gather and disseminate data highlighting citizen's priorities for urgent improvements in health and human rights, while monitoring the performance of their governments. In this case, the design and implementation of the tool was used by community-based activists to provide direct support to women living with HIV and using drugs – including ART literacy and awareness about Covid-19 prevention, psychosocial support, and food aid. Through rolling out the tool and collating its findings, Dristi Nepal forged stronger links with civil society organisations, bilaterals and government partners. From July 2020, when Nepal's lockdown was lifted, Dristi Nepal members played a leading role in new advocacy engagements – in which members of civil society took stock of the impacts of the Covid-19 epidemic, assessed the government's performance, and formulated their future demands.

ITPC Rapid assessment References

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