Community action for people with HIV and sex workers during the COVID-19 pandemic in India

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Abstract
Sex workers have been one of the marginalized groups that have been particularly affected by India’s stringent lockdown in response to the coronavirus disease 2019 (COVID-19) pandemic. The sudden loss of livelihood and lack of access to health care and social protection intensified the vulnerabilities of sex workers, especially those living with HIV. In response, Ashodaya Samithi, an organization of more than 6000 sex workers, launched an innovative programme of assistance in four districts in Karnataka. Since access to antiretroviral therapy (ART) was immediately disrupted, Ashodaya adapted its HIV outreach programme to form an alternative, community-led system of distributing ART at discreet, private sites. WhatsApp messaging was used to distribute information on accessing government social benefits made available in response to the COVID-19 pandemic. Other assistance included advisory messages posted in WhatsApp groups to raise awareness, dispel myths and mitigate violence, and regular, discreet phone check-ins to follow up on the well-being of members. The lessons learnt from these activities represent an important opportunity to consider more sustainable approaches to the health of marginalized populations that can enable community organizations to be better prepared to respond to other public health crises as they emerge.

Keywords: antiretroviral therapy, community, emergency response, India, sex workers

Background
On 25 March 2020, India went into lockdown in the first phase of government-imposed public health measures to curb coronavirus disease 2019 (COVID-19). The health system in the country suffered a major resource crisis arising from the tremendous burden of the urgent care needs of those presenting with the disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). While the country mourned the lives lost to COVID-19, the everyday lives of citizens changed profoundly under public health measures intended to mitigate the impact of the pandemic. The pandemic and the lockdown in particular have had myriad social and economic effects.

For society’s most vulnerable, in terms of socioeconomic status, the unintended consequences of these restrictions have been devastating. A recent article by Lucy Platt and colleagues underscored the importance of reaching sex workers, a severely marginalized population vulnerable to the HIV epidemic, the effects of which have beenaccentuated during the COVID-19 pandemic.1 In this perspective paper, we describe the response of a sex worker organization based in Mysore, Ashodaya Samithi, which is known for its community-driven health interventions.2,3 Ashodaya has restructured its HIV health service delivery approaches while addressing the basic needs of sex workers amid the disruptions wrought by COVID-19. In particular, we highlight the innovative strategies that Ashodaya has cultivated.

Ashodaya is a well-established organization of more than 6000 female, male and transgender sex workers across four districts of Karnataka.4 Ashodaya’s leadership works with key stakeholders, including the police, the media, health-care providers, government authorities, political leadership and several others, to address violations of the human rights of sex workers and to advocate strongly for the decriminalization of sex work. With respect to health care, Ashodaya advocates for access to health services, including primary health care, HIV services, and sexual and reproductive health services.

India’s particularly tight lockdown, intended to slow the spread of COVID-19, has posed a major challenge to the daily functioning of Ashodaya and has had severe consequences for the lives of its members, who derive much of their income from sex work. Loss of livelihood and lack of access to health care and social protection have intensified their vulnerabilities, dramatically impacting their lives to the extent that many are unable to sustain themselves and their families.5,6 Based on their experiences of implementing community-led HIV programmes, Ashodaya community leaders have redesigned their approaches in response to the following crucial...
questions: (i) What are the community’s imminent needs and how can we meet them? (ii) What social protections does the government provide and how can we enable timely access to these benefits? (iii) How can we dispel circulating myths, address discrimination and violence, and raise awareness in the community around health protection?

Responding to the imminent needs of sex workers

For people living with HIV, the lockdown of Mysore city immediately disrupted antiretroviral therapy (ART) access, as the majority of ART dispensation takes place through the government-run district hospital, although there are two private hospitals that are part of the government ART programme. Between 200 and 250 people per day collect their medication from the district hospital. With the onset of COVID-19, and the lockdown, the district hospital initially became the only designated testing and treatment centre for SARS-CoV-2 in the city, which effectively halted regular ART distribution.

Ashodaya had previously established strong linkages with the district hospital, having built a system of "community health-care navigators" (CHCNs) within the ART centre. CHCNs are part of the Ashodaya community and offer support to patients visiting the ART centre, the counselling and testing centre, and other departments in the district hospital. They assist patients in navigating the complex health-care system and provide ongoing peer support. They also provide support to the staff at the centre by assisting with various administrative tasks. Thanks to this existing relationship, Ashodaya was able to garner support from the ART centre and soon set up an alternative, community-driven ART distribution system. Amid the COVID-19 restrictions, community leaders adapted a community network-based strategy successfully utilized in their HIV outreach programme to form a community-led ART distribution system for sex workers. Although Ashodaya’s response was initiated in Mysore, it was quickly adopted by Ashodaya teams in the other districts where they work.

Establishing this alternative system involved gaining the necessary district-level authorization and securing the necessary resources (including ART stockpiles), collating the available information on members living with HIV and receiving ART, geomapping discreet distribution sites and ensuring privacy at those locations. CHCNs helped in the distribution of ART, as they were already known to those individuals accessing the ART centre. As Ashodaya initiated its new delivery programme among sex workers living with HIV, it began to grow in popularity among other groups of people living with HIV, who started to request Ashodaya’s discreet ART delivery service.

Ashodaya’s approach was aligned with the recommendations of the National AIDS Control Organization (NACO) issued on 23 March 2020. NACO, the central governmental agency for India’s HIV programme, produced advice recommending the dispensation of 3-month supplies of ART to all stable patients and supported community-based ART distribution, in principle. On 14 April 2020, the Ministry of Health and Family Welfare, Government of India, produced guidance identifying essential services to be prioritized. This noted that states should ensure an uninterrupted supply of ART to people living with HIV, through decentralized drug dispensation. It stated that 3-month supplies of ART could be dispensed through ART centres. In updated guidance issued on 1 June 2020, the World Health Organization (WHO) recommended dispensing supplies for up to 6 months, to limit the potential for disruption to supplies of ART and other essential medicines, and promoting community dispensing points. The guidance also noted that, as soon as movement restrictions are relaxed, catch-up campaigns should be considered to improve the coverage of testing, prevention and treatment interventions.

Ensuring access to social protection and confronting discrimination

Owing to the COVID-19 pandemic, government at both national and state levels has begun to roll out a number of social benefits and protections that include food, shelter homes, and financial benefits for individuals and families. Ashodaya leaders created several WhatsApp groups through which they disseminated information on various social benefits and how and where they could be accessed. Community leaders ensured that the information reached many hard-to-reach members through their networks and by word of mouth. This was followed by regular check-in calls to further support access. Local philanthropists were mobilized to provide groceries, sanitizer and masks to the members who remained unreached by the government.

The emergence of the COVID-19 pandemic generated numerous myths and propagated harmful misinformation, giving rise to new forms of stigma and discrimination. Furthermore, there were growing reports of domestic violence faced by sex workers in Mysore. Ashodaya aimed to raise awareness, dispel myths and mitigate violence by posting advisory messages in WhatsApp groups and through regular (and discreet) phone check-ins to follow up on the well-being of members. Counselling services provided as part of HIV services have now been redesigned to meet the growing demand for COVID-19-related psychosocial support.

The way forward

In the period between the beginning of the COVID-19 pandemic and May 2020, Ashodaya was able to provide ART to 1065 people, provide nutritional supplements to 270 people and ensure access to social protection for approximately 3800 sex workers, and it was in regular contact with over 5500 sex workers through calls and individual meetings. Unfortunately, the COVID-19 pandemic continued to progress, as did the challenges faced by the community. Ashodaya continued to find ways to assist its members in the face of tremendous financial losses. In addition, Ashodaya initiated tele-support services to members through its network of allied health-care providers, many of whom had partnered with the organization over the years. Importantly, this tele-support included counselling services intended for those experiencing emerging psychological issues, violence or stigma and discrimination. Ashodaya was also exploring ways of delivering nutritional support alongside ART, organizing ambulance services to
respond to emergencies and providing medical support as required by its members.

Ashodaya also planned to reactivate its crisis response system, which used to respond to adverse situations (e.g. violence, incidents of stigma and discrimination, etc.) faced by the community members and created by various perpetrators such as the police, local goons, neighbours, shopkeepers, clients, etc. This system had been disband because of a lack of funding from the State AIDS Control Programme.

Ashodaya has drawn on its vast experience in community mobilization and outreach to swiftly respond to emerging issues and challenges resulting from the COVID-19 pandemic, helping to ensure continued access to treatment, social entitlements, psychosocial counselling, and accurate and up-to-date information. Ashodaya’s community-led response, while initiated to address imminent and emerging community needs, has been in line with WHO guidance on action related to COVID-19, contextualized for its community and setting. Over the past decade, Ashodaya has been actively working to create an enabling environment for its community. It has established strong relationships with various district departments, including the Department of Women and Child Development; the district legal services authority; the police; local politicians (e.g. members of the legislative assembly); and journalists working in print and electronic media. Ashodaya’s strategic advocacy with different constituencies has significantly contributed to its success in HIV prevention.

These emergency responses provide us with important lessons on how to restructure HIV programmes for key populations during the time of a pandemic. Moreover, these lessons present an important opportunity to consider more sustainable approaches to the health of marginalized populations that can enable community organizations to be better prepared to respond to future pandemics and other public health crises as they emerge.

**Acknowledgments:** The authors would like to thank the members of the community of Ashodaya for their leadership and participation. We would also like to thank the district health department and other relevant departments, the ART centre team, Gilead Sciences Asia-Pacific Region, the Red Umbrella Fund, local political leaders, philanthropists and the advisors of Ashodaya.

**Source of support:** None.

**Conflict of interest:** None declared.

**Authorship:** All authors contributed equally.


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