

LEFT BEHIND UNDER LOCKDOWN

The impact of COVID-19 restrictions on children with HIV and their caregivers in Uganda

INTRODUCTION

It has been one year since the Government of Uganda implemented its national policy responses to COVID-19. These sweeping measures included a suspension of public transport, border closure, further suspension of all private transport, night-time curfew, and the closure of many businesses all put into place during March 2020. Police and security forces enforced these restrictions with violence and arbitrary detention and also used COVID-19 as a pretence to target criminalized populations such as sex workers and lesbian, gay, bisexual and transgender (LGBT) Ugandans. For months, families were unable to move freely, unable to earn an income, and faced major barriers when they sought essential services such as medical care. The Uganda government provided virtually no support to buffer the harm from these policy decisions, despite receiving substantial amounts of emergency COVID-19 relief funding from the World Bank, International Monetary Fund, bilateral donors, as well as contributions from private businesses. The government's decision to carry out a complete restriction on public and private movement as well as a shutdown of the economy resulted in massive suffering. Moreover, these policy measures were launched without meaningful community consultation or preparation.

Unsurprisingly, there was no consideration given to the needs of children living with HIV - as well as others with urgent health needs - to be able to continue their treatment, stay healthy, and get access to food and other essentials while their families struggled with severe economic decline brought about by response to the COVID-19 pandemic. HIV-exposed children and children who did not know their HIV status also faced barriers to HIV testing. Communities raised concerns about the potential for harm, but these were ignored. Immediately after the lockdown started, Health GAP and other HIV and health advocacy organizations began to learn about the devastating consequences of the restrictions for HIV-positive Ugandans. The government's COVID-19 response quickly triggered life-threatening disruptions to HIV treatment, prevention and care for adults and children, undermining years of progress in the fight against HIV in just a matter of months.

Polymakers could have predicted and foreseen the negative impact of the COVID-19 response on people living with HIV, particularly children and other vulnerable groups who already experience a range of barriers to quality HIV treatment and care. The needs of HIV positive children were not prioritized in Uganda's COVID-19 response; just as they have traditionally been an afterthought in the overall HIV response. There were some bright spots; pressure during lockdown resulted in new support for multi-month refills of HIV treatment for children and adolescents, for example.

Pediatric HIV epidemic and response in Uganda

Number of children aged 0-19 living with HIV (2019) = 158,000
Number of new HIV infections among children aged 0-19 (2019) = 13,900
Number of AIDS-related deaths among children aged 0-19 (2019) = 6,000

% of children living with HIV receiving ART (2019) = 64.7
% of infants exposed to HIV who were tested within two months of birth (2019) = 56.3
Number of children receiving ART (2019) = 66,200

Source: [Global AIDS Monitoring and UNAIDS 2020 estimates](#)

To ensure that these grave mistakes are not repeated in the future, and to try to remedy the harms already done, Health GAP, the Coalition for Health Promotion and Social Development (HEPS-Uganda), the National Forum of People Living with HIV/AIDS Networks Uganda (NAFOPHANU) and allies interviewed the caregivers of children with HIV from across Uganda to document immediate and longer-term effects of the COVID-19 response on children and their families. The community-generated evidence confirms that poorly managed COVID-19 restrictions have destabilized Uganda's pediatric HIV response, resulting in preventable suffering for children and their families.

METHODOLOGY

In September and October 2020, Health GAP, HEPS Uganda, NAFOPHANU, and the Tororo District Network of People Living with HIV conducted unstructured qualitative interviews with 88 individuals who are either caregivers of children with HIV and/or people living with HIV themselves. Individuals were asked to share if and how the lockdown had affected their child's/their access to HIV treatment, as well as their lives in general. Potential interviewees were identified through their contact with health facilities and district-level networks of people living with HIV. All interviewees were informed about the purpose and intended use of the research before being asked to confirm their consent to be interviewed. Interviewees came from 12 districts of Central, Eastern and Western Uganda.

Activists who carried out this assessment were:

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Interviewees from Central region (n = number of people)	Interviewees from Eastern region (n = number of people)	Interviewees from Western region (n = number of people)
Buikwe = 3	Busia = 6	Kabale = 15
Kalangala = 5	Iganga = 7	Mbarara = 19
Kayunga = 4	Mbale = 9	Ntungamo = 12
Masaka = 3	Tororo = 5	
Sembabule = 1		
TOTAL = 16	TOTAL = 26	TOTAL = 46

KEY FINDINGS

The COVID-19 response has triggered a cascade of negative effects for children with HIV and their caregivers, starting with abrupt loss of household income. This, in turn, reduced children's access to HIV and other health services, and significantly undermined the ability of children to adhere to their drug regimens, limiting the effectiveness of their treatment. The main challenges experienced by children with HIV and their caregivers were:

Increased poverty and food insecurity

Loss of income during the lockdown caused increased economic hardship for almost half (n = 37) of people interviewed. Many caregivers who earn money through informal and casual work lost their livelihoods literally overnight, because the lockdown was deliberately announced without warning, so people. More than half of families (n = 49) - already poor or close to the poverty line before COVID-19 - quickly ran out of food and other basic commodities such as soap and charcoal. Many children with HIV across Uganda suffered from hunger and a lack of nutritious food. Increased food and commodity prices meant many children and adults with HIV needed external support during lockdown. But very little support came. Less than one in three of the people interviewed (n = 24) said they had received any kind of food support (such as posho, rice or beans) from the government or from non-governmental organizations. Where support was provided, it was inconsistent and irregular, and barely sufficient to sustain the basic needs of the whole family. Families, communities, and other informal support systems were the only lifeline for many children with HIV.

"When the COVID-19 lockdown started, the transport fare to the clinic jumped fivefold from UGX 1,000 to UGX 5,000. Just before the lockdown, my daily wages were only UGX 3,000. And when even this little income came to an abrupt stop due to the lockdown, it was virtually impossible for me to afford to afford the hiked fare. I reported my challenge in getting food, but for this the NGO was not helpful. The help I got from my mother was inadequate and at times me and my children could only take porridge. Lack of food was a major problem, especially for the child on second line treatment who takes her medicines twice a day."

Mother of two children with HIV, Mbale District

"I had no income since my only source of income was hairdressing, and saloons were closed during lockdown. I lacked food for myself and my child. My child lost weight and struggled to swallow her medicines without food. Even after lockdown my business is so low. I didn't receive any relief or support."

Mother of a 10 year old child with HIV, Mbarara District

Restricted access to facilities

"I walked for a long distance to get my ARV refills. On the first day I travelled to the health facility I was not allowed in because they cut down on the number of clients to be attended to in a day. I went back the following day, but I was again sent back because I didn't have a facemask. I didn't get my ARVs. When I went again the third time with my mask on, I was allowed in and given my medicines, but for myself alone and not for my child."

Mother of an 8 year old child with HIV, Mbale District

Although health facilities remained open during the lockdown, 60 percent of people interviewed faced major challenges accessing facilities for routine testing and drug refills. Lockdown measures and bans on public and private means of transport left people with HIV with limited options for getting their children's and their treatment. Some requested permission from local officials to travel to clinics. This often took time and resulted in treatment interruptions. Others used boda-bodas (motorcycle taxis) even though they were banned, often taking longer routes to avoid authorities. This came at huge expense: fares were often 5-6 times higher than usual during lockdown. People living far from clinics reported walking distances of up to 30km, often with their children, and sometimes more than once a month if adult and child clinics were held on different days. Poor communication from facilities about whether children were required to be present in order for pediatric treatment refills to be issued resulted in many wasted journeys to facilities.

KEY FINDINGS

Disruptions to pediatric treatment

One quarter of respondents (n = 22) reported treatment interruptions during the lockdown. Without sufficient food, many children simply refused their HIV treatment. Others who took their medication on an empty stomach suffered side effects such as dizziness, stomach pain and vomiting. Several caregivers of children with HIV reported weight loss and interruptions to pediatric treatment due to lack of food. As a result, many children's conditions deteriorated; some caregivers received confirmation that their child's viral load had increased.

"My son kept crying for food and when I gave him ARVs without enough food. He got dizzy and cried. The situation has left me so depressed. Whenever we didn't have food, we skipped our medicines."

Mother of a 3 year old child with HIV, Iganga District

Because of extreme economic pressures on households, several children had to stay with relatives or neighbours for periods over the lockdown. Primary caregivers reported that this caused disruptions to the child's treatment because alternative carers did not understand the importance of ensuring the child takes their medicine on time, or because they were not informed about the child's HIV status.

"My work closed during lockdown and this left me with no income at all to support the child. I opted to take him to different friends' and relatives' homes for his support but they would ask me to take him away after a few days. I eventually decided to take him to the grandfather's home where he spent most of the lockdown period but there was no one there to support him take his ARVs. I didn't disclose his status. Because his relatives don't know about his status, as a result he often missed taking his ARVs and his health deteriorated. His grandfather called me to take him to hospital, and I decided to stay and struggle with him."

Caregiver of a 10 year old child with HIV, Ntungamo District

Reduced services for people living with HIV

Treatments for opportunistic infections and co-infections such as TB and malaria were disrupted for almost one in ten respondents (n = 8) during the lockdown, but few respondents raised shortages of HIV drugs during interviews. Stock-outs of first- and second-line pediatric treatments reported by people in Ntungamo and Mbarara districts had existed before COVID-19. When patients could be traced, some facilities supported treatment adherence by delivering HIV drugs to their homes, but this was not the case for children with HIV who were generally required to continue their monthly visits to the clinic.

Whilst HIV drugs continued to be available, the people we interviewed reported that other HIV services were disrupted, and quality of care was reduced. Waiting times in many facilities were longer than usual, and appointment times with health workers reduced. For one quarter of respondents (n = 21), viral load and CD4 testing was delayed or postponed until after lockdown. Where tests were carried out, results took longer than usual to come back. Many important psycho-social support services came to a halt during lockdown, as did specialized HIV services for mothers, babies, and adolescents.

"I experienced stock outs of one of my son's combination drugs; there was a stock out of abacavir for 4 months, only lopinavir was available. I had to travel a 27 kilometers round trip to the health center and I would only be given monthly emergency refills. I used to get permission letters from the Local Council to use a boda. Though there was a time I had no money for transport, my son had to swallow his tablet. I had no income during lockdown, I couldn't afford to feed my child well, his viral load even went up during lockdown. I didn't get any support from the government, but I am glad his viral load is now stable again."

Father of an 8 year old child with HIV, Mbarara District

KEY FINDINGS

Variations in support received across regions

Across all regions of Uganda included in this assessment, households experienced loss of income, food insecurity and restricted movement as a result of the COVID-19 response. Levels of support provided to children with HIV and other vulnerable groups varied by district and where children or their caregivers received their HIV treatment. A larger proportion of people interviewed from the Central region had received some form of food support from NGOs including The AIDS Support Organisation (TASO), NAFOPHANU, and Uganda Cares. In the Eastern region, five people said they had received food support and delivery of HIV drugs from TASO. In the Western region, several people received food support from the government or NAFOPHANU. A Member of Parliament for Ntungamo District also provided some support to vulnerable communities.

Further weakening the pediatric HIV response

The COVID-19 pandemic has exposed and exacerbated the fragility of the pediatric HIV response in Uganda, and weaknesses in health and community systems. It has shown that uninterrupted drug supply is insufficient to meet the needs of children with HIV. The lack of emergency social protection and psychosocial support services for children and their caregivers during lockdown, coupled with restrictions on movement, prevented children from maintaining a regular treatment regimen, even where drugs were available in clinics.

Before the COVID-19 outbreak, many of the people interviewed had already been experiencing barriers preventing adherence to pediatric treatment and viral load suppression for themselves and their children. These barriers included chronic poverty, lack of access to food, inability to travel long distances to health facilities, lack of treatment literacy, and stigma and discrimination. The pandemic greatly exacerbated these pre-existing vulnerabilities and resulted in children with HIV being left behind during lockdown without food, healthcare and other basic necessities.

COVID-19 has also highlighted, once again, the resilience of people living with HIV. With the support of their families, communities, and health workers, caregivers have gone to extraordinary lengths to try to respond to the needs of children with HIV as they struggle for life-saving treatment, even in the most challenging of circumstances.

RECOMMENDATIONS

Whether it is a further wave of COVID-19 or a yet-unknown future pandemic, we must learn lessons from 2020 and ensure that children with HIV are not left behind again in the response to emerging health challenges.

The Government of Uganda as well as donor programs, funded by the President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to fight AIDS, Tuberculosis and Malaria (Global Fund) and other international HIV donors must take urgent action now to mitigate the negative effects of the COVID-19 response on children with HIV. We urge them to:

- In consultation with directly affected communities, design, fund and implement an emergency pediatric COVID-19 “catch up plan” to help families recover as quickly as possible,
- Mobilise community health workers and NGOs in a coordinated effort to identify and assess all children with HIV, and refer those whose health deteriorated over lockdown for further testing and support.
- Provide children with HIV and their families with direct financial support (such as cash transfers) and other evidence-based social protection measures that enable them to buy sufficient nutritious food and other essential household goods.

To avoid further devastation for children with HIV, the Government of Uganda, with support from international partners, must plan ahead for a more equitable and rights-based emergency response to future waves of COVID-19 or other pandemics.

Future emergency responses should be designed with communities living with and affected by HIV, including children, and support:

- Financial support for people with HIV and carers of children with HIV to cover loss of income, increased transport costs, increased costs of essential goods, and more.
- Regular distribution of sufficient nutritious food support and other basic supplies to the poorest and most vulnerable.
- Maintain access to psycho-social support services and viral load testing, as well as treatment.
- Exemptions for people with HIV to visit health facilities during future travel restrictions.
- Proactive follow up of children with HIV and provision of community-based drug refills and other services, where possible.
- Adequate personal protective equipment (PPE) for front-line healthcare workers to keep them safe and enable them to continue providing services.
- Strengthening the capacity of communities to monitor and report disruptions to HIV services.

The impact of COVID-19 restrictions on children with HIV in Uganda has been devastating but entirely preventable. Prioritizing the needs and rights of children with HIV in future responses to health emergencies, alongside increased investment in resilient pediatric HIV services, will help to ensure that children with HIV are not left behind anymore.

APPENDIX: CAREGIVERS' RESPONSES

Interview respondent and their children	District (Region)	Impact of COVID-19 lockdown								
		HIV treatment interruption	Other treatment interruption e.g. OIs	Food insecurity & lack of other basic commodities e.g. soap	Restricted / increased cost of transport to facility	Loss of income	Children separated from caregivers during lockdown	Reduced quality / availability of HIV services	Delays to viral load tests / results	Food support received from NGO or government
1 Mother, 38, and child, 7 (both HIV positive).	Bulkwe (Central)	Y	Y	Y	Y		Y	Y		Y
2 Mother, 36, and child, 13 (both HIV positive).	Bulkwe (Central)		Y		Y	Y	Y	Y		
3 Mother, 53, and child, 9 (both HIV positive).	Bulkwe (Central)	Y		Y		Y		Y		
4 Grandmother, 54, and child, 10 (HIV positive).	Kalangala (Central)		Y	Y				Y	Y	Y
5 Caregiver, 38, and child, 3 (both HIV positive).	Kalangala (Central)			Y	Y				Y	Y
6 Caregiver, 20 and child, 7 (HIV positive).	Kalangala (Central)			Y			Y	Y		
7 Mother, 40 and child, 10 (both HIV positive).	Kalangala (Central)	Y		Y	Y					Y
8 Mother, 32 and child, 7 (HIV positive).	Kalangala (Central)	Y	Y		Y					Y
9 Grandmother, 49 and child, 7 (HIV positive).	Kayunga (Central)			Y	Y				Y	Y
10 Caregiver, 34 and children, 7 and 9 (both children HIV positive).	Kayunga (Central)		Y	Y	Y			Y	Y	
11 Caregiver, 58 and child, 6 months (HIV positive).	Kayunga (Central)			Y		Y			Y	Y
12 Grandmother, 66 and child, 9 (HIV positive).	Kayunga (Central)			Y	Y			Y		
13 Mother, 32 and child, 5 (both HIV positive).	Masaka (Central)			Y	Y			Y	Y	
14 Father, 40, and 3 children, 4,5 and 10 (all HIV positive).	Masaka (Central)			Y	Y					Y
15 Mother, 35 and child, 9 (both HIV positive).	Masaka (Central)			Y	Y	Y				Y
16 Mother, 35 and child, 10 (both HIV positive).	Sembabule (Central)			Y	Y			Y		Y
17 Mother and child, 12 (both HIV positive).	Busia (East)	Y		Y		Y	Y			
18 Caregiver, 65, and child, 9 (HIV positive).	Busia (East)			Y	Y	Y				
19 Caregiver, 34 and child, 15 (HIV positive).	Busia (East)				Y					
20 Grandmother, 61 and child, 7 (HIV positive).	Busia (East)			Y		Y				
21 Mother, 42 and child, 8 (both HIV positive).	Busia (East)			Y		Y		Y		Y
22 Mother, 35 and child, 4 (both HIV positive).	Busia (East)	Y		Y	Y	Y	Y			
23 Mother, 39 (HIV positive) (39), Child, 3 (HIV negative).	Iganga (East)					Y				
24 Female, 29 (HIV positive).	Iganga (East)			Y		Y				
25 Child, 14 (HIV positive).	Iganga (East)	Y		Y			Y			
26 Mother, 51 and child, 16 (both HIV positive).	Iganga (East)				Y			Y		
27 Mother, 34 and child, 3 (both HIV positive).	Iganga (East)			Y		Y				
28 Caregiver, 34 and female, 23 (HIV positive).	Iganga (East)	Y								
29 Mother, 30 and child, 8 (both HIV positive).	Mbale (East)				Y	Y	Y			

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30 Mother, 24 (HIV positive) and child, 3..	Mbale (East)				Y	Y				
31 Mother, 29 (HIV positive) and 3 children.	Mbale (East)	Y								
32 Mother, 47 and child, 8 (both HIV positive).	Mbale (East)				Y			Y		
33 Mother, 22 and child, 4 (both HIV positive).	Mbale (East)			Y	Y	Y				
34 Mother, 24 and child, 4 (both HIV positive).	Mbale (East)									
35 Mother, 32 and child, 3 (both HIV positive).	Mbale (East)				Y	Y		Y		
36 Mother, 24 (HIV positive) and child, 3.	Mbale (East)		Y		Y	Y				
37 Mother, 30 and child, 8 (both HIV positive).	Mbale (East)			Y	Y	Y	Y		Y	
38 Mother, 26 and child, 3 (both HIV positive).	Tororo (East)				Y	Y				
39 Mother, 25 and child, 1 (both HIV positive).	Tororo (East)				Y					
40 Mother, 22 (HIV positive) and child, 1 (HIV status unknown)	Tororo (East)				Y			Y		
41 Mother, 23 (HIV positive) and baby (HIV status unknown).	Tororo (East)	Y		Y	Y					Y
42 Grandmother, 61 and child, 7 (both HIV positive)	Tororo (East)			Y	Y	Y		Y		Y
43 Mother and child, 9 (both HIV positive).	Kabale (West)			Y		Y			Y	
44 Aunt and child, 10 (HIV positive).	Kabale (West)			Y	Y				Y	
45 Aunt and child, 11 (HIV positive).	Kabale (West)									Y
46 Mother and child, 12 (both HIV positive).	Kabale (West)			Y		Y				
47 Grandmother and child, 5 (HIV positive).	Kabale (West)			Y	Y	Y			Y	
48 Akandinda Catherine. Caregiver and child, 11 (HIV positive).	Kabale (West)								Y	
49 Mother and child, 8 (HIV positive).	Kabale (West)									
50 Mother and child, 11 (both HIV positive).	Kabale (West)				Y					
51 Mother and child, 2 (both HIV positive).	Kabale (West)								Y	Y
52 Aunt and child, 10 (HIV positive).	Kabale (West)			Y	Y					Y
53 Caregiver and child, 10 (HIV positive).	Kabale (West)			Y	Y	Y				
54 Mother and child, 11 (both HIV positive).	Kabale (West)					Y				
55 Mother and child, 8 (both HIV positive).	Kabale (West)			Y		Y		Y		
56 Mother and child, 11 (both HIV positive).	Kabale (West)			Y		Y				Y
57 Caregiver and child, 7 (HIV positive).	Kabale (West)			Y	Y	Y				
58 Grandfather and child, 7 (HIV positive).	Mbarara (West)		Y						Y	Y
59 Mother and child, 12 (both HIV positive).	Mbarara (West)	Y	Y	Y					Y	
60 Aunt and children, 5 and 8 (both HIV positive).	Mbarara (West)			Y	Y				Y	Y
61 Mother and child, 2 (both HIV positive).	Mbarara (West)	Y		Y						
62 Mother and children, 6 and 11 (both HIV positive).	Mbarara (West)	Y			Y					
63 Mother and child, 10 (HIV positive).	Mbarara (West)	Y			Y					

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64 Grandmother and child, 14 (HIV positive).	Mbarara (West)				Y				Y	
65 Mother, 31 and child, 6 (both HIV positive).	Mbarara (West)	Y		Y	Y	Y				
66 Father, 40 and child, 10 (HIV positive).	Mbarara (West)			Y	Y	Y				
67 Mother, 35 and child, 8 (both HIV positive).	Mbarara (West)			Y	Y					
68 Mother, 29 and child, 8 (both HIV positive).	Mbarara (West)									
69 Mother, 34 and child, 10 (both HIV positive).	Mbarara (West)			Y	Y	Y		Y		
70 Father and child, 12 (HIV positive).	Mbarara (West)			Y	Y	Y				
71 Father, 43 and child, 8 (HIV positive).	Mbarara (West)	Y		Y	Y	Y				
72 Mother, 25 and child, 3 (both HIV positive).	Mbarara (West)	Y				Y				
73 Mother, 42 and child, 3 (both HIV positive).	Mbarara (West)			Y	Y	Y				
74 Uncle, 35 and child, 9 (HIV positive).	Mbarara (West)			Y	Y		Y			
75 Mother (HIV positive) and baby (HIV status unknown).	Mbarara (West)							Y		
76 Grandmother and child, 8 (HIV positive).	Mbarara (West)									
77 Mother and child, 9 (both HIV positive).	Ntungamo (West)	Y		Y	Y					Y
78 Grandmother and child, 15 (HIV positive).	Ntungamo (West)									Y
79 Caregiver and child, 13 (HIV positive).	Ntungamo (West)	Y		Y	Y			Y		
80 Grandfather and child, 14 (HIV positive).	Ntungamo (West)				Y					
81 Caregiver and child, 14 (HIV positive).	Ntungamo (West)				Y					
82 Caregiver and child, 10 (HIV positive).	Ntungamo (West)	Y				Y	Y			
83 Caregiver and child, 13 (HIV positive).	Ntungamo (West)				Y					
84 Grandfather and child, 14 (HIV positive).	Ntungamo (West)				Y					
85 Mother and child, 10 (HIV positive).	Ntungamo (West)	Y		Y		Y				Y
86 Caregiver and 2 children, 10 and 12 (both HIV positive).	Ntungamo (West)	Y						Y		Y
87 Grandmother and child, 12 (HIV positive).	Ntungamo (West)				Y			Y		Y
88 Child, 17 (HIV positive)	Ntungamo (West)							Y		
		22/88 = 25%	8/88 = 9%	49/88 = 56%	53/88 = 60%	37/88 = 42%	10/88 = 11%	17/88 = 19%	21/88 = 24%	24/88 = 27%