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COUNTRY CASE STUDY - HIV IN EMERGENCY CONTEXTS: MAKING PATIENTS HEALTHY: CARING FOR PEOPLE LIVING WITH HIV DURING THE EBOLA OUTBREAK IN SIERRA LEONE

INTRODUCTION

The outbreak of Ebola Virus Disease (EVD) that hit Sierra Leone in May 2014 ravaged communities, severely disrupting general health services and reducing access to those services. The epidemic rapidly spread to all districts in the country, with varying levels of intensity.

In Sierra Leone, as of December 2015, there were 8,704 confirmed cases of EVD, with an additional 5,418 probable and suspected cases. There were 3,589 confirmed deaths due to Ebola, and an additional 400 probable and suspected deaths.¹

¹ WHO Ebola Situation Report, December 16, 2015 <http://apps.who.int/ebola/current-situation/ebola-situation-report-16-december-2015>

HIV Epidemic Overview

Sierra Leone's HIV epidemic has been categorized as mixed, generalized and heterogeneous— meaning that HIV affects different population sub-groups and all sectors of the population through multiple and diverse transmission dynamics.

The health system in Sierra Leone was shaken by the EVD outbreak causing major interruptions in health services. Large numbers of health workers were infected and/or died from EVD, adding further strain to the fragile health system. Compounding this, communities were reluctant to seek care in health facilities because they feared it increased their chances of getting infected with Ebola. People living with HIV were particularly vulnerable to the impact of these challenges because if exposed to a virus or infection, patients with compromised immune systems experience a more difficult recovery. Furthermore, disruptions in HIV care can accelerate disease progression in individuals, increasing the risk of transmission to sexual partners and during pregnancy, birth and breastfeeding. This has enduring public health consequences.

In fact, a rapid assessment of health facilities conducted by the Ministry of Health and Sanitation with support from UNICEF found a significant decline in the uptake of maternal and child health services in October 2014. The results showed there was a 23% decline in the number of PMTCT visits, a 50% decline in HIV testing and a 21% increase in patients lost to follow-up most likely as a consequence of the Ebola outbreak.

Taken together, this meant that community structures and resources would be vital to the Ebola response and to safeguarding the health and well-being of people living with HIV. Historically, the HIV programme relied on peer educators to provide counselling and follow-up of patients. This proved to be invaluable during the height of the Ebola outbreak.

² UNAIDS, UNICEF, WHO 2015 Global AIDS Response Progress Reporting and UNAIDS 2014 HIV and AIDS estimates, July 2015.

³ DHS 2013

⁴ DHS 2013

NATIONAL HIV DATA

In 2014, the adult prevalence was **1.4%**² and ranged from **1.3%** among men and **1.7%**³ among women, indicating that women are disproportionately infected. Adult prevalence is significantly higher in urban **2.3%** (2.5% for women) than rural (1%) areas.⁴ The EVD outbreak was concentrated in urban areas where the number of people living with HIV is higher. An estimated **54,000** Sierra Leoneans are living with HIV, including **29,000** women, **4,300** children and 2,300 adolescents.⁵ At the end of 2014, the approximately 21 percent of adults living with HIV were receiving ART, while the ART coverage for children was approximately 9 per cent.⁶ More than ninety five per cent of pregnant women living with HIV received the most effective ARVs for PMTCT, and **76%** of pregnant women living with HIV received ART.⁷

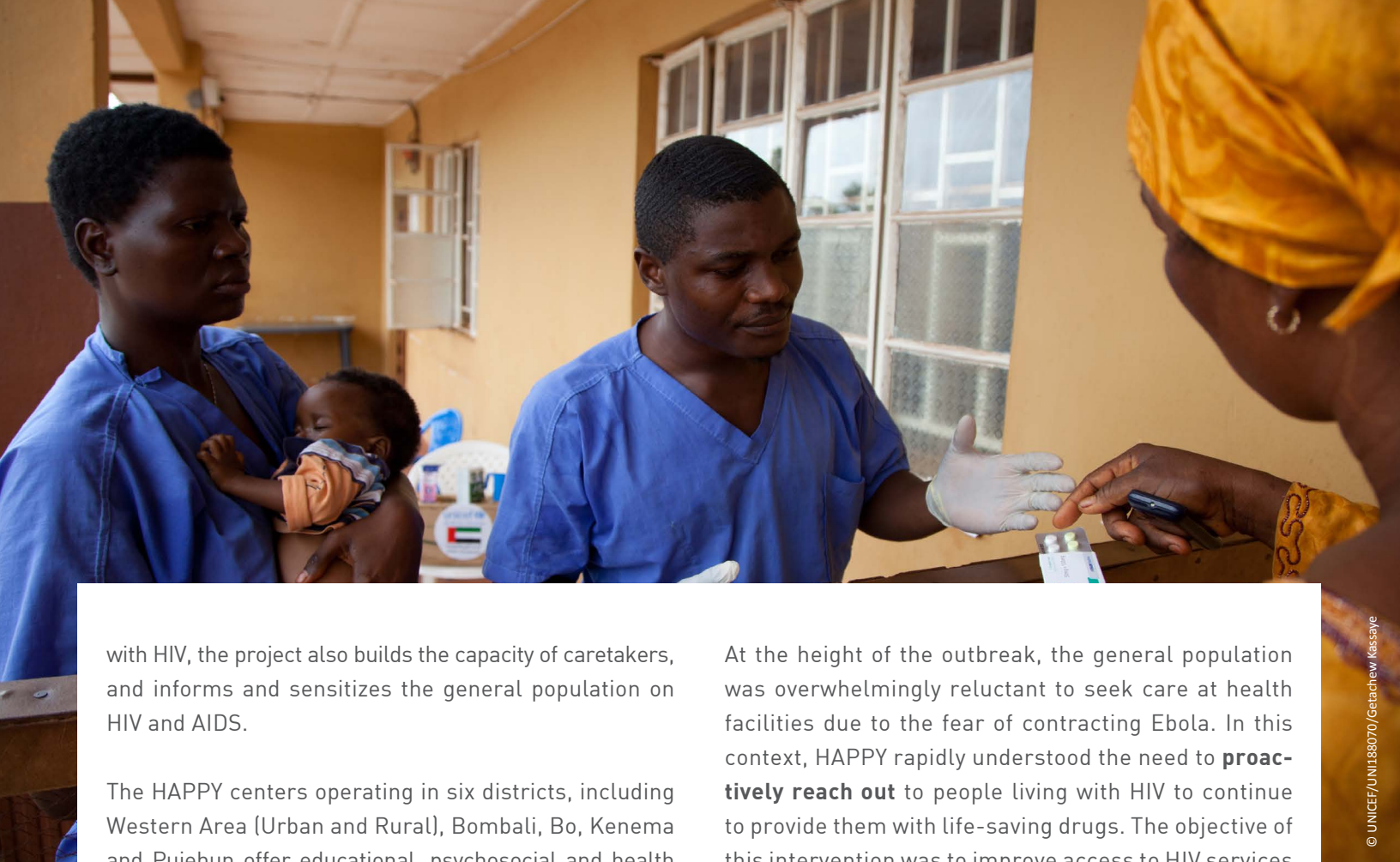
The HAPPY Patient Tracing Project

HAPPY (HIV/AIDS Prevention Project for Youth) is a national non-governmental organization supported by UNICEF. It aims to mitigate the impact of AIDS on the lives of children and adolescents infected and affected by HIV and AIDS through ensuring access to quality care, treatment and support. While primarily focused on providing services to children and adolescents living

⁵ UNAIDS, UNICEF, WHO 2015 Global AIDS Response Progress Reporting and UNAIDS 2014 HIV and AIDS estimates, July 2015.

⁶ Ibid

⁷ Ibid.



with HIV, the project also builds the capacity of caretakers, and informs and sensitizes the general population on HIV and AIDS.

The HAPPY centers operating in six districts, including Western Area (Urban and Rural), Bombali, Bo, Kenema and Pujehun offer educational, psychosocial and health services to children and adolescents infected or affected by HIV to give them an opportunity to make full use of their potential. HAPPY also trains children and adolescents ages 10-17 as peer educators, who conduct one-on-one educational sessions, group theatre, and facilitate the sharing of experiences and strategies for coping with HIV.

The HAPPY centres were also equipped to offer treatment for children and pregnant women already on treatment if the regular ART clinic was unable to provide services. The EVD outbreak increased the loss of confidence in health facilities, as they were considered potential sources of infection. Therefore, the HAPPY resource centre, was used as an alternative site for dispensing ARVs. It was equipped with infection, protection and control (IPC) materials and opened two days a week. Service providers from the clinics delivered health services in the HAPPY centres. All patients entering the HAPPY centre were screened for Ebola (temperature taken and questionnaire completed). A hand washing facility (chlorine soap and buckets), protective gear, (gloves, bins for sharps and other wastes) and IEC materials on Ebola were available in all centres.

At the height of the outbreak, the general population was overwhelmingly reluctant to seek care at health facilities due to the fear of contracting Ebola. In this context, HAPPY rapidly understood the need to **proactively reach out** to people living with HIV to continue to provide them with life-saving drugs. The objective of this intervention was to improve access to HIV services for the 1,444 pregnant and lactating women and 541 HIV-exposed and-infected children in the districts where HAPPY operated, including districts that were most affected by Ebola at the start of the outbreak.

As part of the response, HAPPY launched the **Patient Tracing Project** to ensure ongoing treatment and support for people living with HIV during the Ebola outbreak, reduce the number of patients missing appointments and prevent loss to follow-up. The project facilitated continued access to treatment and care for people living with HIV by tracing patients, supplying ARVs, and providing HIV services at HAPPY centres when health facilities were closed.

As a result, both healthcare staff and HIV-positive patients felt more comfortable going to HAPPY facilities to pick up their ARVs, receive adherence counselling and seek other health care services, despite the fear around Ebola. HAPPY social workers and counsellors provided individual counselling to older children and counselling for the parents/caregivers of younger children. Nurse counsellors from the health facilities conducted outreach

visits to the HAPPY centres at agreed times to dispense ARVs and other medications and supplies. This was important for clients who did not wish to go to health facilities but still needed access to ARVs. Patients who needed additional testing or presented with complications were referred to a fully equipped health facility.

The HAPPY teams were also trained to distribute ARVs and provide adherence counselling to clients who refused to go to the health facility and/or HAPPY centres to pick up their medication, either due to long distances or if

clients were quarantined in their homes or communities. In these cases, the teams brought the medication to their homes and provided them with counselling sessions and information. Clients who were unable to leave their homes were given multi-month supplies of ARVs and caretakers were provided with ARVs for their children. Other supplies dispensed included prophylaxis (septrin), vitamins, and paracetamol. For other ailments, clients were encouraged to report to the nearest health facility and/or the appropriate health facility/ programmes were notified.

Follow-up Care for HIV Patients during the Ebola Crisis

Follow-up tracing is defined as contacting a person living with HIV who does not return for their treatment on time.⁸ While loss to follow-up had previously been a concern for the national HIV programme, this strategy was specifically designed in the context of the EVD outbreak and later incorporated into the national HIV response. HAPPY trained 16 social workers and 30 district HIV counsellors and volunteers from the six HAPPY centres on HIV defaulter tracing in the context of Ebola. The training included screening for signs and symptoms of Ebola, counselling a person without having close contact, and providing referrals for a person with signs and symptoms of Ebola. The process used by the tracer teams are outlined below:

STEP 1 / INITIAL CONTACT

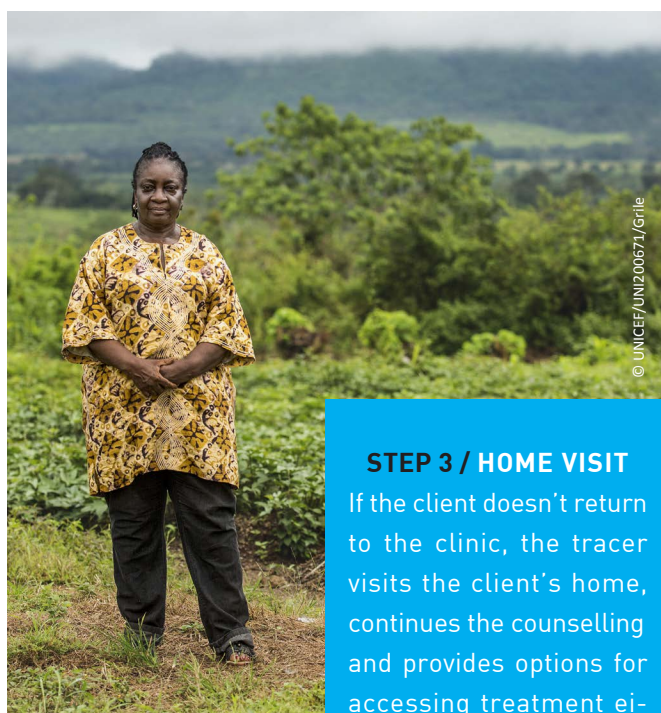
To follow up people living with HIV who missed scheduled appointments, social workers and HIV counsellors attempt to make an initial contact using information from the HIV clinic including the person's name, telephone contact and address. The counsellor then informs the tracers, usually peers who either call or visit the client.

STEP 2 / TRACER CONTACT

Tracers are primarily people living with HIV, which helps to build trust and confidence among clients. In the initial contact, the tracer reminds the client about the missed appointment, explores reasons why it was missed, and requests the client considers returning to the clinic to resume treatment.

STEP 3 / HOME VISIT

If the client doesn't return to the clinic, the tracer visits the client's home, continues the counselling and provides options for accessing treatment either at the health facility, HAPPY Centre; or community-based delivery of ARVs by HAPPY teams. If a client refuses, ARVs are provided directly to clients, and tracers will conduct frequent visits to monitor compliance. Phone numbers are provided to the client to call for assistance or information.



⁸ Definition of loss to follow-up is an individual who does not return to the health facility within 30 days.



Tracer teams worked together to ensure that HIV-positive and-exposed children, adolescents and women adhered to treatment during the Ebola outbreak.

Risk of non-adherence was heightened for several reasons:

- Pervasive fear of EVD infection at public health facilities inhibited people living with HIV from seeking care at normal health facilities
- Health facilities were quarantined and inaccessible
- Travel restrictions imposed as part of EVD control policy
- Service providers were not available either due to illness or deployment for the Ebola response
- Stigma or fear of being mistaken for an EVD patient
- Being quarantined due to close contact with an Ebola patient

The teams discussed the common reasons shared by clients for defaulting, which included fear of being infected with Ebola, feeling too sick to go to the health facility and conversely, improved health and therefore not feeling motivated to continue treatment. The same teams jointly strategized possible solutions, such as providing information on alternative sites to receive treatment and alternative ways to remind clients of appointment dates/times. Tracer teams had weekly meetings with the HIV clinic staff to collect all pertinent information about patients, such as their address and contact details and report back on the results of their visits. Tracer teams were also kept informed on other activities implemented by other partners in the context of Ebola.

If a client living with HIV was quarantined because they were in contact with a confirmed Ebola positive case, tracers informed the surveillance officer assigned to the family that the patient was exposed to Ebola and provided quarantine support such as food, water and non-food items (i.e. charcoal and mosquito coils). Tracers continued to provide ARVs and other medicine to quarantined clients in collaboration with surveillance officers until the end of the 21-day quarantine period.

HAPPY centres served as hubs for collating client information, monitoring clients and reporting on results achieved. All phone calls and home visits were recorded

and outcomes reported back to the HIV clinic where the initial information about the client was collected. Measures were taken by outreach workers and clinical staff to ensure this information remained confidential.

The programme also included regular community sensitization through radio programmes, community outreach and meetings with PLHIV support groups to inform them of the risk of Ebola, and encouraged them to continue to attend health facilities for any other conditions.

Impact of the intervention

When the programme was launched in August 2014, 30% of the 686 children in 12 health facilities had defaulted on their HIV treatment. By the end of the project, 60% of children and 84% of pregnant women who were lost to follow-up were re-initiated on treatment.⁹ Improvements in access and retention were achieved

by triangulating the existing facility data with the information obtained from outreach to patients lost to follow-up. As a result of this experience, the national programme has increased its focus on retention monitoring. As part of the HIV mitigation strategy in the EVD outbreak, the National AIDS Secretariat (NAS) engaged the Network of People Living with HIV (NETHIP) in Sierra Leone to conduct large scale tracing of patients lost to follow-up. As part of the recovery, this model was replicated and adapted in the five districts with the highest HIV burden under the leadership of NAS, with support from UNICEF, UNFPA, UNAIDS and the World Food Programme (WFP). The national EVD recovery plan also featured tracing and follow-up of patients who missed appointments or stopped treatment as a result of the success of the approach implemented by the HAPPY teams.

⁹ Based on HIV programme data from the HAPPY Centre.



LESSONS LEARNED AND RECOMMENDATIONS:

Adaptability: How an Effective Emergency Response Improved Development Programming

In Sierra Leone, the Ebola outbreak demanded that community-based structures and organizations such as the HAPPY centre played a central role in educating communities and delivering basic health services. In turn, the success of this approach influenced HIV programming in non-emergency settings. Similar strategies, namely, peer outreach and proactive follow-up were adopted by the national HIV programme to address persistent challenges retaining people living with HIV in care. The HAPPY project results underscore that actions taken during emergencies can feed into and shape interventions to address chronic illness and improve the health and well-being of mothers and children.

Likewise, building on existing mechanisms such as support groups and a trained pool of counsellors accelerated the pace of implementation. Identifying opportunities to integrate HIV and Ebola in terms of training health staff and peer outreach workers, and providing follow-up care to people living with HIV and those potentially exposed to Ebola was important to the success of the response. Other lessons learned include:

- 1) **Flexible programming and integrated service delivery** to respond to the evolving context and conditions precipitated by the emergency or humanitarian crisis. Surveillance officers allowed tracers to talk to clients over the quarantine fence and provide them with ARVs. In addition, enabling Ebola response teams to deliver ARVs early on would have been another effective strategy, as they visit quarantined homes daily to check if household members had a fever and delivered supplies on a weekly basis.
- 2) **Integrate HIV into training for frontline responders.** Equipping Ebola response teams with basic counselling skills for clients with HIV as part of their training would have also helped address concerns about confidentiality and privacy. Going forward, providing advanced training on HIV to response teams who are ready to be deployed during an outbreak may increase their preparedness to address HIV-related issues in the future.
- 3) **Peer outreach is critical** to reduce the potential impact of stigma during an outbreak as well as stigma associated with HIV.
 - **Engaging people living with HIV as contract tracers** helped to gain the trust and confidence of patients who missed visits or stopped treatment and encouraged them to start treatment again. Training people living with HIV to provide HIV counselling and testing in facilities also increased the comfort level of clients and assuaged fears of breaches in confidentiality. Nevertheless, in a few cases, clients preferred their former counsellors and were reticent about sharing information whether due to resistance to change or fear that, that tracers were part of the EVD surveillance team.
 - **Proactive tracing** of patients through consistent home visits to ensure the same individual return to the health facility improves access to treatment, care and support to patients.

- 4) **Align activities with established, ongoing PLHIV support groups.** Support group members are generally familiar with the lives of their peers and can provide more accurate reasons for missed appointments. Selecting support group members to be tracers is an important strategy as they provide essential information on the whereabouts of clients that were hard to locate. Clients who were not members of a support group were referred to such groups as this contributed to feelings of connectedness and being supported, which has been shown to help improve retention and adherence.
- 5) **The quality of client-provider interaction and communication lays the groundwork for outreach efforts and influences the effectiveness of follow-up care.**
 - Encourage counsellors to **engage the client in small talk** before rushing directly into the counselling session. This includes asking about their family, talking about the weather, social events, etc. This puts the client at ease and increases the likelihood they will share important information about their health status and any psychosocial concerns.
 - Ensure that clients have the facility phone number and encourage them to contact the counsellors and/or facility if they are unable to make their appointment.
- 6) **Data collection and recording is key to effective follow-up**
 - Encourage health workers to **properly record complete contact information**, including directions and landmarks as well as consent to contact patients who may miss appointments.
 - Keep alternate contact information in the case that someone changes residence and check records of existing support groups where client may have been a member to obtain valid and/or current contact details. In some cases, contact information provided was false, non-existent or patients changed addresses. This required additional investigation and effort to trace patients who missed appointments, such as talking to neighbours or known acquaintances, especially if the client had changed their residence.

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