SHORT REPORT

Community engagement following a human immunodeficiency virus (HIV) outbreak in rural Pakistan: Challenges and lessons learnt

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Introduction

The lives of the residents of a small rural community in taluka Ratodero near the town of Larkana in Sindh province of Pakistan was rattled when an unprecedented human immunodeficiency virus (HIV) outbreak was discovered in April 2019. The problem of HIV is not new to Larkana which has already experienced multiple outbreaks among key population at risk for HIV as well as among dialysis patients.[1-3] However, in Ratodero, a town of 150,000-200,000 persons which is 40 kilometres away from Larkana, no such event had occurred in the past. Earlier in 2019, a local general practitioner (GP) of the area had started seeing an unusually high number of young children with symptoms related to HIV infection and acquired immunodeficiency syndrome (AIDS). He frequently referred cases for confirmation to HIV testing centres close to Larkana or Karachi hoping that the rapid rise will get attention from key stakeholders. However, a local journalist broke the news which rapidly caught attention of the country as well as the world. There was media frenzy and the small town of Ratodero was under the limelight.[4] Once the outbreak was established, a cross-sectional study in Ratodero was conducted between April and July 2019 enrolling 31,239 individuals who were tested for HIV out of which 930 (3%) were confirmed to be HIV positive. Out of these, 763 (82%) were persons younger than 16 years and 604 (79%) of these were children aged five and below.[5] Investigation by an international team of WHO experts had reported strong link between HIV infection transmission and unsafe medical practices including reuse of injection and intravenous (IV) drip sets and poor infection prevention and control (IPC) practices.[6]

This opinion piece aims to describe interventions and activities that were conducted as part of community engagement in Ratodero, and share challenges and lessons which were learned.

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The response plan

After the outbreak, all stakeholders including Sindh AIDS Control Programme, Ministry of National Health Services Regulation and Coordination, WHO and other UN partners gathered, and after collaborative efforts developed a comprehensive response plan. One of the key elements of the response was engagement of affected community in Ratodero. This was considered as the most important component as it would have helped in mitigating the impact of the outbreak in this rural community. Following were the main aspects of community engagement:

1. Diagnosing community members infected with HIV and linking them to care and treatment;

2. HIV testing of mothers to check for vertical transmission;

3. HIV testing of siblings and fathers;

4. Reducing stigma and discrimination by involving the community;

5. Increasing awareness about HIV treatment and ensuring adherence among those receiving antiretroviral (ART) medicines.

Community engagement

Bridge Consultants Foundation, a non-governmental organisation (NGO) was sub-contracted by United Nations Children's Fund (UNICEF) to implement the project in Ratodero and adjoining areas from June 2019 to March 2021.

The activities initially started in the taluka of Ratodero and included twelve union councils (UCs) and two town committees of Ratodero and Naudero towns. Soon the coverage was extended to adjacent talukas of Gharhi Yaseen and Sujawal.

Pre-intervention survey

A pre-investigation survey was conducted in the affected

community to determine knowledge, attitude and practices of the community about HIV and their healthcare-seeking behaviours. Data was collected through a questionnaire and total of 618 respondents were interviewed including men and women.

The study found that majority of the affected families were poor and illiterate. Large number of children and adults, who tested positive for HIV were not registered for antiretroviral therapy (ART) or were not fully adherent to treatment. A significant number of mothers, fathers and siblings of HIV positive children did not know their HIV status. Almost 100% of the affected families were living under poverty, were illiterate and engaged in agriculture farming. Many affected families had more than one HIV positive child and in some cases the parents were also HIV positive. Due to poverty, it was the children and women who were particularly malnourished.

Lists of key influential people including UC counsellors, UC chairs, school teachers, religious leaders, women and youth leaders, general practitioners (GPs), lady health workers and community-based organisations (CBOs) were compiled after visiting different villages and towns and consulting the community.

Formation of mothers and fathers support groups

A trained team of outreach workers (ORW) worked in the community and involved the community influential and household members of HIV-infected children with the assistance of the list of HIV positive persons provided by the Sindh AIDS Control Programme. The support groups for mothers and fathers were formed to educate the parents of infected children in the community. By the end of the project approximately 685 mothers and 673 fathers support groups were established and functioning well in the community. ORWs conducted regular sessions with the groups to educate them about HIV and AIDS and answered their questions and concerns. These groups were able to conduct sessions with 5544 parents in the project catchment area. These groups were also engaged by the ORWs to organise psychosocial support for mothers and fathers and around 19,165 parents had participated in the different sessions aimed to provide psychosocial support.

HIV awareness sessions with community leaders

HIV awareness sessions were organised with the community's influential people, school teachers and religious leaders. A total of 100 religious' leaders, 99 school teachers, 98 women leaders, 57 media persons and 30 UC counsellors were trained. They were requested to impart HIV knowledge within the community and play their role in social mobilisation and increasing HIV awareness, especially within the affected community. Since they are a respected part of the community, they played a crucial role in increasing HIV knowledge and in encouraging those who had not tested for HIV.

Linking HIV diagnosed children and adults to treatment and care

The community engagement project through its outreach and other activities identified 1,205 affected families and 1,298 HIV positive persons in the three talukas. Of these 1,298 HIV positive persons, 1,053 were children and 145 were adults. Out of 1,053 HIV positive children, 212 were not linked with treatment and the project team helped them in seeking HIV treatment. There were 47 deaths reported in the community among HIV positive persons.

The community engagement worked as a bridge between patients and the treatment centre to establish links and adherence to ARTs. Maintaining close contact with the treatment centre, the ORWs followed up on patients on ARTs who were missing their follow up appointments, and educated and encouraged them to continue the treatment.

HIV testing of mothers, fathers and siblings of HIV positive children

ORWs, with the helped of the community, identified mothers, fathers and siblings of HIV positive children who were offered free HIV testing in the community ensuring full privacy and confidentiality. All those who had given informed consent were tested by the mobile team. Persons whose initial test was reactive were transported to the nearest testing centre for confirmation testing.

During the project, a total of 7,129 mothers, fathers and siblings of HIV positive children were identified in the community who were not aware of their HIV status. Out of these, 5,363 were tested and 73 (1.4%) were found to be HIV positive. Of these 73, 62 were linked with treatment and care.

Training of GPS of the community on HIV and IPC

A list of practicing GPs was compiled by doing a quick

mapping and with support of local branch of Pakistan Medical Association (PMA). UNICEF and Sindh AIDS Control Programme provided support in developing a comprehensive training module which was used to train 94 practicing GPs of the area in the field of basic HIV/AIDS frequently asked questions and misconceptions as well as IPC.

Monitoring of community engagement activities

All community engagement activities were monitored regularly by senior management of the implementing organisation along with technical staff of Sindh and National AIDS Control Programme and UNICEF. Regular missions from WHO, Joint United Nations Programme on HIV/AIDS (UNAIDS) and United Nations Population Fund (UNFPA) also took place of the site and reviewed community engagement activities.

Challenges

Quality of services at the HIV treatment centre in Ratodero

Providing comprehensive HIV treatment services to more than 1000 individuals including children posed a big challenge. Challenges included:

- Lack of trained human resources such as a qualified infectious disease specialist, a trained paediatrician, pathologist, pharmacist and support staff.

- ART medicines are provided by the National AIDS Control Programme through Global Fund support and there were interruptions in supplies as well as availability of paediatric formulations.

- While Sindh government provided antibiotics, antifungal and multivitamins and analgesics, there were frequent shortages and the patient had to buy out-of-pocket from the local market.

- Necessary laboratory tests were not available at the treatment centre and patients were routinely referred to private laboratories whose charges majority of patients could not afford.

- The ART treatment centre was established with support of UNICEF in the taluka hospital of Ratodero which was managed by Sindh AIDS Control Programme. However, the Sindh Health Department contracted out the whole hospital to an NGO which resulted in lack of coordination between hospital management and the treatment centre.

- ART treatment centre physicians were unable to spend enough time with each patient due of high number of patients.

Poverty and malnutrition among affected population

Majority of families with HIV positive children were poor and HIV-infected children were malnourished. There was limited social or financial support available to these affected families. An endowment fund was announced by Sindh government to support these families. However, during the project and afterwards there had been no concrete progress which could have helped these families.

New HIV cases among children

Even after two years of the outbreak new HIV cases were reported among children and the positivity rate remained more than 1%. Active HIV case tracing strategies are needed to identify all HIV positive children and adults in the community. Initiating ARTs among HIV positive is a proven strategy to reduce the chances of infection transmission.

Infection control practices

Infection control practices at public and private health care facilities is a serious challenge. Although there has been a visible decline in reuse of syringes as indicated by a recent WHO assessment, the use of unnecessary injections, improper disposal of used syringes and management of infectious healthcare waste is a problem. There is no system of hospital waste collection and used syringes are disposed of with household waste. Incinerators at public health facilities remained non-functional.

Lessons learned

1. Effective engagement of HIV affected community is necessary in order to increase uptake of services, such as linking of HIV diagnosed individuals to treatment, care and support, ART adherence and HIV testing and counselling.

2. Proper community engagement enhances the trust and confidence of population in the quality of services provided.

3. Involvement of community leaders including religious leaders, elected representatives, political leaders, and school teachers facilitates access to community and helps in developing links.

4. Continuous contact with affected families through outreach workers and addressing their concerns improves ART adherence and prevents loss-to-follow-up.

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