CASE STUDY

Improving identification of new HIV positive children and adults: the role of community structures

The USAID Applying Science to Strengthen and Improve Systems project (ASSIST), in collaboration with orphans and vulnerable children (OVC) implementing partner, Uganda Private Health Support Program (UPHS), set out to improve case finding of HIV-infected children and their caregivers using a quality improvement (QI) approach in the central region of Uganda. Stigma and discrimination associated with HIV positive results are known challenges to accessing HIV counseling and testing services (UNAIDS 2015). There is an opportunity of using community based organizations that have structures in some communities to address the challenges. ASSIST, UPHS and Fishing Community Health Initiative therefore considered strengthening the capacity of community structures to identify more positives in the community with the help of the new HIV positive case-finding criteria tool to identify HIV positive suspects and refer them for HIV testing and ensure enrolment for children who are not in HIV care. The use of the criteria has improved identification of new HIV positive individuals over a period of 14 months, in 18 communities a total of 144/200 HIV positives have been identified, most of whom were children 0-14 (80) and 64 were individuals 15 and older. Children and direct beneficiaries 15 and older with known HIV status improved to 80% (806/1000) and 81% (621/762) respectively. Of the HIV positives, 100% (128/128) of children and 98% (368/374) of beneficiaries 15 and older are enrolled in HIV care.

Background

UNAIDS has set an ambitious goal to help end the AIDS epidemic by ensuring that 90% of all people living with HIV know their HIV status; 90% of all people with diagnosed HIV infection receive sustained antiretroviral therapy (ART); and 90% of all people receiving ART have viral suppression by 2020 (UNAIDS 2014). To achieve this goal, there is need to ensure that HIV counselling and testing (HCT) services are available to those who need them so that they can know their status and get linked to care and treatment services. Initiatives such as provider-initiated HIV testing and counselling (PITC) at high yield points have resulted in significant improvements in finding new HIV positive individuals (WHO, 2012). Although community outreach services have been used to reach those who have been missed by the health care system, still not all have been reached.

JANUARY 2017

This case study was authored by Esther Nassali, Juliana Nabwire, Esther Karamagi and Mirwais Rahimzai of University Research Co., LLC (URC) and Sserwadda Abdullah of Fishing Community Health Initiative (FICHI). We would like to acknowledge community QI team members of FICHI CSO supporting OVC work. We acknowledge the USG implementing partners Uganda Private Health Support (UPHS) program. The work described was supported by the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR). The project is managed by URC under the terms of Cooperative Agreement Number AID-OAA-A-12-00101. URC’s global partners for USAID ASSIST include: EnCompass LLC; FHI 360; Harvard University School of Public Health; HEALTHQUAL International; Initiatives Inc.; Institute for Healthcare Improvement; Johns Hopkins Center for Communication Programs; and WI-HER, LLC. For more information on the work of the USAID ASSIST Project, please visit www.usaidassist.org or write assist-info@urc-chs.com.
Therefore, improved case finding of HIV-infected infants, children, adolescents and adults through community initiatives to reach those who may have been previously missed by the health care system provides an opportunity to increase coverage and reduce mortality rates due to HIV/AIDS especially among children.

The USAID Applying Science to Strengthen and Improve Systems project (ASSIST), in collaboration with orphans and vulnerable children (OVC) implementing partner, Uganda Private Health Support Program (UPHS), set out to improve case finding of HIV-infected children and their caregivers using a quality improvement (QI) approach in the central region of Uganda.

Understanding the problem

A Fishing Community Health Initiative (FICHI) located at the landing site in Bukakata Sub-County, Masaka District with a high HIV prevalence shared baseline results that showed that 67% (404/603) of the supported vulnerable children aged 0-14 years and 77% (350/450) direct beneficiaries aged 15 and above had a known HIV status. Of the HIV positives, 78% and 79% respectively were enrolled in HIV care. Efforts to support all children and their caregivers to access HCT services at the FICHI Civil Society Organisation (CSO) and other local CSOs yielded a few more HIV positive individuals. A very small number of children and their caregivers were attending outreach events to get tested.

Stigma and discrimination associated with HIV positive results are known challenges to accessing HCT services (UNAIDS 2015). There is an opportunity of using community based organizations (CBOs) that have structures in some communities to address the challenges. The team (ASSIST, UPHS and FICHI) therefore considered strengthening the capacity of community structures to identify more positives in the community. Village health teams (VHTs) were mobilized, oriented on community QI approaches, organised into functional QI teams, and were provided with referral forms and registers to improve documentation. Members of the community QI teams allocated each other communities to work in and monthly follow up would be done.

Functionalising three parish improvement teams

Initially, VHTs were involved in other activities supported by the FICHI CSO such as provision of malaria treatment to children in the community and less on HIV work. The CSO organized and trained both VHTs and para-social workers to form QI teams at the parish level. The role of the improvement team was to work on improving identification of HIV positive persons in the community using a case finding tool, referring them for HCT, follow-up, and linkage to care for those who are HIV positive.

Parish QI teams formed with representation of 5-6 members including, for example, a VHT member and/or a para-social worker, local leader, retired teacher, community members, or other relevant community members in each village. These teams began meeting at the parish office with support from the CSO at least once a month to share progress and make calls to update the field officer/social worker on new positives identified and enrolled in care. The CSO provides each member with a referral book and case management book which are reviewed monthly. The field officers/social worker also identify households they need to make follow up visits with.

Beneficiaries’ perspectives

“I lost my first husband to HIV/AIDS and I was left with 3 children. I got married to another man, however I could not continue taking my ARVs because I feared to lose my marriage.”

“My children could constantly fall sick, had skin diseases but could not take them for treatment because there was no one to support me.”

“Through the constant home visits made by the VHT, I was counseled on the benefits of starting my medication again and testing my children for HIV.”

“Testing was done at my home and my 3 children tested HIV positive. We have all been enrolled into HIV care and our health has improved. My children were enrolled at FICHI and are getting nutrition and continuous psychosocial support.”
Using the HIV positive case-finding criteria

ASSIST, through addressing the 90-90-90 strategy, realised there was a need to support FICHI CSO and parish improvement teams to identify new HIV positives. Through the monthly coaching visits, ASSIST coaches worked with the teams to develop the HIV positive case-finding criteria to be able to identify HIV positive suspects and refer them for HIV testing and ensure enrolment for children who are not in HIV care. The criteria are comprised of three main aspects: (i) identification of chronically/malnourished sick children; (ii) children living in households with a caregiver known to be HIV positive; and (iii) children who have lost parent(s) to HIV/AIDS. While the tool focuses on identifying children, adults found in the household are also encouraged to receive HCT.

The VHTs were assigned to work in their villages to generate a list of households that fit the criteria, make home visits, seek verbal consent, and administer the tool. During the home visit, the VHT provided information on benefits of HCT and early enrolment into HIV care. Children who met the criteria and caregivers who accept to be referred to HCT were provided a referral note to the health centre of choice and the VHTs followed up to get feedback if services were received. Those who tested HIV positive were followed up to ensure they were enrolled into HIV care.

For a period of three months, the criteria tool was tested in two communities at FICHI then spread to 16 communities in the next nine months. By October 2016, it had been spread to 15 more communities by three CSOs.

Results

The use of the criteria has improved identification of new HIV positive individuals over a period of 14 months. At FICHI CSO, through 18 communities, a total of 144/200 HIV positives have been identified, most of whom were children 0-14 yrs (80) and (64) were individuals 15 and older. Spread of use of the HIV positive case finding tool to four CSOs (KIMOSI, Karera, Bantwana and Caring hands) in 20 communities yielded 202/304 HIV positive individuals (52 children 0-14 years and 130 individuals 15yrs and older) in 7 months.

Figure 1: Percentage of newly identified HIV positive children(0-14yrs) and individuals 15+yrs identified and referred in 18 demonstration and 15 spread communities (November 2015- October 2016 and May 2016- October 2016)
Lessons learned

Use of the three criteria in identification by the community teams has been helpful in case finding of HIV infected children and adults (however, it has been more effective among children). In this case, we believe the tool has been very successful because it is administered by people who know their community. The criteria were used in 10 communities with a known high HIV prevalence and five other communities with relatively lower prevalence and the results show that it is effective for both kinds of communities.

In some communities, referrals have not been effective because of long distances to the health facilities to access HCT services. Such identified individuals would benefit from home based testing and counselling services.

Conclusion

To ensure that 90% of all people living with HIV know their HIV status, we need to have more creative ways with which to reach the populations. Providing existing community structures with a case finding criteria is one creative way that has showed promising results of identifying those HIV positive individuals who had not been reached by the health system. The community structures not only support identification of people who are HIV positive but also provide follow up services to ensure linkage to care and support services. ASSIST intends to scale-up the use of the criteria to at least 20 more communities and evaluate the results to be able to inform HIV community programs.

VHT perspective

Community HCT services are available in the community by HIV service providers such as TASO, Medical Research Centre (MRC) but the caregivers fear to test because of stigma associated with HIV positive results. However, door to door home visits to provide counseling on benefits of HCT for the identified children and caregivers using a case identification tool helped us to find those who did not know their HIV status. We have helped them to get to know their HIV status and start medication at the health facilities.