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ORIGINAL ARTICLE

SURVEILLANCE OF A CHRONIC LIVER DISEASE OF UNIDENTIFIED CAUSE IN A RURAL SETTING OF ETHIOPIA: A CASE STUDY

Cindy Chiu[1], Colleen Martin[1], Daniel Woldemichael[2], Girmay W/Selasie[2], Israel Tareke[3], Richard Luce[1], Gidey G/ Libanos[4], Danielle Hunt[1], Tesfaye Bayleyegn[1], Adamu Addissie[5], Danielle Buttke[1], Amsalu Bitew[6], Sara Vagi[1], Matthew Murphy[1], Teshale Seboxa[5], Daddi Jima[7], Asfaw Debella[7]

ABSTRACT

Background: *An outbreak of a chronic liver disease of unidentified cause, known as "Unidentified Liver Disease (ULD)" by local communities was first observed in a rural village in Tigray, northern-Ethiopia in 2001. Little was known about the geographical extent, trend, and epidemiology of the disease.*

Methods: *The Ethiopian Public Health Institute (EPHI) by then Ethiopian Health and Nutrition Research Institute (EHNRI), Centers for Disease Control and Prevention, World Health Organization, and Tigray Regional Health Bureaue established the ULD surveillance system in 2009 to characterize and monitor trends for this emerging disease and to identify cases for treatment and follow up. A large-scale official training was provided to the surveillance staff on case identification, management and reporting. In absence of a confirmatory test, the system used simple case definitions that could be applied by frontline staff with varying clinical training. To maximize resources, health extension workers already conducting household visits in affected communities identified cases and increased community awareness about the disease. A team was placed in Shire, in close proximity to the outbreak region, to provide support and collect reports from health facilities and district health offices.*

Results: *As of September 2011, a total of 1,033 cases, including 314 deaths were identified. Contamination of locally produced grains with several pyrrolizidine alkaloid producing plants was identified cause of the disease. Staff interviews identified that shortage and turnover of trained staff were major challenges.*

Lessons learned: *Long term dedication by frontline staff, using simple case definitions to identify cases, and active collection of missing reports were critical for surveillance of this chronic non-infectious disease of unknown cause in a rural, resource-limited setting.*

Keywords: Surveillance, Pyrrolizidine, Liver Disease, PALID, Tigray, Ethiopia

INTRODUCTION

A chronic liver disease of unidentified cause, called "Unidentified Liver Disease (ULD)" by the local community, was first observed in a rural village in the northwestern region of Tigray, Ethiopia in 2001.(1) ULD was characterized by epigastric pain, abdominal distention, as cites, and hepatosplenomegaly, with case fatality rates estimated at 30% to 40%.(1-3) Having ruled out infectious causes with initial investigations patients were investigated for potential toxic etiologies.(1-6)

Basic epidemiological questions considered to characterize the disease included geographic, temporal, and seasonal trends, case demographics, clinical characteristics, and incidence and mortality rates. An active surveillance system was established in 2009 to determine the magnitude and distribution of ULD, identify trends of the outbreak, link ULD cases with clinical care, and inform health officials and funding agencies of resource requirements. An assessment was undertaken two years after the surveillance system was established. We conducted this case study to report the results from the assessment and share the lessons learned from implementing the ULD surveillance system in Tigray.

[1]CDC (USA); [2] Tigray Agriculture Bureau, [3] WHO - Ethiopia ,[4] Tigray Health Bureau, [5] Addis Ababa University
[6] Suhul Hospital, Tigray; [7] Ethiopian Public Health Institute

METHODS AND MATERIALS

Setting: Tigray is a remote, semi-arid region that is one of the most drought-prone and food insecure regions of Ethiopia.(7,8) Affected villages were rural with rugged terrain, limited means of transportation and access to healthcare, and limited or no electricity. The health posts and centers were basic with limited clinical services and staff; most frontline staff had limited clinical training.

Stakeholders: The Ethiopian Public Health Institute (EPHI), by then Ethiopian Health and Nutrition Research Institute (EHNRI), the United States Centers for Disease Control and Prevention (CDC), the World Health Organization (WHO), and Tigray Regional Health Bureau (TRHB) established an active surveillance system in the Tigray region to monitor the ongoing ULD outbreak. The ULD surveillance system was implemented through a strong partnership and collaboration between EPHI and CDC,WHO, and TRHB. EPHI was the central coordinating body overseeing the surveillance system. Other stakeholders were health facilities, district health offices and North-western Zonal Office of the Tigray Region, and stakeholders providing funding. (Figure 1)

Case definitions: Simple sign and symptom-based case definitions that did not require laboratory capacity were designed to detect cases. Suspect cases were individuals with abdominal distension identified by history or on physical examination or a household member with similar symptoms and/or abdominal pain/cramps for at least two weeks. Possible cases were those who met the definition for a suspect case and also had a hepatomegaly and/or splenomegaly on physical examination.

Implementation: A large-scale training on the ULD surveillance system was provided in 2010 to the staff involved in the surveillance. A standardized surveillance form was used to capture case demographics, disease history, signs and symptoms, and laboratory test results. Due to staff shortage in March 2011, EPHI and TRHB collaborated with agricultural team temporarily assigned in Shire to conduct animal and plant studies to oversee the implementation of surveillance activities. Case fatality rates were calculated to monitor the effect of treatment and follow-up on patient prognosis. Data from the surveillance system were also used to allocate medications to health facilities to treat patients. When several health facilities reported medication shortages, TRHB reviewed its operations to more effectively guide medication management and distribution.

Reporting: As of September 2011, 13 districts were under active surveillance in the Northwestern, Central and Western Zones in the Tigray Region. Typically, each district health office was overseeing four to six health centers and over 20 health posts. ULD cases were identified when they self-presented at local health facilities. In order to actively detect cases, health extension workers (HEWs) from health posts who were already performing household visits for other public health purposes such as malaria prevention were trained on ULD and the simple case definitions. They referred cases for care to local health centers, which then referred more complex and severe cases to hospitals. Health facilities sent surveillance reporting forms to the district health offices, which were compiled and sent to the Zonal and Regional Health offices; there the data were entered in electronic formats and sent to EPHI and shared with ULD investigation partners. Due to limited transportation capability to deliver paper reports, EPHI placed a surveillance team in the Northwestern Zonal Office in Shire, the town in closest proximity to the outbreak districts, which actively collected missing reports from the health facilities when passive reporting failed.

Monitoring and Evaluation: Health centers, where the majority of the patients were managed, communicated regularly with the district offices via weekly phone calls and quarterly meetings. The district offices also conducted quarterly monitoring visits with health centers, health posts, and communities for quality control and to ensure that the information collected was consistent, accurate, and complete.

In September 2011, CDC, In collaboration with the local partners, conducted a qualitative assessment of the implementation of the surveillance system two years after its establishment. We interviewed 20 staff in all levels of the surveillance system, visited nine sites (two health posts, three health centers, one hospital, and district, zonal and regional health offices), and reviewed the documentation and processes used for surveillance activities. Interviews covered training, case identification and management, data collection and reporting, supervision and feedback, and suggestions for system improvement. Health facilities and offices were visited based on availability; therefore, the findings represent the views of the sites visited and individuals interviewed.

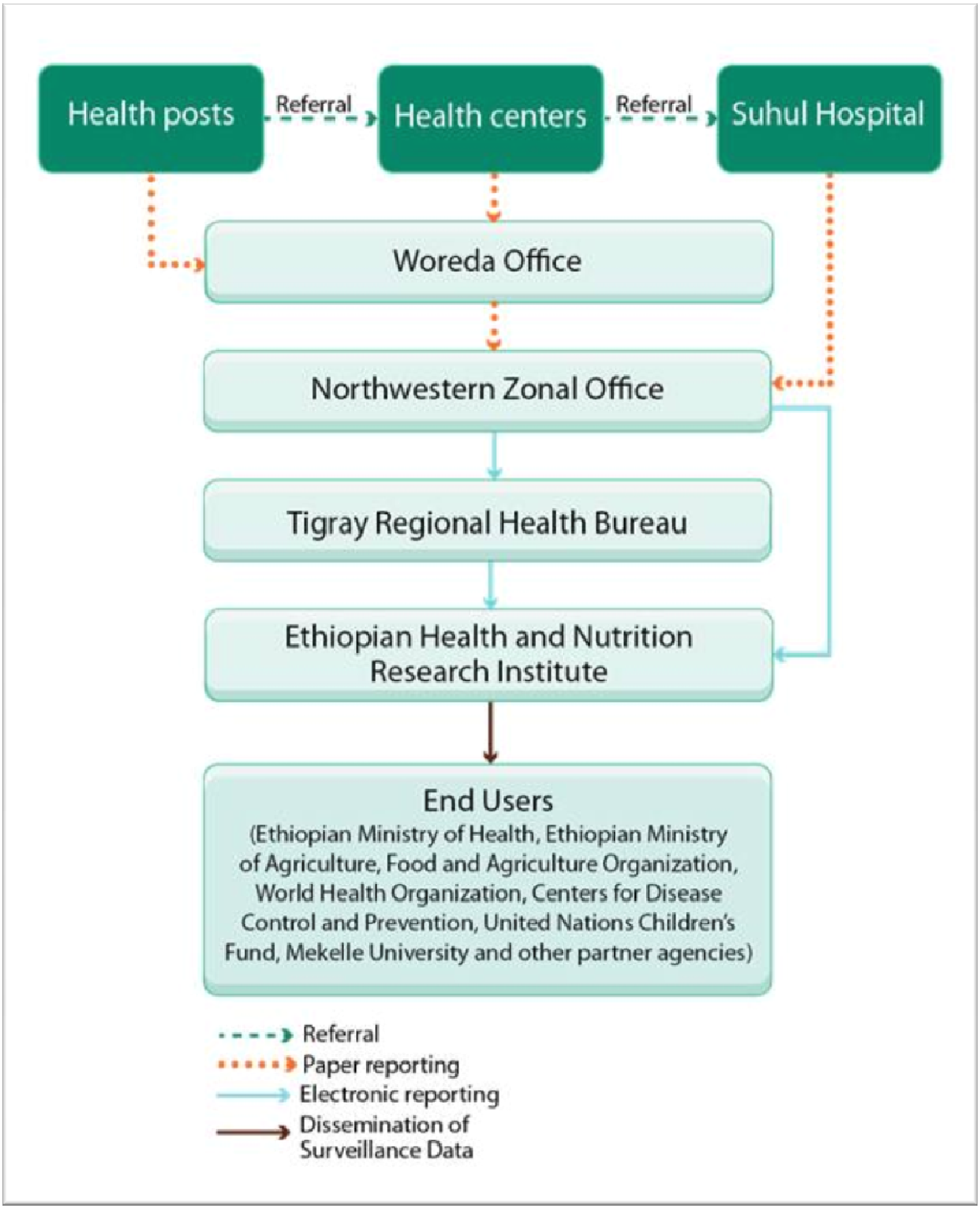

Figure 1: Information Flow in the Unidentified Liver Disease Active Surveillance System in Tigray, Ethiopia

RESULTS

The ULD surveillance system met a number of challenges and successfully achieved its objectives (Table 1). As of September 2011, the system identified a total of 1,033 cases, including 314 deaths. The ULD surveillance had important interventions intended to improve the surveillance system through making sure that there is proper understanding to the case definition of ULD by frontline health workers, through introducing improvement modalities into the currently existing surveillance system and through interventions to address issues related to staff turnover.

There were many challenges and lessons learned in establishing and ensuring sustainable implementation of surveillance system reported here (Table 1). We have outlined three major ones here that may be applicable for other surveillance systems in similar settings (Box 1).

Conducting surveillance for a chronic disease of unknown etiology with no diagnostic test presented additional challenges that were addressed by using simple case definitions to identify cases and ensuring detected cases received treatment and were monitored for long-term disease prognosis. Below is the summary result of findings related to the ULD surveillance implementations and important lessons drawn.

The importance of dedicated frontline staff: This surveillance system used traditional paper reporting, which posed significant logistical challenges for frontline staff. Dedicated frontline staffs were critical to the success of the surveillance system, District offices need to provide adequate supplies such as reporting forms and be supported with logistics including transport which were critical required to successfully conduct active case finding and reporting. They also need to be provided with timely updates including sharing of surveillance reports. During our interviews, 70% (7 out of 10) of the frontline staff (health facility and district office staff) said they would like to receive reports as one form of feedback.

Overcoming staff shortages and need for regular training: In a typical health post, staff included a nurse and a HEW who visited six to eight households every day. A health center typically had a medical director, surveillance focal person and nurses. Forty-three percent (three out of seven) of the health facilities and district offices visited said that reporting was not done when the surveillance focal person was away as there was no trained person to replace him. In addition, there was staff turnover during the previous year in two out of seven (29%) of the health facilities. A large-scale official training on the ULD surveillance system was conducted in 2010; however, among interviewed staff at health facilities and district office, only 60% (6 out of 10) had received the official training, and 80% (8 out of 10) requested additional official training.

Active collection of reports. Due to staff shortage, EPHI and TRHB were resourceful and in March 2011 asked the agricultural team temporarily assigned in Shire to conduct animal and plant studies to also oversee the surveillance activities; during this time there was a general impression among the staff that surveillance was functioning optimally. The team visited district offices and health facilities to monitor progress and collect missing reports. However, this temporary assignment ended in Dec 2011, which left no surveillance staff in Shire to perform this function.

Table 1: Challenges and Strategies used in Implementing Unidentified Liver Disease Active Surveillance System in Tigray, Ethiopia.

Challenges	Strategies	Outcomes	Lessons Learned
Unknown etiology and absence of diagnostic test			
*Unknown etiology *No confirmatory diagnostic test *Limited and varying clinical expertise among healthcare workers	*Developed simple case definitions *EHNRI trained staff on case detection and reporting *Health extension workers - Referred suspect cases to health centers for confirmation - Educated community on ULD	*Health extension workers - Increased ULD awareness - Identified cases - Referred cases for treatment	*Frontline staff were critical in increasing ULD awareness in the community and conducting active case finding.
Implementation of traditional paper-reporting system			
*Electronic reporting was not feasible - Limited telecommunication - Unavailability of electricity *Paper reporting was challenging - Long distances and challenging terrain - Lack of transportation - Lack of reliable postal services - Shortage of reporting forms	*Surveillance staff at health facilities -Travelled up to 40km by foot or available transport to conduct paper reporting - Copied forms at their own cost - Hand-wrote reports when forms ran out *NW Zonal staff visited district offices and health facilities to actively collect missing reports not captured by passive reporting	*Frontline surveillance staff successfully delivered paper surveillance forms to report cases *Active collection of missing reports improved timeliness	*Dedication of the frontline staff was critical to ensure case reporting. *Active collection of missing reports overcame transportation issues.
Staff shortage and turnover			
*Limited number of surveillance staff *Reporting often stopped when focal surveillance staff were away *High staff turnover	*Health facilities trained new staff who had not undergone official training *Shire agricultural team was assigned a dual role and oversaw the surveillance activities in NW Zonal office	*Many staff requested regular official training * Temporary placement of Shire agriculture team in NW Zonal office was effective in collecting missing reports,	*Regular official training will be necessary to address staff turnover and train back-up staff.

Box 1: Summary of main lessons learned

* Dedicated frontline staff willing to perform active case finding and reporting under difficult conditions was critical for the success of this surveillance system.

* Official training conducted in 2010 was highly effective; however regular training will be necessary to address high staff turnover as well as to train back-up staff at all reporting sites.

* Active collection of missing reports from health facilities and district health offices was instrumental in maintaining the high level of operation of this surveillance system.

***Conclusion and recommendations*:** The surveillance system played a critical role in monitoring the outbreak of ULD in Tigray. As has already been reported (9-11), for optimal functioning of a surveillance system in a rural, resource-limited setting where a paper-based system is the only option, adequate transportation, communication, training, record keeping, and staff incentives need to be provided.

To ensure sustainability of this surveillance system, the following recommendations could be considered: (1) provide regular official training;(2) utilize common resources from other programs to maximize resource support for collecting and delivering reports; (3) provide feedback by sharing surveillance reports to engage and motivate frontline staff; (4) conduct regular reviews to continually monitor and address the immediate challenges to the system.

In 2011, with evidence from multiple studies, the investigation group concluded the cause of illness to be contamination of locally produced grains with several pyrrolizidine alkaloid (PA) producing plants, and ULD was renamed to PA-induced liver disease (PAILD) (1, 3, 4, 6, 12). Ongoing support to the surveillance system to ensure continual disease monitoring as interventions to disrupt PA exposure are implemented in the community.

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