ELIMINATE TB PROJECT

TB Survivors Club Meeting. Photo Credit: MSH

TECHNICAL BRIEF

STRENGTHENING COMMUNITY TB PREVENTION THROUGH TB SURVIVOR CLUBS IN ETHIOPIA: LESSONS FROM THE ELIMINATE TB PROJECT

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SUMMARY

Ethiopia's Health Extension Program (HEP) has been a key approach to community-based health care delivery since 2003, focusing on critical health priorities such as TB prevention and control. However, the contribution of TB cases from community referral to overall TB case detection has consistently fallen short of 20%, highlighting the potential to reach the 25% national target. The Eliminate TB Project piloted an innovative peer-led intervention engaging TB survivors as community health advocates across 74 districts serving 17 million people.

Between October 2020 and September 2024, 84 TB survivor clubs comprising of 615 members (39% female) were established through partnerships with three local organizations in Amhara, Oromia, and southern regions. Survivors who had completed TB treatment volunteered to support Health Extension Workers (HEWs) in the identification and referral of people with presumed TB, contact tracing, TB preventive treatment (TPT) administration, adherence counseling, and return of patients that had previously been lost to follow-up. Club members received structured counseling on infection prevention, case detection protocols, and health education delivery.

Over four years, TB survivor clubs conducted 111 community mobilization sessions, reaching approximately 30,000 people. Members referred 126,428 people with presumptive TB, resulting in detection of 12,096 active TB cases (10% yield). In contact investigation activities, survivors traced 142,486 household contacts of bacteriologically confirmed pulmonary TB cases, screening 93%, and identifying 1,280 additional TB cases. Among 19,692 eligible child contacts under age 15, 86% were initiated on TPT with completion rates exceeding 90% for those receiving adherence support. Survivors provided adherence counseling to 1,966 drug-susceptible and 199 drug-resistant TB patients and successfully returned to care for 1,773 people whose treatment had been interrupted, and 152 patients previously lost to follow-up.

Despite challenges, including survivors' socioeconomic vulnerability and conflict-related disruptions in Amhara, TB survivor clubs appear to be a feasible community-based intervention for TB case finding, contact tracing, and treatment support.

BACKGROUND

The Global Plan to End TB 2023–2030 notes that facilitating engagement of TB survivors in TB programmatic design could ensure that TB services are people-centered and meet the needs of affected communities. It also suggests that investing in TB survivor networks and organizations helps build the capacity for survivors to engage effectively in TB governance (Stop TB, 2022).

Ethiopia started its Health Extension Program (HEP) in 2003. The HEP is an important strategy to address key health issues in the community. It has 18 packages across programmatic areas, including family health, disease prevention and control, and hygiene and environmental sanitation. The current HEP packages are relevant to addressing the disease burden among largely rural-dwelling Ethiopians. Recent changes, including two additional packages on non-communicable diseases (NCDs) and mental health, and the inclusion of additional interventions under the original packages, were effective in increasing care-seeking behavior among rural communities. The HEP has mainly

focused on the prevention of infection and vaccine-preventable diseases. It includes awareness creation through community-based health education. The HEP is implemented by health extension workers (HEWs) and community structures linked to them. HEWs are women trained on the HEP packages and serve their populations at health posts and within their communities (Assefa et al., 2019; Ethiopia Ministry of Health, 2020; Willis-Shattuck et al., 2008).

HEWs play a key role in TB prevention activities such as health education, TB screening, referral of people with presumed TB, contact investigation, and adherence support. However, the percentage of people with presumed TB referred from communities among overall TB notifications has never exceeded 20% in the last decade in Ethiopia, while the expectation is above 25% (WHO, Global TB Report, 2024).

INTERVENTIONS

The Eliminate TB Project, funded by the U.S. Government, worked to improve community TB care through engaging local organizations to address TB among populations at high risk for the disease and provide patient-centered care in their communities. These local organizations started as partners to the project in 2020 to engage TB survivors and established them into clubs to support HEWs to improve community TB care. The survivors brought their unique perspectives of having experienced the effects of having had TB and undergoing treatment, including the social and economic burden of the disease. With appropriate orientation and counseling, survivors were expected to educate and counsel others affected by TB.

TB SURVIVOR CLUB ESTABLISHMENT AND COORDINATION

A TB Survivor Club is a club established by volunteers of previously treated TB patients who were cured or/and completed anti-TB medications. Clubs were established with the help of health facility TB focal persons and HEWs that support the survivors while they are taking their TB treatment by providing health education, and adherence counseling.

Through the Eliminate TB Project's local partners Amhara Development Association (ADA), Oromia Development Association (ODA), and Renaissance through Research, Education, and Advocacy for Comprehensive Health Service (REACH) Ethiopia (figure 1), the project implemented community-based TB care (CBTBC) activities, including implementation of: a national catch-up campaign to find missed TB cases, enhanced community-based screening and contact investigation, sample referral for GeneXpert testing, provision of TPT, and community DOTS. The CBTBC activities by HEWs were augmented by the country's Women's Health Development Army and by TB survivor clubs. The local organizations supported the health facilities to establish TB patient clubs and supported the club members to implement CBTBC.

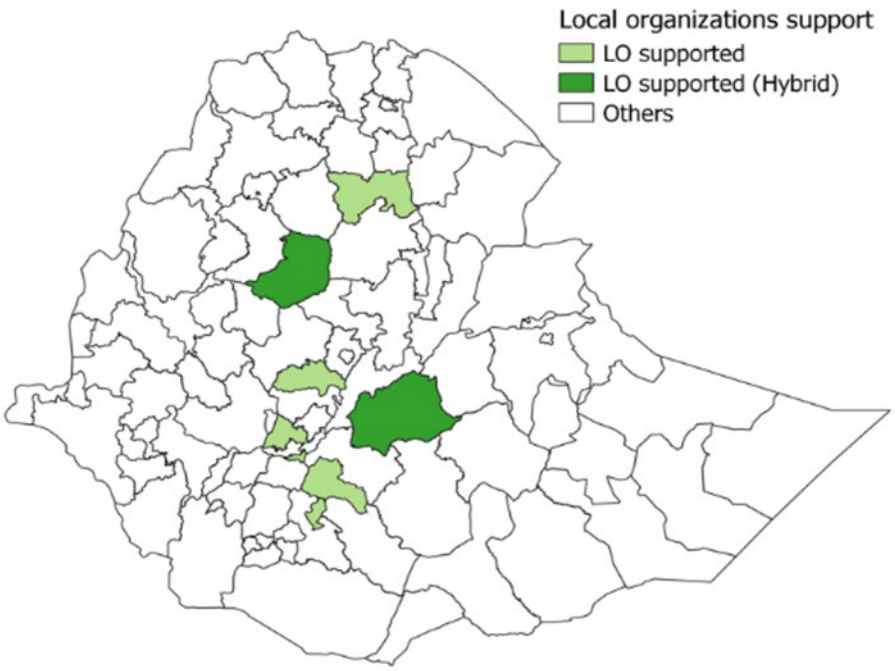

Figure 1. Map local organization-supported zones

Note: Local organization (LO)-supported zones, Southwest Shoa (ODA), North Wollo (ADA), Gedeo and Hadiya (REACH Ethiopia)

During October–December 2020, TB survivors clubs were established at 74 woredas (districts) supported by the three local organizations partners that serve a population of about 17 million people. A total of 84 TB clubs were established with 615 members, with at least one club per district or health facility in a district (table 1). Each TB club has an average of seven members and include people with TB-HIV co-infection. The proportion of females among the TB survivors club was 39%. Only volunteer TB survivors that were on DOTs and declared cured or their TB treatment completed were selected to be part of the club.

Table 1: Overview of TB clubs in districts supported by the Eliminate TB Project's local partner organizations, October–December 2020

Local Organization	# districts	# health centers	# health posts	# TB survivors	
				# clubs	# active members
REACH Ethiopia	34	147	632	33	289
ODA	20	98	468	20	109
ADA	20	121	597	31	217
Total	74	366	1,697	84	615

After the clubs were established, HEWs provided club members with orientation on identification and referral of people with presumed, infection prevention at community level, adherence counseling for TB patients on treatment, and TPT. Consensus was also built on standard operating procedures for community TB activities, health education, and adherence counseling. Club members were also oriented on how to register and report on these activities.

Figure 2. TB survivor club orientating another club at West Shoa zone

RESULTS AND ACHIEVEMENTS

PERFORMANCE OF TB SURVIVOR CLUBS

Active social community mobilization and health education

Quarterly advocacy and social mobilization sessions were conducted, in public gatherings and at schools. Between October 2022 and September 2024, TB survivor clubs conducted 111 community mobilization sessions (figure 3), reaching nearly 30,000 people (9,576 community members and 20,047 students).

Figure 3. Health education by TB survivors at health facility

Referral of people with presumed TB

TB survivors worked with health facility TB focal persons and HEWs to detect and refer people with presumed TB from the community to diagnostic health facilities. This activity was monitored monthly to check the number of people being identified with presumed TB and referred.

TB survivor club members identified and referred 126,428 people with presumed TB to diagnostic facilities between October 2022 and September 2024. Of these referrals, 12,096 (~10%) were diagnosed with active TB. There was an increase in the number of people with presumed TB referred from communities to health facilities. There was a decline in the number and proportion of people with presumed TB identified and active TB cases detected (figure 4).

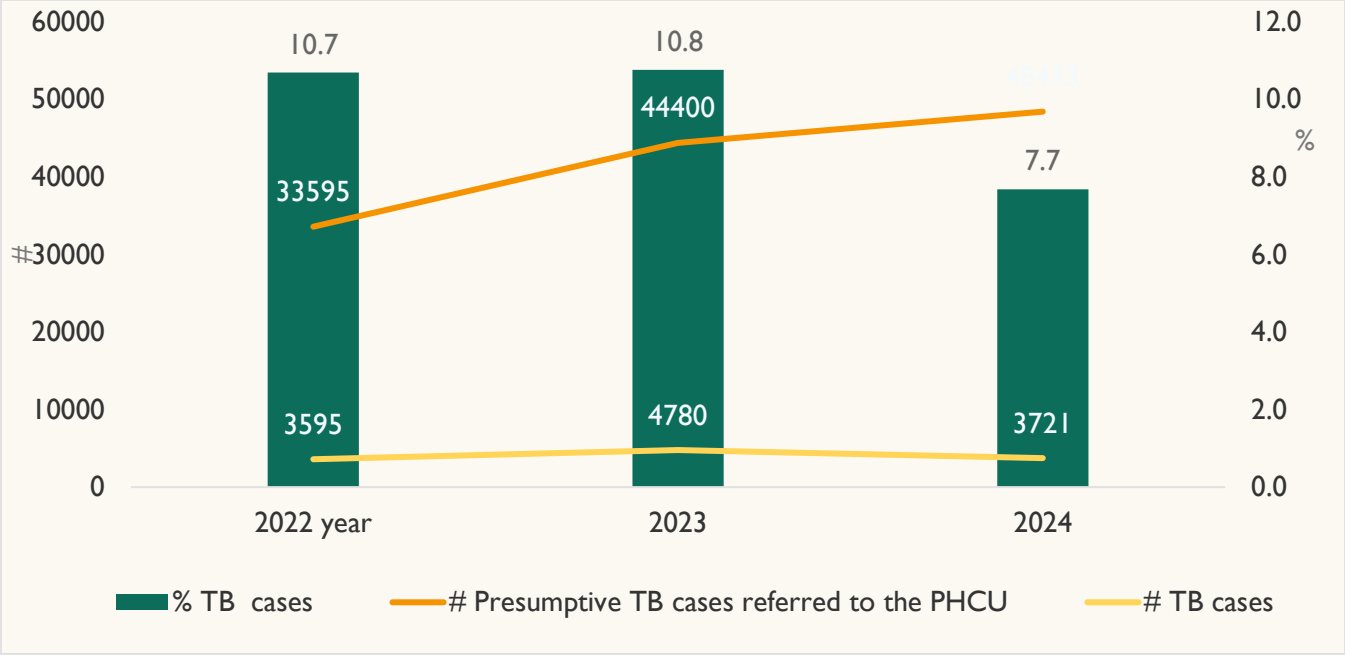

Figure 4. People referred by TB survivor clubs, October 2022–September 2024

Contact tracing and TB preventive treatment

Contact tracing was conducted by TB survivor club members in districts supported by the partner local organizations. The survivors traced 142,486 contacts of nearly 40,000 bacteriologically confirmed pulmonary TB (BCPTB) cases. Of these, 93% were screened, of which 1,280 TB cases (1% of screened contacts) were identified. They also identified 19,692 eligible contacts under 15 years of age and started 16,943 (86%) of them on TPT. The screening rate improved from 84% to 98%, TPT coverage increased from 89% to 95%, and TPT completion rose from 88% to 97% (table 2). The relatively lower TPT coverage in 2023 could be due to the conflict in the northern part of the country, specifically affecting ADA.

Table 2: TB survivors' contribution to contact tracing and TPT, October 2022–September 2024

Indicator	2022	2023	2024	Total
# index cases (BCPTB)	14,369	12,171	12,873	39,413
# of contacts identified around the index TB cases	47,897	45,077	49,512	142,486
# of contacts screened for TB	40,351	44,487	48,297	133,135
% screened	84	99	98	93
# of TB cases detected	339	576	365	1,280
# of children who are household contacts of cases with BCPTB index cases and eligible for TPT (0-14 years of age)	4,470	9,049	6,173	19,692

Indicator	2022	2023	2024	Total
# of eligible children started on TPT (0-14 years of age)	3,968	7,116	5,859	16,943
% TPT (0-14 years of age)	89	79	95	86
# TPT completion (0-14 years of age)	3,492	6,760	5,683	15,935
% TPT completion (0-14 years of age)	88	95	97	94

Club members also volunteered to serve as treatment supporters for some TB patients while they were taking the drugs. TB survivor club members provided adherence support to 1,966 people with drug-susceptible TB (DS-TB) and 199 people with drug-resistant TB (DR-TB). All people who received adherence counseling completed their treatment and were cured, contributing to cure and treatment success rates in the project-supported regions.

TB club members also play an important role in TB prevention by providing adherence counseling for children on TPT. A total of 5,770 children under age 15 on TPT received counseling and completed their TPT (table 3).

Table 3: Adherence support provided by TB survivors clubs, October 2022–September 2024

Indicator	2022	2023	2024	Total
# of DS-TB patients on DOT provided adherence counseling	497	847	622	1,966
# of DR-TB patients provided adherence counseling	68	93	38	199
# of children on TPT given adherence counseling	2,522	2,149	1,099	5,770

Tracing people whose treatment had been interrupted and those lost to follow-up (LTFU) from TB care

A total of 2,369 people whose TB treatment had been interrupted, and those previously LTFU were traced back to anti-TB treatment in the three-year implementation period, of which 444 were children on TPT (table 4).

Table 4: TB survivors traced people whose treatment had been interrupted and those LTFU, October 2022–September 2024

Indicator	2022	2023	2024	Total
# of people whose treatment had been interrupted returned to care	1,367	102	304	1,773
# of patients previously LTFU traced and return to treatment	30	52	70	152
# of children (0-14 years) previously LTFU traced and placed on TPT	105	238	101	444
# overall traced	1,502	392	475	2,369

CHALLENGES

Establishing a TB survivor club requires effort to mobilize and train individuals to join, in a context where many TB survivors are living in poor socioeconomic conditions.

In the Amhara region, the local organization ADA faced major challenges due to ongoing conflict, which affected the implementation of community TB care. However, TB survivors continued providing adherence counseling and served as treatment supporters.

LESSONS LEARNED AND WAY FORWARD

TB survivor clubs play a vital role in addressing TB care at the community level. The engagement of TB survivors has proven effective in raising community awareness, providing health education, referring presumptive cases, tracing contacts, detecting TB cases, and contributing to community TB initiatives. Adherence counseling by survivors improved treatment success rates and completion of TPT. Engaging TB survivors is a feasible and acceptable strategy for reaching high-risk populations, especially in conflict-affected areas, and it enhances ownership and sustainability of the community's TB program. This initiative could be scaled up across other zones and regions to strengthen patient-centered community TB care.

ACKNOWLEDGMENTS

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