I. Introduction

In the Democratic Republic of Congo (DRC), tuberculosis (TB) is a disease that is accompanied by a heavy socioeconomic and health burden. The DRC is among the 30 countries that bear 87% of the global TB burden (1). According to WHO estimates, 270,000 people fell ill with TB in 2018, which translates into an incidence of 321 cases per 100,000 population (1), of whom 31,000 (12%) were people living with HIV. Of the 270,000 people estimated to have TB in 2018, only 171,682 were notified, leaving 100,000 people (37%) undetected by the national health system. WHO estimates that around 53,000 people died from the disease in 2018 (1). TB and HIV coinfection is also a major health challenge in the DRC; according to UNAIDS, the percentage of people living with HIV and receiving TB treatment was 40% in 2017, compared with 22% in 2015 (2). Despite some progress, TB remains the number-one killer of people living with HIV in the DRC.

In order to increase TB detection and improve TB services at community level, the International Union Against Tuberculosis and Lung Disease (The Union) implemented the Challenge TB project, funded by the United States Agency for International Development (USAID) from April 2015 to March 2019, in collaboration with local community organizations. The nongovernmental organization Fondation Femme Plus (FFP) was one of the organizations supported by The Union for implementation in 12 health zones in two provinces, Maniema and Kasai-Central. This case study focuses on the community-based TB activities carried out by FFP in Kasai-Central between June 2018 and March 2019.

2. Description of the problem

Kasai-Central is one of the 11 priority provinces selected by the National Tuberculosis Programme (NTP). The rate of TB notification is extremely low, particularly among children and people living with HIV. It is estimated that 56% of TB cases were undiagnosed and untreated in 2018, detection of TB cases had stagnated for more than 10 years (1). The distance from the TB diagnostic and treatment centres (Centre de santé de diagnostic et de traitement) is a major obstacle.
to accessing TB services, in particular for poor populations living in rural areas, who cannot afford to pay for transport to the health centre or for the medical consultation, which costs between 3000 and 8000 Congolese francs (US$ 2–5 at 2019 exchange rates). These logistical and economic barriers are exacerbated among internally displaced populations, who are fleeing interethnic conflicts and live in precarious health situations and, often, in confined spaces, making them more vulnerable to TB. The poor knowledge about TB in the general population and in high-risk groups is also a huge obstacle to TB control efforts (3). According to WHO, 10–20% of TB cases occur in children; however, the detection rate in children from birth to 5 years, living in the same household as a parent with TB, is very low in the DRC (4); as a result, only one child in four is placed on TB preventive treatment and infant mortality linked with TB is still high (/). Among people living with HIV who are on antiretroviral therapy, only 39% are on preventive treatment. Developing strategies to improve awareness and find people with TB in the affected communities is essential in order to reduce the number of TB notifications, particularly among children and people living with HIV.

3. Proposed solutions

FFP is a community-based organization which has specialized in community mobilization and psychosocial support for people living with HIV for over 25 years. Although TB awareness messages have been an integral part of FFP’s work from the start, it was not until 2013 that community-based TB screening was added to the service package for people living with HIV, as part of the implementation of the WHO ENGAGE-TB approach. The Challenge TB project in 2015 enabled FFP to capitalize on these lessons and good practices and to replicate them in Kasai-Central.

Involvement of key stakeholders

As part of its community mobilization activities for TB in the province of Kasai-Central, FFP has focused on finding missing people with TB in the communities around 28 health centres with TB services (out of a total of 98 in the province), covering eight of 26 health zones. Before the activities were implemented, FFP approached the health authorities, in particular the Provincial Leprosy and Tuberculosis Programme of Kasai-Central (a provincial body of the NTP), the provincial coordinator of the National AIDS Control Programme and the district medical officers, to identify the different stakeholders that needed to be involved when carrying out TB activities at community level: civil society and community-based organizations, opinion leaders, village heads (in rural areas), neighbourhood representatives (in urban and periurban areas) and heads of local authorities (e.g. mayors). Advocacy was conducted in advance with these key players at both provincial and local level, to ensure their support during implementation.

In collaboration with the local TB programme, FFP recruited 112 community mobilizers. The mobilizers were mostly men (70%) and came from the targeted communities; they included former TB patients, people living with HIV and leaders from local community-based or faith-based organizations. Training was provided jointly by trainers from the Provincial Leprosy and Tuberculosis Programme and FFP. The training curriculum, based on the Integrated Tuberculosis Programme in Primary Health Care (PATI V), was the same curriculum used for institutional community health volunteers in the DRC (locally referred to as relais communautaires or “RECO”). In addition to the general concepts of TB, the training focused on community-based approaches to the management of TB, household contact tracing and home visits, safe sputum collection and transportation, community mobilization and awareness of TB, including action against stigma and discrimination, and advocacy targeting health-care providers and community leaders. Once trained, community mobilizers were linked with health centres (four mobilizers per centre); their activities covered the whole cascade of HIV and TB services, including TB prevention, coinfection, screening, referral and treatment support. The populations targeted by these activities were local communities in general, prisoners, pregnant women (in the context of prenatal consultations), miners, communities not covered by the TB diagnostic and treatment centre and TB contacts.

Household contact tracing

As systematic contact tracing has proven to be a particularly effective approach for improving TB prevention in affected households and identifying people with TB, especially in children and people living with HIV, a targeted strategy was implemented in collaboration with the health centres. Whenever a person was diagnosed with TB by the health centre, and he/she gave the corresponding agreement, the information was shared with the community mobilizers and they visited the home to screen household contacts. The mobilizers used a standard questionnaire to identify people with symptoms of TB and referred or accompanied them to the health centre; if the person was not well enough to go in person, mobilizers collected the sputum on-site and transported it to the laboratory. These home visits were also an opportunity for the mobilizers to educate family members on TB prevention within the household.

Additional data from the National Strategic Plan for Tuberculosis Control 2018-2021.
Focus on children and people living with HIV

To address the high notification gap in children and people living with HIV, the mobilizers focused particularly on these two populations. When the index case was HIV-positive, the mobilizer recommended that the children in the household be systematically screened for HIV and referred or accompanied them to the nearest health centre. Whether or not they were living with HIV, children under the age of 5 years with no symptoms or clinical signs of TB were systematically referred to a health centre for a period of six months. For children with symptoms of TB, the mobilizer referred them and/or accompanied them to the nearest diagnostic facility. When TB was confirmed within the household, the community mobilizer systematically performed a rapid HIV test (if the reagents were available) or referred the person to a health centre to be tested. For people living with HIV in the household of an index case, starting TB preventive treatment was systematically advised, after exclusion of active TB. As the diagnosis of TB is more difficult in people living with HIV, who are frequently asymptomatic and often cannot produce sputum, mobilizers advised them to watch out for the clinical signs of TB: prolonged fever, night sweats, cough, physical weakness, anorexia and continuous weight loss, shortness of breath and chest pain. Screening for TB in people living with HIV was carried out regularly, every six months or when one of the clinical signs of TB appeared, either by mobilizers or at the health centre.

Consultation at a reduced price

People with presumptive TB who were referred to a health centre for TB screening received an FFP referral voucher from the mobilizers, which gave access to the medical consultation at a reduced price (e.g., 1500 Congolese francs instead of 3000). Once TB is diagnosed, people in the DRC receive free TB treatment.

Treatment adherence and psychosocial support

All people diagnosed with TB received HIV counselling. When TB/HIV coinfection was diagnosed, antiretroviral therapy requiring a single daily intake was recommended, to improve TB and HIV treatment adherence. Once TB treatment was initiated, the role of mobilizers focused on supporting people in improving their therapeutic compliance. The mobilizers provided both psychosocial and treatment adherence support. Through regular home visits during the initial phase of TB treatment, community mobilizers ensured that the treatment was taken correctly; they then identified and prepared a person within the family to provide continuous treatment support. When necessary, mobilizers also provided nutritional support and/or addressed stigma and discrimination, sometimes within a single household, to improve the quality of life of the person with TB. In addition to the activities at household level, community mobilizers also conducted mobilization and TB awareness-raising campaigns within the affected communities, as well as among community-based organizations of people living with HIV.

4. Outcomes

Between January 2018 and March 2019, the activities implemented by FFP in Kasai-Central enabled the identification of 2421 people with TB, contributing 88% (2421/2740) to the total TB notifications in the targeted areas in Kasai-Central. (5). TB detection in the FFP intervention areas of Kasai-Central had increased from 598 people in 2017, of whom 531 (88%) had been screened by FFP community mobilizers, to 1660 people in 2018, of whom 1449 (87%) had been screened by FFP (5). The activities implemented by FFP at community level were shown to be particularly effective, as they more than doubled the number of people with TB diagnosed and treated.

Key results

Between January 2018 and March 2019, community mobilizers deployed by FFP in Kasai-Central referred a total of 21,554 people with presumptive TB in the eight health zones; 2421 (11%) of these people were diagnosed with TB.

As part of active case-finding activities among TB contacts, FFP community mobilizers systematically investigated 1277 index cases indicated by the health centres. A total of 27,903 contacts were identified and informed, and 10,273 of them benefited from a home visit by a community mobilizer; an average of eight contacts were visited per index case. As a result, the mobilizers referred to the health centres 7639 contacts with presumptive TB (36% of the total of 21,554 persons with presumptive TB referred by the mobilizers), and 1041 (14%) of them were diagnosed with TB, translating into 43% of the total number of persons with TB identified through the intervention (1041 out of 2421).
Community mobilizers collected and transported to the health centres a total of 9692 sputum samples, 10% of which tested positive for TB. The time gap between detection and initiation of TB treatment was on average four days. An additional 253 sputum samples were transported to the laboratory for the purpose of treatment monitoring. According to the FFP team, community mobilizers noticed a rapid improvement in TB awareness within the targeted communities. Certain false beliefs, such as the perceived link between TB and witchcraft, were replaced by correct information about TB, which enabled people infected with or affected by TB to improve their health-care-seeking behaviour. Also, some people from the community came spontaneously to seek the FFP referral voucher in order to access the medical consultation at a reduced price.

5. Lessons Learned and Challenges

Distance from TB services
The long distance between communities and health facilities was a major challenge for the people involved in the intervention, both the community mobilizers and the people referred to the facilities. No transport incentive was provided for community mobilizers as part of this intervention because of a lack of funding. Transport costs should be budgeted for in future interventions.

Sociocultural barriers
Community mobilizers encountered certain sociocultural barriers while carrying out their activities, such as the community’s ignorance of human rights and health, particularly with regards to access to care, and poor knowledge of the modes of transmission and prevention of TB.

Economic barriers
Community mobilizers also identified economic barriers within the community. In fact, the heaviest burden is placed on poor households, in which people with presumptive TB referred to a health facility did not have the resources to pay for a consultation. The FFP team noted that reducing economic barriers, through a referral voucher allowing consultations at reduced cost, can be key in improving access to health services, especially for people experiencing extreme poverty. As part of the intervention, FFP negotiated lower consultation charges for people with presumptive TB referred by community mobilizers; the negotiation proved more difficult with private faith-based health centres than with public ones.

Stockouts at health facilities
The frequent stockouts at the health centres also affected the implementation of FFP activities. Shortage of reagents and drugs hampered HIV testing and the diagnosis of coinfections, the treatment of opportunistic infections and the provision of preventive TB treatment. This particularly affected TB/HIV coinfected people and children under 5 years.

Collaboration with local authorities
Support from the political and administrative authorities greatly facilitated the implementation of activities; in particular, it ensured good collaboration with the health facilities, which was indispensable for the implementation of household contact tracing by the mobilizers. The close collaboration between FFP, NTP and the National AIDS Control Programme, through their provincial coordination offices, facilitated both the implementation of the activities and the monitoring and evaluation of the intervention, particularly through joint supervision visits and data validation workshops.

Profiles of community mobilizers
The diverse profiles of the community mobilizers, ranging from community leaders to people living with HIV and former TB patients, ensured endorsement of the intervention by key community actors and improved sustainability.

Household contact tracing
Among the different activities implemented by FFP (awareness campaigns, etc.), contact investigation around index cases was the most effective approach in finding missing people with TB. This activity often allowed several people with TB to be detected within the same household. This success was achieved, among other things, by involving and informing those close to the index case, as they are the ones most committed to the well-being of the people in their household.

Specimen transport
The health centres often do not have the diagnostic capacity to analyse the samples collected for diagnostic or treatment monitoring purposes and diagnostic centres can be very far from health centres. Sputum transportation by community mobilizers helped to compensate for the long distances that often separate diagnostic facilities from the health centres.
6. Conclusion

In countries with a heavy burden of TB and limited access to care, the so-called “passive” approaches to detecting TB at health centres produce inadequate results, leaving a large number of people with TB still missed by the health system. The implementation of active case-finding strategies at community level is not only instrumental in finding missing people with TB, but also raises awareness in affected communities and households, addresses misconceptions and improves care-seeking behaviour. In addition, the existence of community-based activities targeting people living with HIV constitutes an opportunity to integrate TB into these activities and to build on the existing expertise and services. The HIV/TB integration strategy implemented by FFP is one of the key principles advocated by WHO in the ENGAGE-TB approach and has been proven to work in the DRC, where the next step should be the scale-up of active case-finding at community level and the integration of TB/HIV activities in the 11 provinces identified by the NTP where TB detection is particularly low. The mobilization of actors and stakeholders at all levels will be essential to make this scale-up a reality. According to FFP’s experience, this requires continuous advocacy with health and political authorities, to promote ownership of the interventions, as well as capacity-building among community leaders for greater involvement in the fight against TB. Collaboration between local authorities, health centres and community actors is a key prerequisite for implementing community-based services and must be systematically pursued, in particular to harmonize the training of community actors, coordinate supervision of activities and improve data validation and quality.

3 Rapport d’évaluation rapide sur les aspects liés aux populations clés et à l’environnement légal dans la lutte contre la tuberculose en RDC [Rapid evaluation of aspects of key populations and the legal environment of tuberculosis control in DRC]. Kinshasa: Club des Amis Damien (CAD) and Stop TB partnership; 2018.