Supporting families with tuberculosis during COVID-19 in Khayelithsa, South Africa

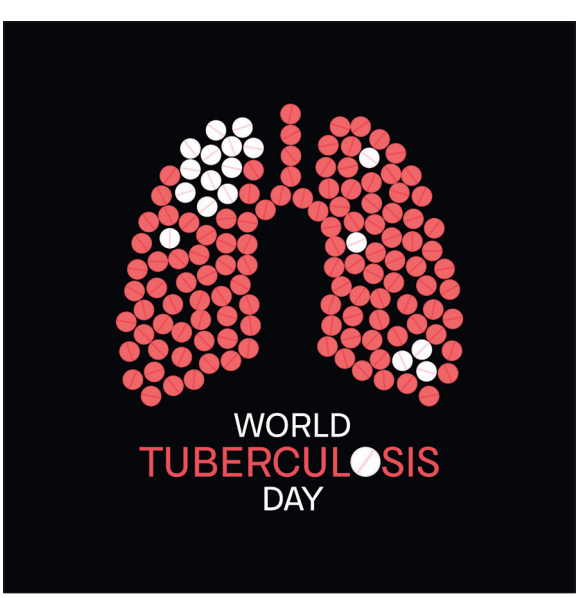
"When the lockdowns first started, we thought it was the worst thing that could happen to our family", recalls Esihle (not her real name), her eyes shining with tears. "We could not work, you see, and without any money coming in, we all had to move back home to my mother's place. My brothers did too, all of us, with all of our children. There were nine of us living in that one small shack! But then my brother started to cough and I did too, and things got much, much more difficult for us all."

Esihle's story is one that is all-too common, reflecting the lived experiences of families all over the world, whose tenuous socioeconomic circumstances were frayed by the public health measures put into place to stop the spread of SARS-CoV-2. But while the world's attention was diverted elsewhere, another respiratory infection—tuberculosis—was thriving, perversely enabled by the steps taken to stop COVID-19. It is well documented that tuberculosis transmission occurs within households and is exacerbated by poverty, malnutrition, and overcrowding, conditions that all ballooned in magnitude as public health measures aimed at mitigating COVID-19 were enacted. Add to that the fact that health-care systems were challenged in dealing with COVID-19—forced at times to limit numbers, close entirely (leaving sick people with nowhere to turn), or reassign staff to COVID-19 activities (leaving other vital programs unstaffed), and the perfect storm for worsening the TB pandemic occurred. As the number of people diagnosed with and started on treatment for tuberculosis plummeted, tuberculosis transmission likely increased, since the best infection control measure for stopping the disease is the rapid identification and initiation of therapy for those who are sick. Nobody who was paying attention could, therefore, claim to be surprised when the WHO announced that, for the first time in more than a decade, deaths due to tuberculosis rose in 2020.

In the South African city of Cape Town, the same problematic pattern was being witnessed, with a disturbing drop-off in tuberculosis diagnoses and treatment initiations. This was a particularly concerning trend for severe and drug-resistant forms of tuberculosis (DR-TB), which are common in many of the townships surrounding the city, including Khayelitsha, where Esihle and her family live. Khayelitsha is home to a population of an estimated half a million people, and with almost 200 people being diagnosed with DR-TB annually, it is considered one of the world's DR-TB hot spots. The health authorities (City of Cape Town and the Provincial Department of Health of the Western Cape) have been responding to the DR-TB pandemic in a number of ways over the years, including through a long-standing partnership with the medical humanitarian organisation, Médecins Sans Frontières (MSF). Actors from these public–private collaborative groups quickly sprang into action to try to address the negative impact of COVID-19 on DR-TB.

Early efforts were aimed at improving infection control practices in the clinics as well as providing health promotion and education about signs and symptoms of COVID-19 and tuberculosis. Providing integrated tuberculosis and COVID-19 screening and testing was also a key pillar of the early phases of Cape Town's TB recovery plan enacted in Khayelitsha, as were activities aimed at supporting clinic staff to be able to stay engaged with tuberculosis-related work, even as they continued to respond to COVID-19. But when it became clear that even with these interventions, both tuberculosis and DR-TB were still not being diagnosed at pre-COVID-19 levels, the partners utilised their existing community-based networks to shore up DR-TB outreach activities focused on households.

The joint programme aimed to provide diagnostic, treatment and preventive services for DR-TB within the households of persons newly diagnosed with the disease. As part of this package of services, people newly diagnosed with DR-TB were offered clinic- or phone-based counselling and support to disclose their DR-TB status to members of their household. Permission was sought from the newly diagnosed individual to arrange for a visit in the household so that screening and diagnostic activities for people living together could take place. Most people newly diagnosed with DR-TB agreed, and the health teams—usually, at first, a single nurse who could then also request additional support from lay counsellors, community health workers,



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For more on the **spread of COVID-19** see **Commission Statement** *Lancet* 2020; **396:** 1102–24

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For the **WHO Global Tuberculosis Report** see https://www.who.int/publications/i/item/9789240037021/

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For more on **outreach activities** see *Int J Tuberc Lung Dis* 2021; **25:** 587–89

For more on **preventive therapy** see **Comment** *Lancet Child Adolesc Health* 2021; **5:** 159–61

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For more on **tuberculosis and COVID-19** see **Spotlight** *Lancet Respir Med* 2022; **10:** 231–33 and **Spotlight** *Lancet Respir Med* 2022; **10:** 233–36

and a physician, if needed—then arranged to visit homes at a date and time convenient for the family. Doing household visits reduced clinic travel costs for families, allowed for assessment of psychosocial and economic vulnerability, and contributed to building trust between the health-care team and the households.

Activities conducted during the household visit focused on children, adolescents, and vulnerable adults and included: 1) documenting all persons aged 18 years and younger residing in the household both at the time of the visit and in the month preceding the diagnosis; 2) counselling aimed at stigma reduction, tuberculosis education, and support through the diagnosis and treatment processes; 3) weighing all family members to assess for possible weight loss (adolescents and adults) or changes in growth trajectories (children); 4) performing a basic physical examination; 5) offering HIV counselling and testing for willing family members; 6) screening for tuberculosis symptoms (including cough, fever, weight loss, night sweats, lethargy, or reduced playfulness in children); 7) facilitating planned referral for persons with possible tuberculosis to clinics as needed for a full medical assessment and chest radiography; 8) collecting sputum or stool samples for tuberculosis testing among those with symptoms; 9) coordinating follow up and providing results; and 10) initiating preventive therapy for DR-TB among those who qualify for such treatment and in whom active DR-TB had been ruled out.

Although formal analyses are ongoing, the programme has been perceived as a success overall. Almost 300 individuals have been reached through these family-focused activities since the community household programme became fully operational in September, 2020. Those who have benefited the most in terms of improved diagnosis appear to have been children. In the years before the COVID-19 pandemic, paediatric DR-TB represented less than 5% of the overall DR-TB burden in Khayelitsha, with fewer than 10 children diagnosed each year. Since full implementation of the community-based, family-focused programme, however, 33 children have been diagnosed and started on treatment, representing almost 15% of those treated for DR-TB in Khayelitsha. This is a notable achievement at a time when in almost all other settings and populations, DR-TB diagnoses and treatment initiations have gone down. Almost all of these paediatric patients had non-severe disease and a majority have been able to be fully treated in the community (through a combination of home and primary care clinic visits) with child-friendly approaches, including paediatric formulations of medications.

Improvement of paediatric DR-TB diagnosis has been a significant achievement for the family-centred programme in Khayelitsha; an equally important aspect of the work has been the ability to care for children with DR-TB in their homes and communities. Although South Africa has been a global leader in the decentralisation of many types of care for DR-TB, the treatment of children has been stubbornly entrenched in a only few tertiary facilities around the country. Such highly centralised care for children often means they are kept away from their families, schools, and support systems for prolonged periods of time, which can have major negative psychological and social consequences. In Khayelitsha, the care of children with DR-TB was done largely by primary care physicians and nurses, who could be supported remotely by experts when needed. A multidisciplinary team led by an MSF social worker also helped address the other health and social needs the children and their families faced during these trying times.

Although the absolute numbers of children diagnosed and treated is small and the programme has encountered barriers—including the availability of vehicles and fuel to transport staff as well as adapting best practices to protect staff and families from COVID-19 transmission while out in the community—it is one model of how partnerships between government services and a non-governmental organisation can be utilised to enhance tuberculosis recovery efforts, especially for populations at high risk. It also illustrates the value of moving tuberculosis diagnosis, prevention, treatment, and support efforts away from facilities and into the community. The experience also revealed ways in which the health-care system needs to be fortified—through investment in continuing education and support for staff at all levels, enhanced planning for service provision, and adequate supply chain and logistic mechanisms to protect health-care workers—to continue providing those services that must still be delivered in health-care facilities.

Although there were some initial concerns that people living with DR-TB would be reluctant to be visited in their homes, most of the people living with DR-TB who participated in this project were enthusiastic about these efforts. As Esihle reported, "When I started to cough too, we were all so scared. We thought it was COVID, but when I finally went to see the doctor a few months later, we found out that I actually had DR-TB. The counsellors asked if they could come to our home and talk to my family, and I said they could, even though I was ashamed for them to see the way we were living. But the nurses and counsellors who came to our home—we owe them our lives. They found out that three of the children also had DR-TB and were able to start them on treatment too. And they helped get my brother to the hospital. I don't know what would have happened if they had not come."

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