Children as Caregivers

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I returned to George Health Centre in June 2014, after a six-year absence. When I left in 2008, the TB Corner was in transition, moving out of the open-air carport, a space it had occupied temporarily each day for several years. At that time, an international NGO was building a new, permanent TB Corner, on an open plot of land, close to the entrance of the Health Centre but tucked away from the daily hubbub of clinic activities. By 2014, this new TB Corner had been in use for years. I arrived to see it for the first time late on a Monday afternoon, well after the daily drug distribution had finished. I walked, together with Olivious, through its open doors and into the large room where patients and their family members sat each day while waiting to receive their medication. This room took up most of the space in the building, and there were two smaller offices used by staff, visiting researchers, and for more private conversations.

For just a moment, Olivious and I were the only people in the room. We stood together, feeling a cross breeze blow through windows. The permanence of the concrete walls struck me. TB had a location. The TB nurses and TB treatment supporters no longer had to haul paper charts, medicine bottles, benches, and tables out of storage each morning and into storage each afternoon. They had not done so in years. Sleek educational posters hung on the walls, alongside carefully handwritten signs that offered instructions to staff, volunteers, and patients. Files were arranged on wooden shelves that hung on the wall next to the table where the TB nurse sat as she called up each patient.

The blue plastic cover on the nurse’s table caught my eye. It read ZAMINDS—referring to the Association of Medical Doctors of Asia—Multisectoral and Integrated Development Services, an organization funded by the Japanese government that has carried out many TB projects with George Health Centre. I
looked at the Zambian Government and ZAMINDS logos that were printed across the cloth and was reminded of how public-private partnerships and multilateral funding shaped the Health Centre’s ability to treat the many people suffering from TB. Then I noticed something about the patients treated through this particular project. They were children. Not only did TB have a permanent location in the clinic; children had a place in this location.

In October 2013, the World Health Organization released its first ever roadmap for the prevention of childhood TB. This marked a substantial shift from the adult-centricity of most medical and public health programs on TB. The roadmap—a thirty-eight-page report that offered guidance and resources—called childhood TB a missed opportunity:

Many children who present with TB disease represent an opportunity missed by the health system to have prevented the disease. This is particularly the case for infants and young children: studies consistently show that most cases of TB in children occur in those with a known contact who has been diagnosed with TB, which is frequently a parent or another close relative of the child. Infants and young children are at particularly high risk for severe, disseminated TB disease and for TB-related mortality. And yet it is all too common to have the child of a parent who has TB to present with TB meningitis, which is frequently fatal, and if not, often results in marked and permanent disability. This could be prevented by screening children who are contacts of people diagnosed with TB and by providing preventive therapy for children younger than five years of age at the time TB is diagnosed in a parent or family member. (World Health Organization 2013, 11)

In certain ways, this focus on missed healthcare opportunities was responding to the pleas I heard from guardians in George, who expressed concerns over what would happen if their children became sick with the disease. The guardians wanted the clinic to do more to help prevent TB transmission to their children. The WHO’s focus also responded, very belatedly, to a study conducted in Zambia from 1997 to 2000, in which researchers at the University Teaching Hospital carried out autopsies of children who had died with respiratory disease. These autopsies showed a high rate of undiagnosed TB disease in the children (Chintu et al. 2002). Another article, published just prior to the release of the WHO’s Roadmap for Childhood Tuberculosis, reasserted the need for better prevention of childhood TB in Zambia and also better diagnostic and treatment services for children with active disease (Kapata et al. 2013).

Floyd Makeka, a lead TB treatment supporter whom I have known for years, came out of the TB Corner’s back office. My unfamiliar presence in the space seemed to make him, too, see the many changes that had occurred through the years. The three of us walked around the room. We chatted about our health and
our families. Olivious had married, had a son, and moved away from George since the last time she and Mr. Makeka met. Mr. Makeka’s children were small when I knew him. They were grown now. His wife continued to have back problems but was, generally, in good health. With the help of their children, she had started a new business selling grilled fish and meat in the evenings. Mr. Makeka was busier than ever at the TB Corner. Still, the household struggled to make ends meet. TB treatment supporters such as Mr. Makeka are considered volunteers, receiving small stipends, or no stipends at all, for work that requires tremendous amounts of time as well as physical and emotional energy, and also carries risks.¹

Mr. Makeka took me into the office to introduce me to the new TB nurse, Mercy Mwale. Ms. Mwale, it seemed, brought energy to the Corner that matched the hope radiating from its walls. Upon learning about my previous work with the children, she grew serious. They were struggling to serve children who had TB, she said. According to their records, there were thirty-eight children (from newborns up to sixteen years old) with active TB that needed treatment from the Corner. Twenty-four more children were on isoniazid preventive therapy to treat latent, or inactive, TB infections.

One year prior to my visit, and with the help of ZAMINDS, the TB Corner established Friday as the designated day to treat children. While the pediatric TB day and extra supportive services that the project provided had benefits, the project was coming to an end, and it had exposed the complexities of social issues involved in treatment. Not all children’s guardians collected the children’s medicines regularly, and the clinic workers struggled to get guardians to return. The Friday schedule offered one way of focusing just on children’s special needs. It seemed like this was a good thing in their opinion, but it also represented a burden when adult household members were also on treatment and needed to come to the clinic on other days to collect their medication. Older children sometimes came alone, and these children seemed to do okay, at least with collecting the medication. The entire process of scaling up services to children revealed even further what both Ms. Mwale and Mr. Makeka already knew: a range of social and economic factors structure who gets treatment and who does not in resource-poor settings.

The international focus on childhood TB has created new types of TB patients—children. The international scramble to diagnose and treat children with TB is vital. However, child-specific diagnostics and treatments, alone, will not solve the problem. Without adequate institutional and economic resources, children and their family members will continue to do much of the work of supporting treatment, this time for children. Children’s chances on TB treatment, just as the chances of the sick adults whom I wrote about throughout this book, will depend on the contingencies of their relationships.
The new focus on children raises many questions: For example, what will it mean to be a child, or family member of a child, diagnosed with TB, a disease with a long and complicated history? How will TB diagnosis reflect on a child’s personhood and life prospects and on the personhood and life prospects of other family members, particularly family members who have suffered from the disease? How will treatment shape the interdependence between children and specific adults? What types of work are children doing to support their own treatment and the treatment of siblings? What are the implications for women’s livelihoods and security? Who will receive blame if treatment fails?

Answering these questions will be critical to determining the directions that TB programs need to take and the institutional supports needed to assist children and their families. The answers are not found in boardrooms of international organizations or in large-scale epidemiological studies. They rest heavily on an understanding of the forms that care takes in particular settings and how these forms transcend the boundaries of home, clinic, and nation, and change through time. Such answers, as I have argued throughout this book, demand an ethnographic approach to illness that underscores children’s actions, relationships, dependencies, and interdependencies.