



Introduction

Maureen Nkhoma opened her eyes as I walked into her yard. Grabbing ahold of the well-worn quilt that covered her, she raised her head to acknowledge me. Her children, eight-year-old Loveness and twelve-year-old Bwalya, were hanging laundry nearby. She directed them to prepare the sitting room in their three-room house. “Outside is no good for a visit,” she told me, as the wind swept dirt from the bare ground. It was a crisp August morning in Zambia’s capital city, Lusaka.

“Get in,” Maureen said, when she saw me hesitate at the door to her house. I had been watching her as she rose slowly on legs weakened from extended sickness and disuse. She walked toward the house with her gaze to the ground. Each uncertain step she took was filled with an effort that, I realized only later, she did not want me to see. At her insistence, I went into the sitting room ahead of her and took a seat across from Loveness and Bwalya. We sat in silence until Maureen joined us.

Maureen had tuberculosis (TB), a diagnosis that came after months of weight loss, fever, and night sweats, and a cough that had lingered for much too long. For the past thirty years, TB has ranked among the most pressing infectious diseases in the world, its presence and deadliness driven by political upheaval, public health neglect, poverty, and under-resourced healthcare systems, and made so much worse by the emergence of the HIV epidemic.¹ Globally, an estimated 9 million people become sick with and 1.5 million people die from the disease each year (UNOPS 2015).²

TB transcends national borders.³ Globalization has increased the mobility of people, and complicated notions that TB—or any infectious disease—will remain confined to a particular nation or region. At the same time, TB offers a stark example of how global politics and policies have carved up the world in unequal ways, structuring who suffers from infectious diseases, who gets treatment, and

who recovers.⁴ Ninety-five percent of the deaths attributed to TB, for example, happen in middle- and low-income countries (World Health Organization 2015).

HIV and TB are an especially lethal combination in resource-poor areas. In Zambia, where Maureen Nkhoma lives, the incidence of TB rose dramatically in the 1980s, and in conjunction with the emergence and growing presence of HIV.⁵ Debt to external lenders along with international policy reforms were gutting Zambia's healthcare system during the 1980s and 1990s, leaving the country unequipped to deal with the dual epidemic. TB medications ran short in Zambia during the latter part of the twentieth century. Antiretroviral therapy (ART) for HIV was unavailable to most people in the country until 2004, the year that ART was rolled out in government health clinics. People with HIV died ugly deaths, and these deaths were often the result of TB.⁶

Maureen's family was preparing for Maureen's funeral, her aging mother told me, when "everything changed." After months of undiagnosed illness, Maureen was hospitalized and tested positive for HIV. She was diagnosed with TB two weeks later, after her condition continued to decline while in the hospital.⁷ In previous years, both diagnoses would have affirmed the family's concerns that Maureen would soon die. However, by 2007, the year that Maureen was diagnosed, medications for TB and HIV were widely available in Zambia at no cost to patients.

The new availability of no-cost medications for HIV and TB was not unique to Zambia. At the turn of the twenty-first century, significant global shifts in treatment policies, global markets, and funding streams were reconfiguring access to treatment around the world.⁸ These shifts offered Maureen, like so many of her contemporaries in Zambia and elsewhere, hope for a "second chance at life" once diagnosed.⁹ Second chances, though, are not a given in this new treatment-focused environment. As anthropologist Susan Reynolds Whyte has observed in the context of the rollout of ART in Uganda: "To realize the second chances, care must be given and taken continuously" (2014a, 2).

On the day that I visited Maureen and her children, Maureen did not yet know if she would have a second chance at life. She labored to reach the room where I waited with Loveness and Bwalya. When she finally arrived, she sank in exhaustion into the cushions of an overstuffed chair. After catching her breath, she glanced approvingly around the room. The walls were crumbling and couches threadbare. Yet, the concrete floor was swept and polished in a deep red. I noticed with embarrassment that the only traces of dirt were in the shapes of my own shoe prints. The tables were dust-free. Decorative cloths were freshly laundered and carefully draped over each couch cushion. I followed Maureen's gaze as she inspected each item in the room in turn, and then she turned to address me.

Connecting the condition of the room to the state of her care, Maureen said: "The children are taking good care of me. People would think it is the elders who

are helping and cleaning the place, but it is the children.” Maureen drew attention to the quality of her children’s care. The children were not just taking care; they were taking good care of her. Their care was so good that people would think it was “the elders.” The elders—her mother, brother, and other adult relatives—were not able to take such good care. They, too, had their own care needs and demands on their time. Months later, after Maureen completed more than eight months of TB treatment, she observed that her recovery from TB—her second chance at life, to use Whyte’s phrase—was due, in large part, to her children’s care.

A taken-for-granted assumption has shaped much global health research and policy work on infectious diseases around the world. This assumption is that adults, young or old, give care to the sick—an assumption that dismisses the many children who also give care to the sick. For example, millions of children in sub-Saharan Africa are estimated to provide some level of care as a result of the HIV epidemic.¹⁰ More thoroughly discussed in the context of the HIV epidemic is the crisis of care that HIV has created for the children after their guardians have died.¹¹ The availability of treatment for HIV has helped raise life expectancy in heavily HIV-affected areas from what it had been before treatment. As a result, many children in sub-Saharan Africa and beyond now live with adults who benefit tremendously from medications, and yet face recurrent care needs.

Children as Caregivers takes the transition to and continued pursuit of universal treatment for TB and HIV as a critical moment in which to examine care between children and their ill family members. This book is set in a particular place, a poor urban settlement in Zambia, which has one of the highest rates of infectious disease in the country. The stories I tell in the following pages took place at a time (2005 to 2008, with follow-up research in 2014) when the delivery of health services to people with TB and HIV were changing many things about what it meant to receive such diagnoses. Yet residents were, and still are, grappling with the devastation the diseases wrought in their settlement during prior decades. Even with medications, deaths from TB and other HIV-related causes continue.

At its heart, *Children as Caregivers* is about how intergenerational care happens when infectious disease becomes woven into structures, relationships, and the rhythms of day-to-day life.¹² The argument I present throughout this book is that a focus on children’s care for and by sick adults offers much-needed insight into global health problems and programs. This is no small argument; billions of dollars each year are invested in global health programming.¹³ My argument has three interrelated themes. First, global processes, policies, and programs do not just affect children. They are also transformed by the intimate and everyday acts that occur between children and their family members.¹⁴ In this respect, a study of care between children and their sick guardians can offer needed perspectives

on larger political economic shifts, among these the increasing urbanization and feminization of poverty, brutal cuts to governmental healthcare spending, the uptick in magic-bullet approaches targeting specific diseases and groups, and the significant presence of non-state actors in the provision of services in middle- and low-income countries.

Second, a focus on relations between young children and ill persons offers important insight into the forms that care and sociality are taking within settings affected by high rates of infectious disease. Specifically, within recent infectious disease epidemics and outbreaks, target group categories such as orphan and vulnerable child, street child, and child-headed household have become the focus of media attention, humanitarian work, and academic research. By highlighting children's loss and isolation, such categories suggest that abandonment and isolation are what script children's lives. A focus on children's everyday interactions and relationships not only contextualizes their lives, but also honors the dependencies and interdependencies they cultivate and the meanings of such dependencies to their own and other peoples' lives.

Finally, children shape and are affected by global health, humanitarian, and medical programs, even when such programs are designed to exclude children. The global systems of public health and biomedicine are always contextualized pursuits, as Julie Livingston has shown in her study of cancer treatment in Botswana. Everywhere in the world, Livingston has reminded us, "doctors, patients, nurses, and relatives tailor biomedical knowledge and practices to suit their specific situations" (2012, 6). Part of seeing children as social actors is acknowledging that they, too, tailor global health, humanitarian, and biomedical systems of knowledge and practice to their particular circumstances, and as a means to make life more livable for themselves and other people. Understanding how they do so, I argue, is central to making policies accountable to children's circumstances and more relevant to their daily lives as well as the lives of their family and community members.

I have chosen to focus on TB, a disease that is overshadowed by HIV in social science research on children in sub-Saharan Africa. A study of TB in sub-Saharan Africa is in one sense a study of HIV, but from a different angle. While many illnesses and other ailments are viewed as signs of HIV's presence, TB strongly indexes HIV, even in the absence of a positive test result. With the increasing presence of ART, a biomedical TB diagnosis has also become the time when many people receive HIV diagnoses because of policies of direct HIV testing after TB diagnosis.

A study of TB offers much more than a lens onto the HIV epidemic. TB is the target of one of the farthest-reaching standardized global health interventions: the World Health Organization's (WHO) directly observed treatment, short-course (DOTS) strategy. DOTS has increased the availability of no-cost, outpatient TB

treatment around the world and introduced a range of practices for monitoring treatment. Zambia reached 100 percent “DOTS coverage” in 2003 when all TB treatment programs run out of government health centers were based on the DOTS principles of testing, treatment, medication, observation, and reporting. The country’s embrace of DOTS has precipitated a number of public-private partnerships aimed at treating the disease within the DOTS model.

Treatment coverage does not necessarily mean that medicines are accessible, nor should it imply that treatment adherence is an uncomplicated process of supplying drugs to the people who need them. As anthropologist Ian Harper (2006) has observed in Nepal, the DOTS protocol can feed into existing social hierarchies and be counterproductive to patient support. In this respect, attention to age and intergenerational relations offers a needed, and yet missing, perspective on DOTS in particular and standardized disease treatment protocols in general. A focus on children is especially compelling because TB has long been considered an “adult’s disease,” not only because of its association with HIV in sub-Saharan Africa, but also because of the difficulties in diagnosing TB in children. Children under fifteen years old account for only about 6 percent of the global burden.¹⁵ Further distancing children, DOTS-based programs worldwide view caregivers as integral to TB treatment success, but these caregivers are assumed to be adults—an assumption that this book will soon dispel.

CHILDREN AND THE PRACTICE OF BEING CLOSER

Throughout my research, I asked many questions and received many answers, but I have returned, in my thinking, to one particular question and its most common answer. I asked children living with adults who had TB: “How has this illness in your home changed your life?”¹⁶ I posed a similar question to the adults with whom the children lived: “How has TB changed your child’s life?” And child after child, adult after adult, offered me a similar response. The children made statements such as “I always wanted to be close to [my sick relative], now I want to *be closer*.” The children’s parents, grandparents, and other sick guardians said: “The children always wanted to be close to me, but now they want to *be closer*.” At first I did not know what to make of these answers. “Being closer” seemed like a vague answer to my equally vague questions. Yet, I found the consistent references to proximity difficult to dismiss because of the infectiousness of TB. They were especially difficult to ignore when I witnessed children’s attempts to stay close to relatives and the amount of effort entailed in sustaining such physical and emotional proximity.

The references people made to children’s proximity hint at one of the central paradoxes of infectious disease: transmissibility creates conditions in which proximity is desired and necessary, and also feared. This is particularly true in

settings where institutional and economic resources to treat infectious diseases are scarce. Relationships in such context are everything. Proximity can mark the quality of a relationship and serve as a critical strategy for social and biological survival, especially for people who are the most dependent upon others for their well-being. Let me offer an example to make this more concrete. On the day of Elesia's TB diagnosis, I sat in the house where she and her children, Abby and Chiko, were temporarily staying. Elesia was on the couch, next to several family members. Family members were discussing who in the family should care for Elesia and where they should send her children. Elesia stifled a series of coughs as she and her family worried about her six- and ten-year-old daughters' susceptibility to infection. Based on clinical advice about the infectiousness of TB and the rigorous eight-month treatment program, some family members suggested that it was best to separate Elesia from her children.

Over the course of two weeks, Elesia's sister gathered resources to move Elesia to her house on the other side of the city. Elesia's brother moved his wife and children to another relative's house to make room for Abby and Chiko in the house where he lived. Meanwhile, Abby and Chiko resisted the separation from their mother. They did so in specific verbal and nonverbal ways. They stayed closer to the house than they had before the family debate. They showed their ability to respond to their mother's physical needs, and they kept her company, prayed with her, and encouraged her to get better. They reflected on their futures without their mother and on the possibility of their mother's death while outside of their watchful care. There was no one who had more at stake in their mother's recovery than they did and this, they believed, made them most suitable to monitor her treatment and care. Elesia also wished to avoid the separation. However, by the time of the move, she was so sick that she had little energy to resist her family members' efforts.

When children spoke of wanting to be closer to specific persons, they were directing attention toward their relationships and dependencies as well as their strategies for cultivating interdependence. Their attempts to stay close evoked many of the ways in which anthropologists have studied care: as a form of work, as a sentiment and affective state, as an obligation and type of exchange, as an engagement with biomedicine, and as a process structured by social and economic inequality (Buch 2015, 279). Their care-based efforts to sustain relationships did not always work, as in Abby and Chiko's case, but children tried nonetheless, sometimes going to great extremes and, including, in the case of one young boy, running away from two different households in which he was placed.

Throughout this book, I examine the shared vulnerabilities of children and ill persons. I look most closely at how children attempted to minimize these vulnerabilities through cultivating relationships with specific ill guardians through acts of care. My intention is not to valorize this relationship between children

and their sick relatives or downplay age-related inequalities and the scarcities that the children faced. Rather, I see the notion of “wanting to be closer” as a heuristic for examining children’s social action. Since the 1970s, researchers in childhood studies have argued forcefully that we cannot understand children’s lives without paying attention to children’s own perspectives on their lives.¹⁷ Their argument—an argument for which there is much proof—is that children interpret the world around them and act in ways that reproduce and also change this world. The attempt to remain close to particular ill persons, thus, represents one way in which children experienced and responded to illness and uncertainty, and also drew on the resources they had at hand—including the resources of biomedicine and the globalizing discourses of childhood—to craft particular approaches to care for themselves and other persons, in an attempt to maintain a sense of normality and retain hope for their futures.

How we define children’s care for sick adults matters. Because children’s caregiving was largely ignored by social scientists until rather recently, much research on children as caregivers has focused on the work of care, emphasizing children’s domestic and nursing activities, their cooking, cleaning, nursing, bathing, feeding, and more. This positions children’s care within the much larger body of research on children’s domestic work,¹⁸ which has made important contributions to our understandings of children’s roles in economic life and shown that children’s work can be quite significant in particular times and places.¹⁹ A fundamental premise in childhood studies is that childhood is not a fixed life stage.²⁰ The cross-cultural variability in children’s work exemplifies this premise. While there are universals shared by all young children around the world, such as small physical size and early dependence on persons older than them to meet their basic needs, there is much more variation in what children can and are expected to do. Furthermore, larger-scale processes—capitalism, urbanization, globalization, and, as I argue in this book, the changing apparatuses of global health—factor into what children do and also into ideologies about children’s care work as normative and necessary, or out of place.

There is a tendency when examining children’s work to want to identify it as good or bad, harmful or helpful. Children who carry out care work may be, in some cases, more vulnerable than children who do not, but this is not always the case. To draw a line between the acceptable and the harmful with regard to children’s domestic work, international aid organizations and policy makers have relied on particular indicators, including age and amount of time spent engaged in domestic tasks. As anthropologist Rachel Bray (2003) has argued, such measures and, in fact, the international preoccupation with children’s work above other aspects of their lives, can erase the contexts within which children’s work is situated, thus hiding more than they reveal about children’s insecurities and needs. Bray has offered the example of a young girl in South Africa. Responding

to a survey on child labor, the girl gave answers that appeared to show that she did not engage in much domestic work at all. Her answers seemed like positive indicators of her well-being. However, when Bray went to the girl's home, she noticed that there were few chores for the girl to carry out because the household had almost nothing to clean or cook. In such a setting, Bray observed, a child's involvement in domestic work might actually be a positive gauge of social and economic security. In the example from my own study, Abby's and Chiko's inability to perform care work for their mother did not mitigate their vulnerability. Instead, it threatened their ability to influence the course of their mother's illness and, in their interpretation of events, their relationship with their mother and sense of security in the present and future. The point is that standardized measures only tell a partial, often decontextualized story, and this story does not always match children's experiences or their understandings.

Because children's contributions in households are highly variable, context specific, and do not map neatly onto age-based categories, the extent and nature of children's domestic work is hard to grasp. As anthropologist Pamela Reynolds (1991) has shown in her study of children's work in subsistence agriculture in Zimbabwe, one of Zambia's neighboring countries, anthropological research techniques are critical to understanding children's work in all of its complexity. Children's work, she suggested, can be at the same time obscured, not considered work, and also highly valued and valuable. It can also vary through time with the changing needs and capacities of households and children, making it hard to understand children's contributions at just one point in time. By following particular children through time, Reynolds was able to identify that children provided adjustable labor for households, filling in where needed and assisting other household members, typically women, when they were overburdened. Though Reynolds does not address illness, her points hold especially true in care for sick persons. The notion of being closer to the sick is far less vague if we think about care needs as constantly changing and if we consider staying close to an ill person as one way in which children remain knowledgeable of and able to do something about such health needs and changes.

Children's attempts to become even closer to specific guardians during illness were about much more than providing adjustable labor. As the example of Abby and Chiko demonstrates, the notion that children wanted to be closer also hints at another form of work—the work involved in retaining intergenerational and kin relationships. Anthropologist Fiona Ross (2010) has observed that the work of retaining social relationships is unending and frequently becomes most evident during crises, such as illness and death, when relationships threaten to dissolve and when social isolation and rejection become real possibilities. She has written about this work in terms of the temporality that illness and dying impose on ill persons: “Illness, death and talk of illness and dying insert new forms of

time into daily routines and everyday life. Caring is pierced by waiting; plans are hollowed by uncertainties; time becomes rigid and drifts simultaneously. It is within and across these qualities of time and not solely those of chronology, seasonality and genealogy that social worlds are crafted and refashioned. The return to life involves . . . the crafting of relationships so that they again take a recognisable and socially sanctioned form” (2010, 198). While Ross was referring most specifically to adults who were ill, her observations are suggestive of the temporality that a guardian’s illness might impose on children as well. As I will show throughout this book, children linked the survival of specific relatives to their own future prospects. Retaining closeness in proximity and affect served as a strategy to shape not only the social and biological survival of sick guardians, but also the social and biological survival of the child. This strategy was context specific and pulled from a range of discourses about proper relationships between children and adults and the types of relationships children need to attain livable futures.

Children’s attention to their proximity to sick guardians highlights the broader inequalities that the children faced in their daily lives, as well as their attempts to do something about such inequalities. Anthropologist Frederick Klaitz (2010) has offered insight on this point in his research in Botswana on how people were attempting to sustain relationships in the midst of the HIV epidemic. He suggested that broader economic inequalities in wage labor and access to resources had reinforced people’s tendencies to assess the state of their relationships through the places in which they gave and received care. In Klaitz’s words, Botswana “have tended to experience social inequalities as aspects of gendered and generational relationships within domestic or housed spaces . . . As a result, they commonly take steps to reshape their own and other people’s manner of imagining such relationships” (2010, 18). They did so through activities that occurred in households on a daily basis, such as bathing, nursing, drinking, visiting, and praying. While Klaitz’s observations were based primarily on women who were members of an Apostolic congregation, and not children, they resonate with the ways in which the children in my study worked to refashion their identities and relationships through activities that occurred between themselves and their sick guardians, in homes and on a daily basis.

Close attention to the place of care reveals both the inequalities children face and need to manage and also the increasingly global facets of childhood. Children received a range of messages about their schooling, rights, vulnerability, and work that they incorporated into their understandings of their situations and the care they gave and received (Skovdal and Ogutu 2009). These globalizing discourses of childhood, as I will argue throughout this book, cannot be measured against local discourses of childhood. They are localized in children’s everyday lives. For example, the children in my study used categories, such as the

category of the orphan, to interpret the social isolation that might occur if they were separated from a particular guardian. They understood their care work in particular places and for specific adults as a means of securing an education (and, thus, a future). They also construed activities carried out for the “wrong” adult as something that could inhibit their schooling. Abby, the girl I mentioned earlier who wished to stay with her mother to give her care, had been out of school since her mother became sick, but she saw her chances of returning to school as higher if she remained in her mother’s care, rather than in her uncle’s. In her mother’s household, she was a caring daughter who responded to the needs of her mother. The potential for reciprocation remained there, despite her mother’s debility. In her uncle’s house, she saw herself as a domestic worker whose actions and attempts to develop a relationship and also receive resources went unreciprocated.

Research on children’s experiences of caregiving frequently embraces dichotomous thinking: assessing children’s care as negative or positive; seeing childhoods as local or global; and positioning children as caregivers or care receivers. This framework, I argue, limits our understandings of children’s care. *Children as Caregivers* examines children’s care in all of its complexity and “as many things all at the same time” (Orellana 2009, 118).²¹ In the following chapters, I will show children’s care for sick persons as a process of commensurability in which some children and ill adults forged—or attempted to forge—a common vulnerability, one in which boundaries between healthy and sick, adult and child became blurred.²² It was this common vulnerability that the children and their ill guardians were referencing when they spoke of wanting and needing to remain close to one another.

GETTING CLOSER

I wrote this book as an anthropologist who has worked for a number of years in the delivery of public health in Zambia, both prior to and during the research and writing of this book. I arrived in Zambia, first, as a Peace Corps volunteer and have since worked on a number of health assessments and interventions, with (or contracted by) the World Food Programme, UNICEF, and the Zambia AIDS Related Tuberculosis Project. Throughout this time, which spanned from 1999, when I joined Peace Corps, to my most recent anthropological fieldwork in 2014, I have seen how children’s perspectives can become sidelined in the delivery of health services, even when services are aimed at children. I have also seen a growing emphasis on children’s participation in public health interventions and community development, and I have struggled with my colleagues who work in the delivery of public health to identify ways to make children’s participation in such processes meaningful.²³

My interest in studying children's experiences with TB treatment and care grew out of my affiliation with a Lusaka-based nongovernmental organization, the Zambia AIDS Related TB Project, or ZAMBART.²⁴ Before beginning my own study of children's caregiving, I assisted ZAMBART staff with a project they were carrying out with schoolchildren. The project involved asking schoolchildren in heavily TB-affected settings to disseminate information about TB and HIV to their family members, with the hope that children might compel family members to get tested. It was the first TB project to involve children as health promoters in their communities, which made the project uniquely situated to answer a question that had never been asked: Do children have a role to play in TB prevention programming?²⁵ The children were already playing roles in their households, well beyond what the project envisioned. However, what exactly the children were doing in their households was hard to ascertain from their responses. We were missing the ethnographic details of children's daily lives with TB, and this raised further questions for me about what current and past public health efforts were also missing about the household management of the disease. This was a methodological problem that we could not solve within the confines of that project and certainly not within the many other studies of TB in Zambia and elsewhere that excluded children.

Much of what researchers know about people's experiences with TB comes from interview and survey-based studies, frequently carried out retrospectively and outside of the usual place of care, the home.²⁶ Such studies have identified important aspects of TB diagnosis and treatment, and yet they fail to adequately describe the range of social relationships that shape therapy management.²⁷ Instead, they hint at factors such as access to clinical resources, shortage of medications, and feelings of wellness that can only leave us to imagine the daily lives of TB sufferers and their household members. They frequently ignore children entirely. In the previous section, I demonstrated how statements about children's desires to stay close to ill persons helped me understand children's experiences and strategies in households affected by illness. The notion of being closer—or getting close—also offers an apt metaphor for ethnographic fieldwork.²⁸ Ethnographic fieldwork is about physical and social proximity: being in a particular place and close to particular people. Ethnographers live, work, or visit with people repeatedly over time. Observation and participation in daily life brings researchers closer to people's daily lives and relationships than other social science and community-based methodologies, which tend to rely on a limited number of interactions conducted outside of the usual places where people live, work, receive care, and generally carry out their daily activities.

THE RESEARCH

Because I wanted a closer perspective on daily life with TB, I chose to situate most of my research in the clinic and in houses in one particular place—George—a poor residential area that is located on the geographic and economic margins of Lusaka. Lusaka is both the capital of Zambia and the largest city in the country, with around 2 million residents in 2015, in a country of more than 15 million people. Approximately 70 percent of Lusaka's residents live on just 20 percent of the city's land, in low-income areas that encircle the city (World Bank 2002). George is one of these settlements. Through various exclusions, residents of George face high risks of infectious diseases such as TB. It has been estimated that the incidence of active TB in George is 800 in every 100,000 individuals per year (UNICEF 2008), a number nearly double the country-level incidence.

George is a favored location for international nongovernmental organizations (NGOs) and research for several reasons. The health statistics in the area provide the methodological as well as moral and practical justifications that researchers and practitioners need to show funders. There is an infrastructure for and history of health projects at the government health center in George. There is also a clear need to improve and provide services that are sorely lacking. The first time I went to George was in 2005 with my colleagues at ZAMBART, who were working with the government health center to carry out research on TB diagnostic testing and promote TB reduction initiatives.²⁹ Since that first visit, I have carried out my own fieldwork in the settlement in 2005, 2006, 2007 to 2008, and 2014, with the help of two research assistants who lived in George, Emily Banda and Olivious Moono.

The central observations in this book come from twenty-five households, each of which I visited weekly during my 2007 to 2008 fieldwork, and then again in 2014.³⁰ Of these households, seventeen households had an adult member (eight women and nine men) who had been diagnosed with active TB at the initiation of my research. Eight households were comparison households, households in which no one had been diagnosed with TB for the previous five years.³¹ Because I was interested in examining children's care, I focused most directly on children between the ages of eight and twelve years old. All twenty-five households had at least one child in this age range, for a total of thirty-eight children (twenty girls and eighteen boys). I chose this age group because children of this age are so frequently left out of global health and medical research, which has focused primarily on children under age five years and fifteen years and older. In addition to the observations, interviews, and other methods I carried out in these twenty-five households, I also administered a broader survey across two hundred households in George, carried out observations in clinical sites of TB treatment, and conducted participatory workshops with children.³²

One of the many things I find so valuable about ethnographic research and writing is the ability to combine many different forms of evidence, from observations made while participating in activities of daily life to interviews, structured surveys, performances, archival materials, and much more. I find such an approach not only necessary for examining health and illness, but also critical to understanding children's experiences and perspectives. In recent years, much has been written about the best ways to include children in research, with many debates and discussions about the value of various, usually participatory techniques.³³ As will become evident throughout this book, I relied on many techniques for working with children, including observations in their households as well as more participatory approaches, such as performance, group discussions, games, and drawing. (View the children's drawings at <https://www.flickr.com/photos/childrenscaregivers/>.) Flexibility, variability, and constant reflection defined my approach to research with the children. My analysis does not privilege any one method. I draw on all of the methods I used to bring me closer to understanding children's strategies for and perspectives on care.

ETHNOGRAPHY AND ILLNESS

Ethnographic research aims to humanize people, but infectious diseases can be dehumanizing. Airborne diseases such as TB produce fears—both real and imagined, with the lines often blurring between the two. Many people over the years have asked me if I was worried that I would contract TB. I was concerned for myself and also for Emily and Olivious and the people we might expose if we became sick. We took precautions, but there were also limits.³⁴ Complete avoidance would have meant shunning the things that humanize people during illness, such as sitting quietly together or entering a bedroom to offer words of encouragement to a person who could not get out of bed. People made counter attempts to avoid transmitting TB to us. They stifled coughs and made sure that we sat near doors that were opened wider than usual to let air circulate. We paid attention to these signs and adjusted our behavior. Paying attention to proximity—and also limiting our proximity—served to build the relationships that were essential to this research.

Tuberculosis, like most serious diseases, creates crises in households that shape the research relationship, particularly during initial diagnosis and at times when symptoms are severe.³⁵ Another question that I receive frequently is: How much did I intervene in or help the households in my study? This question comes particularly from students and practitioners of medicine and public health who are new to ethnographic research and worry about the ethical implications of observing suffering. I have two responses. The first is that I did provide some assistance. Emily, Olivious, and I put people in touch with various aid programs

that gave monthly allocations of food and other resources. The three of us were frequently asked for biomedical information. Emily and Olivious gave advice based on their previous work with HIV- and TB-related programming, and we contacted doctors and TB nurses to field questions we could not answer. I sometimes gave money for transportation to health centers or the University Teaching Hospital, or for follow-up X-rays or diagnostics tests. I brought nutritious foods to households when it seemed that there was not enough food in the house. While I have no illusion that I was more than a blip in people's lives, I acknowledge that my presence shaped illness management and illness trajectories and, therefore, the research in ways that I will never fully know.

My second answer to this question addresses a broader concern, especially for people with previous experience working in or studying medicine, public health, and social work who are accustomed to interventions. I reiterate the value of slowing down in a global public health research environment that values action, speed, and efficiency.³⁶ This slowing down forefronts listening first and not assuming that we know what is best for people in different circumstances from us. In teaching interview techniques in health research, I have learned that many people unfamiliar with ethnographic interviewing are inclined toward correcting or judging people who say things that fall outside of the parameters of biomedicine, taking an expert stance that positions them as knowledge producers. This contradicts a fundamental aspect of ethnography in which informants are the knowers and the ethnographer is the person striving to know (Madison 2012). I teach that the benefits of listening and taking a nonexpert position are many. Such a position enables us to learn how things work on the ground and to get past our taken-for-granted assumptions about people's lives. It allows us to question received ways of categorizing people and problems and intervening in people's lives. That is, listening to people and seeing issues from multiple perspectives can offer more appropriate pathways for changing the delivery of healthcare and medicine (Biehl and Petryna 2013a; Pigg 2013).

OVERVIEW OF THE BOOK

Each chapter in *Children as Caregivers* engages children's perspectives on their circumstances, while addressing a different aspect of the children's daily lives. The chapters progressively build to develop a fuller understanding of the children's caregiving within a setting heavily affected by infectious disease. The first chapter, "Growing Up in George," situates the reader in the urban residential area where the children lived, describing the many factors, including global restructuring and a history of international development agendas, that have shaped the landscape and children's life chances. The children's perspectives on this

landscape offer lessons applicable to the growing array of global health efforts in poor, urban environments around the world.

In chapter 2, “Residence and Relationships,” I move my analysis into the domestic sphere and examine children’s changing roles in and across households in the HIV era. Family has become a critical concept in global endeavors to assist children in settings affected by infectious disease. Many observers have identified the limits to families’ abilities to care for children in places with high burdens of adult illness and death. The notion of children “in family care” as opposed to “outside of family care,” on the streets or in institutions, has gained particular traction in international attempts to provide resources to children. Despite the explicit attention given to the notion of family in research and program development in HIV-affected areas, children’s roles as family members have not been adequately conceptualized. This chapter focuses on the active ways in which children were shaping family networks and attempting to cultivate relationships with particular people in order to receive good care.

Caring for children can be particularly challenging during illness and, in many places in Africa and around the world, aspects of TB and HIV diagnoses can exacerbate these challenges. Chapter 3, “Between Silence and Disclosure,” explores the issue of disease disclosure to children, starting with the observation that most adults in my study did not disclose their TB diagnoses to their children. Increasingly, public health research seeks answers to why adults do or do not disclose disease diagnoses to children, and the effects of disclosure on children’s present and future well-being. I suggest that this line of investigation, which focuses on what is not said, obscures the many ways of knowing and communicating about illness. This chapter calls for an extreme broadening of definitions of disclosure to include the silent presences of disease and acknowledge the relationship-building practices that occur in the absence of a named disease. I make an even broader point about how we theorize children’s and adult’s agency within infectious disease epidemics, and how this has ramifications on global health programming and research.

Chapter 4, “Following the Medicine,” continues to show children’s active involvement during illness through describing their participation in and responses to changing TB control measures in Zambia. In the twenty-first century, TB drugs have become increasingly available and regulated by a range of international donors and actors, and in compliance with the World Health Organization’s DOTS strategy. Even though the children were rarely allowed at the clinical site of TB treatment in George, they viewed their actions outside of this site as integral to TB treatment adherence. They appropriated the global discourses of TB treatment and used these to attain belonging and make claims to households. Children’s uses of the materials and discourses of TB treatment offer

a strong case for the value of children's perspectives on global health technologies, even when such technologies are not aimed at children.

TB treatment has not been a magic bullet. Poverty, an overburdened health-care system, and many other factors prolong and worsen suffering from the disease in George and other heavily TB-affected areas in sub-Saharan Africa. Families assume much of the expense as well as the work of caring for people with TB, just as they have for other debilities and diseases. Within families, however, the expense and work of caring is not distributed equally, and women in particular, in all parts of the world, face the highest caregiving loads. The social and economic inequalities that shape women's burdens of care work also make women more vulnerable to infectious diseases, including TB. Chapter 5, "Care by Women and Children," provides an in-depth view of two women's illness trajectories. In both cases, there was a seeming absence of adult kin involvement in the women's care. Children filled this void. This chapter underscores the significance of gender and age-related inequalities, while also showing how women and children attempted, through proximity to one another, to minimize the disruptions to their present and future well-being. Chapter 5 reaffirms a common theme throughout the book: social relationships shape the kinds of care people get, and children must be viewed as part of—rather than at the margins of—caregiving relationships.

I continue to draw out the importance of including children's caregiving actions and relationships in my conclusion, "Children and Global Health," as I tie together the central lessons from the book. This concluding chapter shows the immediate and dire need for far more complex understandings of children and childhoods than those presently held within the field and practice of global health. In both this concluding chapter and a postscript on recent efforts to treat childhood TB, I offer lessons and questions as funding and programs increasingly turn their attention to children.

A NOTE ON WRITING

Children's views are the central focus of *Children as Caregivers*. I have attempted to remain true to the accounts that the children offered, while acknowledging that I have filtered their words and experiences through my own interdisciplinary lenses (those of anthropology, childhood studies, and public health). I wrote this book with several distinct audiences in mind, among these: students and other people interested in global health disparities, practitioners working in disease control or with child welfare programs, anthropologists who focus on illness and caregiving, and childhood researchers from various disciplines. In writing for different audiences, I agonized over word choices and wondered how my descriptions brought me closer to or farther away from the terms the children

used to describe their experiences. I discovered, as Barrie Thorne has written, “that different angles of vision lurk within seemingly simple choices of language” (1993, 8). Because of this, I wish to make explicit some of my language choices and challenges.³⁷

In both scholarship and policy documents on children living in adversity, children are frequently labeled or categorized according to particular circumstances or needs. These are cultural constructions, as I will show throughout this book. They hold specific purposes in policy and research: to account for need, bring attention to a particular social issue, or study the extent of a problem. Common labels used within the HIV epidemic are orphan and street child. The labels *child carer* and *child caregiver* are also entering into the vocabulary of researchers and practitioners to indicate children who care for people who are sick, debilitated, and elderly, or for younger children. Most children I knew in George would not categorize themselves in these ways, or they would use such labels only very selectively. Because of this, I have tried to limit categorizing the children by labels except in cases in which the children used them or I directly discuss literature and programs aimed at a specific category of children. Avoiding such terminology removed the limitations I had in my own thinking, particularly on what care and family might look like. It enabled me to identify many aspects of care that I had previously not considered and also see the interdependence in children’s actions and sentiments.

I struggled, too, with the language I used to write about TB and HIV. Most public health and medical research makes disease diagnosis an explicit part of study participants’ identities. In certain ways, my work is no different because of my focus on people diagnosed with TB. However, I have not focused solely on these diseases and I have purposely left some diagnoses unwritten. As I will show, HIV and TB were not named so directly in many of my conversations, and many guardians and their children actively resisted having their lives reduced to diagnoses, preferring to fashion themselves in other ways, as, for example, mothers, fathers, daughters, sons, or grandparents. TB and HIV were ever-present in family life, and yet there was much more to children’s lives and relationships than the TB or HIV diagnosis, which I show throughout this book.

A main goal of the book is to offer the details and context that are so frequently missing in reports and articles on infectious disease prevention and on childhoods in adversity, as well as to provide new frameworks for viewing illness, treatment, childhood, and family. My account focuses specifically on children’s lives at one place and time to make real for the reader the hardships children face while also showing how children create relationships, make do, and give meaning to life within such constraint. I have worked to show readers the value of ethnographic research and writing for understanding these challenges as well as honoring children’s creative responses to adversity. I have also

worked to show ethnographers of global health the value of including children in their analyses. I hope that my work will make readers question the status quo in global health research and practice concerning children. I hope, too, that my work will introduce some avenues for change in global health programming and policies and that children, in particular, will experience such changes as beneficial.