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Children's Roles in Tuberculosis Treatment Regimes: Constructing childhood and kinship in urban Zambia

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Abstract

In Zambia, the burden of HIV-related diseases such as tuberculosis has received substantial international attention. Zambians experience and participate in a range of globally produced programs to manage TB and cure TB sufferers. Guided by the WHO's Directly Observed Treatment, Short-course (DOTS) protocol, TB treatment regimens now emphasize adherence to medications as the primary way to achieve cure. This article aims to understand how adherence models enter into the daily lives of children who live with and care for adult TB patients in an area disproportionately affected by the disease. I suggest that children domesticate adherence models, using them as strategies to safeguard identities, relationships, livelihoods, and futures that are increasingly under threat in the age of HIV. They draw on TB treatment and the hope and agency it affords to hold onto a version of childhood in which they are cared for by adults who will advocate for their wellbeing.

Keywords

Children; Adherence; Tuberculosis; HIV/AIDS; Africa

The HIV epidemic and rise in infectious diseases such as tuberculosis have contributed to unimaginable demographic challenges in southern Africa. In Zambia, healthy life years are estimated at 40, and average life expectancy at birth is 48 (WHO 2011b). The country has one of the youngest populations in the world, with 46.2 percent under 15 years old (PRB 2010). And 1,300,000 children aged 17 and under have experienced the death of at least one biological parent (UNICEF 2011). Even more children contend with the frequent and debilitating illnesses of parents, grandparents, aunts, uncles, and siblings. In 2010, for example, TB incidence was estimated at 462 in every 100,000 individuals (WHO 2011a).

The above statistics speak to the fragility of life, but offer little insight into children's experiences, their agency, and the ways in which they cultivate relationships when adults fall ill with life-threatening diseases. In 2007 and 2008, I carried out ethnographic research in 25 households in George, a low-income residential area in Lusaka, to examine children's actions when adults became sick with TB. I expected to observe a shift in household caregiving, with children taking primary roles in care for the sick and household maintenance activities. However, my research suggests a more complicated version of children's agency, in which the children in these households drew on biomedical TB treatment regimens as important materials for shaping the types of childhoods and futures they wanted. I witnessed children's attention to medications and biomedical procedures for treating TB, and their efforts to ensure adult adherence to treatment regimens.

In this paper I attend to the domestic practices that have emerged at the juncture of epidemiological and demographic shifts and new TB treatment protocol by examining how children used medications to cultivate relationships and reaffirm belonging to households, social categories, and identities. TB offers a particularly informative site for examining children's belonging and relationship-building in the current era. It has become the subject of significant global attention since the World Health Organization (WHO) declared TB a global emergency in 1993 and subsequently introduced a global framework for TB management, Directly Observed Treatment, Short-course (DOTS). DOTS was developed as a universally-applicable technology with powerful potential to cure TB and stop its transmission in countries worldwide. Its implementation rests on five broad measures: (1) government commitment to TB control; (2) TB testing through sputum microscopy; (3) standardized and supervised (or observed) medical regimens; (4) an uninterrupted supply of medication; and (5) efficient recording and reporting systems (WHO 2004). In 2003, the WHO officially recognized Zambia as a country that had reached 100 percent DOTS coverage, an "achievement" preceded by significant restructuring of the National TB and Leprosy's Program's (NTLP) delivery of TB services and ample assistance from donor organizations. It also shifted conceptions of TB care in Zambia, giving primacy to medical intervention and behavioral change over other forms of social, economic, or political change (Farmer 1999, Harper 2006, Koch 2006). The most visible element of the DOTS protocol is its attention to observation of daily ingestion of TB medications. While initial discussions envisioned the surveillance of daily drug ingestion occurring within health centers, more recent conversations have shifted the focus to "community contributions to TB care" and "community DOT" as a means of supporting overburdened National TB Programs and making TB treatment more patient-centered (WHO 2003). Public health practitioners increasingly discuss the integral roles that community health workers and family members might play in promoting treatment adherence (Cavalcante et al. 2007, van den Boogaard et al. 2009, Wandwalo et al. 2004).

I am interested in the social implications of this substantial attention to patient adherence to medication. Specifically, I join other anthropologists in examining how universal treatment programs have shaped everyday efforts to direct life projects (Biehl 2005, Koch 2006). My concern here is in how TB treatment adherence enters into domestic attempts to safeguard identities, relationships, livelihoods, and futures that are increasingly under threat in the age of HIV. Such inquiry moves us beyond debates about the feasibility of involving family members as observers of TB treatment adherence (Newell et al. 2006, Frieden and Sbarbaro 2007), to an examination of how universal policies and their ideologies transform and become meaningful in local contexts and to particular actors, namely children. A focus on children's responses to TB treatment offers unique insight into how global TB technologies have shaped and become a resource in some children's life projects.

While children are exposed to TB and the suffering it causes in their households and communities, they are rarely the "targets" of TB-related programming or participants in research on DOTS (Bond et al. 2010). In Zambia, children's proximity to TB becomes a subject of inquiry—and source of concern—only when adults fall ill and children are seen as at risk of TB exposure. When viewed as at risk, the roles children play in household and family maintenance and the meanings they ascribe to their activities are ignored (Ansell and van Blerk 2004, Robson 2004). By attending to children's experiences, this paper acknowledges both the importance of children's social action and the reality that children's "voices, views and visions" are frequently silenced or constrained in policy and research (Honwana and de Boeck 2005: 2). I aim to disrupt the adult-centrism that shapes TB-related literature and public health campaigns, programming, and practices by examining how children experience and respond to TB within a landscape significantly altered by the disease and efforts to control it. I build on a rich scholarship in the anthropology of

childhood that considers children's participation in research as necessary for understanding their experiences, meaning-making, and social action (Christensen and James 2008, James and James 2004, Hardman 1973). The frameworks I develop also contribute to more recent efforts in anthropology to hold both children's extreme vulnerability and their agency in view (Cheney 2007, Rosen 2007).

Building on Klait's (2011) theory of the "domestication of inequality," I argue that children have domesticated public health and biomedical messages about treatment adherence and observation of the sick. I demonstrate how children in my study positioned themselves close to the sick to ensure adherence. What was at stake for the children was not just the life of a parent or guardian but their social positions in households and families and, therefore, their access to material and emotional support. I suggest that helping an adult follow the medication—children's performance of adherence—served as an attempt to remain in normative categories of childhood and avoid becoming "orphans" and "street children," whom they defined as destitute, abandoned, and lacking belonging.

Methods

My interest in studying children's experiences with TB treatment grew out of my pre-doctoral affiliation with the Zambia AIDS Related TB Project (ZAMBART), a Lusaka-based NGO. As I assisted ZAMBART staff with data collection and analysis on their research projects outside of my primary research site (Bond et al. 2010), I became increasingly preoccupied by questions that we could not answer through focus group discussions and community observation, such as: How were households managing under the strain of TB? What were children doing and experiencing in households affected by TB? In 2005, ZAMBART staff introduced me to healthcare workers in George, where I chose to situate my doctoral research.

I began my 15-month ethnographic project in July 2007 with the assistance of two local research assistants, Emily Banda and Olivious Moono. As long-time residents of George, Emily and Olivious served many roles: guides into daily life, tireless researchers, and skilled interpreters of Nyanja, the predominant language spoken in George. While I had learned Nyanja during more than three years as a Peace Corps Volunteer in Zambia (1999–2002) and undertook intensive language tutoring during 2005, 2006, and 2007, Emily and Olivious helped me understand the subtleties embedded in everyday talk, and Olivious translated all tape recordings.

This study was a household-based study that focused on the roles and experiences of a range of household members to situate children's experiences within the context of daily life. The project started with the recruitment of 25 households comprised of 162 household members (38 children between the ages of 8 and 12) who participated in 10 to 12 months of ethnographic research. Seventeen households were recruited directly after an adult was diagnosed with TB at the government-run health center in George. At diagnosis or during the initial collection of TB medication, we approached TB sufferers or family members to briefly explain the project. If people expressed interest in the study, we made follow up visits to their homes to further explain the research, answer questions, and administer informed consent and assent. We followed each household during treatment and after recovery or, in one case, the death of the TB sufferer. While most household members participated in research activities, we focused more explicitly on engaging children, ages 8 to 12. I chose this age range as a manageable subsample of children to avoid dramatic differences in physical capabilities and maturation.

Eight households participated in the research as “comparison” households, defined as households without TB sufferers for five years prior to recruitment. In George, the distinctions between households with and without TB are artificial and time specific. Individuals in most comparison households had cared for sufferers in the past and were caring for non-household TB sufferers in the present. Six months into the study, Juliette, who lived in a comparison household, was diagnosed with active TB after a long quest to diagnose her rapidly deteriorating health.

In Zambia, much research on TB treatment adherence relies on survey methods (Kaona et al. 2004, Mweemba et al. 2008, Mulenga et al. 2010). The importance of participant-observation for understanding TB treatment cannot be overstated. While survey-based studies may claim to be patient-centered when retrospectively asking patients to recall factors preventing treatment adherence, they fail to adequately describe either the experience of TB treatment or the range of social relationships that shape therapy management (Harper 2006). 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 domestic lives of TB sufferers.

Participant-observation and child-oriented methodologies served as my primary research methods. Alongside Emily or Olivier, I carried out daily observations in the clinic and visited each home at least four times a month for extended observations. During home visits, we engaged in conversations, participated in chores and leisure activities, and helped with routine care for the sick. On days when I worked with one assistant, the other assistant visited homes on her own, an activity that prompted different forms of observations and conversations because of my absence. After each visit, we carefully documented our interactions, observations, and conversations. By recording events as they unfolded through time, we were able to capture the experience of TB treatment in ways less mediated by preconceived ideas and assumptions (Chapman and Berggren 2005).

I supplemented participant-observation techniques with extended interviews and discussions, based on insights gained through observations, conversations, and participation in the households. In the households, I asked questions about care seeking, stigma, support mechanisms, and the effects of tuberculosis illness on children from an adult’s perspective. At the end of the research, I held a focus group discussion with volunteer TB Treatment Supporters, who were also longtime residents of George, to inquire about treatment issues raised in the households.

Because children are not always easily incorporated into research through the use of conventional participant-observation or survey techniques, my assistants and I engaged a range of methods to actively involve the children, which I have discussed in-depth elsewhere (Hunleth 2011). We used drawing as a starting point to build rapport and gain insight into children’s everyday experiences and their understandings of households, families, and illness. We gave the children tape recorders and encouraged them to tell stories and also interview their siblings and household members. With the children’s insistence, we also provided them with pictures to “talk with” during their recordings (pictures taken from Rohr-Rouendaal 1997). Children frequently used these pictures as starting points to discuss illness and their social situations. Finally, we set up six children’s workshops with the 8 to 12 year olds in the households. These workshops took place outside of the children’s home and were aimed at eliciting their viewpoints through generalized group discussions and role-plays.

Northwestern University's Institutional Review Board and the University of Zambia's Research Ethics Committee approved this research. All names listed in this paper are pseudonyms.

Following the Medication

The DOTS strategy and attendant programming has substantially increased the availability and visibility of TB medications in George and ushered in new rules and protocol around TB medications. Embedded in the DOTS framework is a fear of “treatment anarchy,” the inconsistent access to or usage of TB medications (WHO 1997). This fear hinges on concerns over non-adherence as a contributor to the emergence of multi and extremely-drug resistant TB (MDR-TB and XDR-TB). MDR-TB in Zambia remains low at less than two percent (ZAMBART 2011), a figure that, for the NTLP, situates drug resistance as a future concern and has led public health actors to recommend patient adherence to drug susceptible regimens as the most important route to averting resistance (Mulenga et al. 2010).

The third tenet of DOTS addresses patient adherence through a mechanism known as DOT, the direct observation (or supervision) of treatment. This method of patient observation through daily contact was shown to achieve cure in low-resource countries, where healthcare infrastructure could not support hospitalization (Raviglione and Pio 2002, Styblo 1989). In effect, DOT shifted TB from a hospitalize-able to an outpatient condition. The focus on DOT has received criticism for exaggerating patient agency and ignoring the structural conditions that make daily observation difficult or undesirable (Leinhardt and Ogden 2004, Harper 2006). While DOT still generates staunch support (Freiden and Sbarbaro 2006), the means of observing or supervising patients has been the subject of much research and practice, prompting a shift in language and practice to a more patient-centered approach to TB care (Harper 2010). Efforts include the use of trained community volunteers who visit patients daily in their homes (Shin, et al. 2004). In Nepal, Newell and colleagues' (2006) research demonstrated that family members might serve as viable treatment observers. In Zambia, a recently completed study has shown a significant reduction in TB burden in communities, including George, where skilled and experienced counselors regularly visited households with recently diagnosed TB patients and addressed TB as a household—rather than individual—concern (ZAMBART 2011).ⁱ

The mechanisms used to monitor TB medications and ensure adherence in George represent a bricolage of global, national, and local approaches. Zambia renewed its commitment to DOTS in 2002 after a turbulent period in the 1990s when the NTLP nearly collapsed due to healthcare system restructuring and the withdrawal of external donor funding for specialized TB programming (Bosman 2000). After the NTLP regained external funding and support in the twenty-first century, TB focal persons were appointed to government health centers to coordinate TB services according to DOTS protocol. In George and other clinics serving large populations of TB patients, this restructuring translated into the establishment of TB Corners, physical and temporal locations for managing TB treatment and monitoring medication. TB Corners take varied and dynamic forms depending on health center architecture, populations served, and types of assistance given by NGOs.

The TB Corner at George Health Centre was the only place in George where residents could access free TB treatment. It was situated in a covered carport, attached to the main clinic building. In 2007 and 2008, the treatment in George and Zambia more generally was a “short-course” regimen that lasted at least eight months and consisted of two phases: a two-

ⁱMy study overlapped with the household counseling study in George. However, on advice from researchers at ZAMBART, we conducted our studies in different households.

month intensive phase and a six-month continuation phase. Concerns over the development of drug resistance to rifampicin, an active component in intensive phase treatment, meant that patients or family members were required to attend the TB Corner weekly during the intensive phase. They collected continuation phase medications monthly. While continuation phase is supposed to be a time when patients experience a return to health, such linear progression from sick to well did not occur for many people in my study, whose health declined when they stopped intensive treatment, due perhaps to HIV, poor living conditions, inadequate access to nutritional foods, and the removal of key medications in the continuation phase treatment.

Attending the TB Corner regularly was no small accomplishment. George Health Centre is set in a fenced compound in the oldest section of George. Because there is no public transportation to the health center, almost everyone walks; the very ill are carried or pushed in wheelbarrows. The journey can take up to an hour depending on where a person lives in George. Once at the clinic, the wait in the Corner was long because of the number of people on treatment and the institution of regular treatment monitoring.

Concerns about treatment “default” in George guide activities both in and outside of the TB Corner. Each morning, activities commence with an educational session, during which community volunteers, NGO workers, and nurses speak on issues of TB treatment adherence. In coordination with the implementation of DOTS programming, a Japanese NGO had trained a set of local community volunteers in George to serve as TB Treatment Supporters. They helped in the TB Corner, visited patients in their homes, and spread TB treatment messages around the community. The NGO’s website explains the TB Treatment Supporter program:

Since TB treatment requires rigid drug adherence and failing to do so leads to a huge risk of producing multidrug-resistant TB, the patients need support from family members and neighbors while coping with social discrimination and stigma. This program is establishing a model to protect communities by the communities... As awareness and understanding on TB among [George] compound residents have been enhanced, and drug adherence has improved, the TB mortality rate has reduced. (AMDA-MINDS 2008)

Here, awareness, education, and an encouraging family and community environment, rather than direct observation, are seen as tools for cultivating adherence.

The messages advocated by the TB Treatment Supporter and other DOTS-enhancing programs radiate out from George clinic in subtle and blatant ways. During the time of my study, TB messages circulated, most literally, in the form of an NGO-sponsored truck that regularly drove through the settlement, making calls for people to get tested and treated at George Health Centre. In the children’s workshops I carried out in December 2007, I asked the children in my study to tell me what they “knew about TB.” They responded with statements marking the necessity of biomedical treatment and the dire consequences of non-adherence. In the words of a girl in one workshop: “If you don’t follow the medication, you die.”

Following the medication is a phrase that has gained prominence in local parlance. Most basically, it refers to taking TB drugs every morning for eight months, and also the complex of activities around taking medication such as eating, resting, and avoiding strenuous chores or work obligations. It suggests that responsibility for adherence rests on patients and their family members who encourage and help them through giving medicine, carrying out chores, and offering encouragement. The real work of adherence occurs in the home.

Domesticating DOTS

I am interested in how TB medication, the rules of treatment, and the community outsourcing of care have combined to create new ways of forming relationships and maintaining households in George. My observations with children living in TB-affected households lead me to suggest that the children were “domesticating” TB treatment. This suggestion pulls together and builds on several recent theories concerning DOTS, the pharmaceuticalization of public health, and the forms that domestic life and individual agency take under conditions of poverty and HIV in Africa.

I argue, with other anthropologists, that DOTS-guided programs enter into much more complex economic, moral, and social worlds than proponents might wish or even acknowledge. Erin Koch (2006), for example, starkly demonstrates the unexpected consequences of universal treatment programs through her analysis of the trafficking of TB-infected sputum in prisons in postsocialist Georgia. Prisoners attained and used TB-infected sputum to achieve positive TB diagnoses, which (when they were not caught) allowed them access to better housing, food, and medical care. Koch characterizes such subterfuge as a form of agency. Her rich observations are suggestive of the ways in which universal treatment programs may provide individuals in dire circumstances with resources to manage harsh realities.

Biehl (2005, 2007) has described a political economic context in Brazil in which decentralization of healthcare, the individualization of treatment, reduced funding for healthcare, and the emergence of free drug distribution converge to create a situation where family members act as proxy treatment managers. He suggests: “Illness becomes the ground on which experimentation and breaks in intimate household relations can occur. Families can dispose of their unwanted and unproductive members...on the basis of individuals’ noncompliance with their treatment protocols” (2005: 22). As Biehl has demonstrated through a detailed ethnography of the social abandonment of a woman named Catarina, the breakdown in household relations occurs along other lines of inequality such as gender discrimination and market exploitation.

Inequality, Frederick Klaits (2010) argues, is increasingly experienced and managed through domestic relationships in Botswana in the wake of neoliberal policies and the HIV epidemic. Using the term “domestication of inequality,” Klaits suggests that a dual-sided process has emerged where inequalities are not only increasingly experienced in domestic relationships but are also morally assessed and managed through them. By focusing on women, who have fewer opportunities in the labor market, Klaits demonstrates that the performance of domestic activities is central to Tswana women’s efforts to maintain household positions. Their wellbeing, he suggests, hinges on their ability to compel others to provide resources through domestic activities such as nursing, feeding, bathing, and cooking.

I suggest that the children in my study domesticated the rules of TB treatment (in short, DOTS) in an active attempt to maintain household belonging and secure care. Children domesticate DOTS under conditions that make children’s access to resources and positions in households highly insecure. While children’s participation in domestic activities in southern Africa is not new, and neither is their mobility among households (Colson 1958, Hansen 1990), the reasons for their participation and mobility have changed in the HIV era (Ansell and van Blerk 2004). The topic of care for children has generated substantial global attention because of adult morbidity and mortality in HIV-affected areas. In a review of recent literature on childcare in South Africa, Bray and Brandt (2007) take issue with current conceptualizations of the family, which assume that independent adults care for dependent children. They argue for more complex analyses of child and adult care as a “two-way”

relationship. “[T]his opens up conceptual space for understanding the potential positive impact that children’s input to these relationships has on adult well-being, and hence on adult abilities to continue caring and fulfilling other roles in the home and family” (2007: 11). An examination of children’s domestication of DOTS offers insight into children’s active agency, while also acknowledging how changes in global adherence protocol enter into strategies to safeguard identities, relationships, livelihoods, and futures.

Making Children’s Roles Visible

When I first began studying children’s involvement with TB, I found it difficult to ignore the absences, silences, and concerns around children’s proximity to the disease. Because of its close biomedical association with HIV, TB now primarily affects people between the ages of 20 and 35 years (MOH 2005). Most patients in the Corner were in this age range or older, and children were conspicuously missing from the daily bustle of Corner activities. Their absence seemed to contradict their important and acknowledged role in running errands. Children in George are frequently seen buying vegetables at the market, carrying messages to and from neighbors, and frequenting small tuck shops to buy drugs such as Panadol (a pain reliever) for household members. In June 2008, I organized a discussion with two TB Treatment Supporters, local retirees Maxwell and Godfrey, to ask specific questions about TB treatment delivery in George. When I asked why children were rarely seen in the TB Corner, Maxwell suggested that TB Treatment Supporters might have something to do with this rarity: “We look at the age. Maybe if they’re 14 or 15 [years old] it’s okay. But not 10, because we restrict. We don’t allow children.”

Children’s proximity to the TB sick was not just under debate in the clinic, but extended into the homes of the sick. On the day 10-year-old Abby’s mother, Elesia, was diagnosed with TB, the extended family gathered to decide who should care for Elesia and where to send Abby and her 6-year-old sister, Chiko. Based on clinical advice about the infectiousness of TB, the family advocated separating the children from Elesia. After Elesia stifled a series of coughs, she asked me if I knew of any injections to prevent her daughters’ infection. Elesia explained that her daughters’ help, love, and encouragement were indispensable to her recovery. Elesia expressed a common dilemma: children are critical providers of care to the sick, and they are also vulnerable. As the family debated where the children might go, I wondered about the insecurities Abby, Chiko, and Elesia faced. Were they more vulnerable apart or together? At the heart of this question is the need to contend with two (or more) types of vulnerabilities—childhood and illness—simultaneously and in relation to each other. The answers to these questions rest heavily on the ability to examine children’s experiences and voices as part of the complex social bases of care.

In December 2007, after carrying out research with Abby for several months, I asked her to explain how she knew her mother had TB. Her answer pointed to the isolating practices involved in avoiding disease transmission. She told me: “When my mother came back from the clinic she was using her own utensils and we were told [by their mother] not to eat left out food by her or use her face towel.” Abby and her sister were also told that they could not sleep in the same bed with their mother, a common measure advocated by nurses and TB Treatment Supporters to decrease children’s likelihood of infection. While sharing a bed was frequently a necessity in crowded homes, it also reinforced relationships and social positions. These isolating—though well-intended—rules about children’s proximity to their loved ones were cause for concern for children who feared abandonment. In the midst of such isolating messages, the children co-opted DOT as their responsibility and, therefore, carved out a role for themselves within their households.

Adults praised and encouraged children's home-based involvement with medication. When I first met Moffat, a man who suffered from TB and was also on antiretroviral treatment (ART), he sent his 11-year-old son Steven to the bedroom to show me his medications. Moffat smiled with pride as Steven explained when Moffat was supposed to take each pill. In a similar manner in February 2008, seven months after her grandmother had begun TB treatment, eleven-year-old Rose recounted a fictitious story about a man who was just diagnosed with TB. I had given her a series of pictures to view as she told stories on my tape recorder. Referring to a picture of a person in a hospital bed, Rose said:

This is my father. He is suffering from TB and he is telling his children: "I am sick my children. But my children, I am taking my medicine, I went to the hospital and I was given this medicine. In case I might forget my dosage, you should remind me and they have also given the vitamins. These are the TB tablets. I was also told to eat a lot of food and fruits." He later got better because he followed his medication very well. My father didn't die. I love you dad.

While Rose's father had never suffered from TB, her grandfather, baby sister, and mother's brother had all completed TB treatment and her grandmother was nearing completion. In Rose's quote, we see how medicine offers a measure of hope and a way to reaffirm relationships as Rose's fictitious father explained that he needed his medication and that his children had a role to play in giving it. Even though he did not reference death, it becomes clear that his life was at stake in Rose's final comment that her "father didn't die."

The children's monitoring of medications aligned not just with the rules of DOT, but with children's roles in households in Zambia, where a good child is considered to be one who is responsive to adults. Conversely, a child who does not listen to adults' commands is considered naughty. It was no surprise, then, that when I surveyed adult TB patients their most common response about children in their households was that the children had become more caring, an emotion and practice demonstrated through their attentiveness to the sick person's wishes. Both children and adults marked such attentiveness by invoking a child's willingness to bring TB pills and drinking water for taking the pills. Care was also marked as a child's encouraging words about the TB treatment. During October 2007, I conducted a survey with the 17 adult TB patients in my study in which I asked an open-ended question about how children had "changed" since they had initiated treatment. The responses were strikingly similar to Mr. Simwonde's following statement about the changes he noted in his 11-year-old son Mulenga: "He encouraged me that I should keep taking my medicine everyday."

Elesia's daughter, Chiko, took adherence to the rules of TB treatment one step further when she offered to take a repeat TB test for Elesia, which Elesia had been delaying for weeks. Pulmonary TB patients in Zambia are required to submit follow-up sputum samples two months into their treatment. The diagnostic tests alert health practitioners about the efficacy of the medication and mark a transition from intensive to continuation phase medications. Instead of submitting sputum, Elesia continued to collect intensive phase medication weekly from the clinic. She told me that it was just too painful to walk so early to the clinic and produce the sputum needed for the test. As Elesia spoke to me about her struggles to produce sputum, Chiko interrupted, telling Elesia that she would give the doctors her own sputum for the test. Elesia's lack of adherence to the diagnostic rules of TB and her continued use of intensive phase medications distressed Chiko and her sister, Abby, who wished to usher their mother through treatment to recovery. The delay symbolized a prolongation of an illness in which there was a looming threat of separation or death.

Performing Adherence

The children became exceptionally concerned when they were not allowed to monitor treatment adherence. Consider 9-year-old Luka and 11-year-old Paul's situation. In 2007, Luka and Paul's father, Musonda, started to cough, lose weight, and suffer severe body pains. His legs swelled to twice their size and he could no longer breathe easily. Accompanied by his wife, he made several extended visits to George Health Center. On his second visit to the clinic, Musonda was referred to another health center, farther away from his home, where he could have an X-ray taken because there were no X-ray machines in George. The X-ray confirmed suspicions that Musonda suffered from pulmonary tuberculosis, but by that point he had become quite debilitated. Luka and Paul were in charge of bringing him his medication and a glass of water each morning. It is not easy to take TB drugs, which include a large pill that is difficult to swallow. As Paul once told me, it took particular persistence to get his father to take the medicine when his suffering became too severe and dying seemed like a desirable alternative to bare existence. In children's own admissions, they reminded, convinced, and at times begged adults to take their medicine daily.

Six months after Musonda was diagnosed with TB, his condition became so dire that his wife, and the boys' mother, took him to the University Teaching Hospital (UTH), the main hospital in Lusaka, a one-hour bus ride from George. Luka and his brother were visibly and understandably anxious as a result of their father's hospitalization. Earlier in the day, I had visited UTH to see Musonda, who was in the TB ward but suffering from a severe case of pneumonia. I delivered news of Musonda's much improved condition to his family who had gathered in the home. Luka and his brother took my recorder outside and directed messages quietly into the machine. Luka said:

My dad is in hospital and I feel tired. And since the time he went to hospital, he has not come out... So I asked the doctor if we [Luka and Paul] are allowed to go to [ward number] E21. He said "no." I don't know what to do. Maybe to go through the window? Children are not allowed and the building is tall. So doctor, take care of my father because we won't be coming to see him with medicine everyday in the morning before he eats anything.

When I listened to Luka's recording that night, I was struck by his version of adherence, which suggests that children (and families more generally), rather than medical professionals, are responsible for ensuring adherence. In a reversal of clinical roles, Luka tells the doctor to attend to his father's medication because "we won't be coming to see him with medicine everyday in the morning before he eats anything."

Luka's views on treatment adherence are, perhaps, best explained through role-plays enacted by children in my study. Let me offer a bit of context to set the scene. In December 2007, I invited children to join me at a children's workshop where the children discussed, played games, and used role-plays to offer their views on illness and caregiving in George. I divided the children into groups and asked each group to create a role-play about "living in a home with a sick person." I avoided using phrases like "taking care of" so that the dramas would not take on the prescriptive tone of many public health skits that focus on how people should act toward one another. And I did not offer suggestions about what disease the sick person in the skit might suffer from. Thrilled to be in the spotlight after a sugary snack and two hours of sitting on long concrete benches, the children turned what I expected to be short and shyly enacted snapshots of homes in crisis into detailed and lengthy dramatic performances.

All role-plays carried out in the different workshops focused on medication, offering insights into children's views on how and who is best suited to observe adherence. Consider the following role-play enacted by Abby, Alick, Mulenga, and Agnes. All four children were living with an adult who was currently taking TB treatment, two mothers, a father, and a "sister" (maternal relative). In their skit, a young girl's mother, played by Abby, starts coughing violently. Agnes, who played the daughter, took a break from washing the dishes to ask Abby: "Mommy, what is the problem? Why are you coughing, coughing? Your cough isn't finishing [getting better]. Do you have a 500 [US\$ 0.10] so we can go to the clinic?" Abby handed her daughter the money as Alick, Abby's husband and Agnes's father, returned from work. At the clinic, Abby receives a diagnosis of TB and her daughter and husband are given pills. The clinician gives them instructions on how Abby should take them and he alerts them to watch Abby take them. They return home, with Agnes keeping careful watch over her mother's medicine. Her concerns over her mother's proper use of the medicine culminate in her father attempting to take over her duty of providing medicine. When Alick motions as if he is giving medicine to Abby, Agnes yells: "No, daddy! It's only one [tablet]!" She grabbed the medication from her father and reinstates her role as the primary treatment observer. The role-play continued, with Alick playing the clumsy husband and Agnes the knowledgeable young girl in charge of treatment.

When adults became sick, children frequently positioned themselves to be the caregivers who reminded and encouraged adults to take their medication. For example, children in George frequently spent school holidays in the homes of relatives. However, I noticed that the children in TB-affected households were rarely going "on holiday," even when relatives wanted them to visit. I asked 12-year-old Kelvyn why he did not stay with his uncle's family nearby during a school holiday, like he had always done before his mother fell ill. He responded, "Who will remind mommy to take her medicine?" Statements like Kelvyn's suggest that providing daily TB medication may have been a chore that children could readily carry out within the constraints of TB illness, but it was much more. The need to ensure daily treatment served as a way for children to express and perform particular relationships and identities, while negating others.

TB Treatment and the Category of Child

Kin and age categories are reinforced, performed, and contested through daily TB treatment. By expressing concerns that relatives, doctors, and even family members might not care enough to encourage or remind their sick parents or guardians, the children in my study were showing that they themselves cared enough. The result, as the cases below demonstrate, was not only hope that the sick person would recover, but also an attempt to reinforce their belonging in particular households and to particular people.

I first met Musa when his 25-year-old brother, Patrick, was diagnosed with TB. After Patrick's diagnosis, their mother Judy sent Musa to live with an uncle, a kilometer away. The move was meant to relieve strain on household resources and protect Musa from TB infection and the burden involved in caring for the extremely ill. To an outsider, Musa's daily life in his uncle's home might have seemed more desirable. His uncle was better off than Judy, and he lived in a larger home with leisure items such as a television, radio, and video games. When I asked Musa to draw a day at his uncle's house, he gave me three pages of drawings, offering a detailed account of a day that consisted of riding a bike, playing video games, watching a baby, watering the garden, and sitting alone, "just thinking." Notably, he was alone most of his days there and had only developed a close emotional bond with another young boy who lived in and carried out work for the household.

After a week in his uncle's household, Musa moved back with his mother, Patrick, and his older brothers. According to Judy, he simply showed up and started helping with house chores. I asked Musa why he had returned and if something had happened at his uncle's home to prompt the move. He replied that he needed to help Patrick take his medication.

Patrick did need people to help him take his medicine. He could no longer walk or even sit up on his own. During the last month of Patrick's life, my visits to the household revolved around Patrick's medical regimen, with Musa discussing the ways in which they were and were not able to get Patrick to follow the medication. Patrick was no longer eating, something he needed to do to gain strength and because the clinic rules of treatment emphasized proper nutrition. After Patrick had died, the family wondered what they had done wrong when they had "followed the medicine."

Over the months after Patrick's death, I learned just how much Musa worried that separation might cause Patrick and his mother to forget or give up on him. In a series of informal conversations and tape-recorded stories, Musa suggested that children without caring relatives do not finish school. Instead, they start smoking, drinking, and "having habits of stealing and insulting big people." And they eventually move to the streets. Musa's father had died years before, but he had an older brother who provided him with material things and doted on him. His mother ensured that he went to school and, when she could afford it, paid for him to receive extra tutoring. Musa viewed both his mother and Patrick as advocates—people who loved and cared for him and wanted him to receive an education and succeed in the future. While life in his uncle's house may have been easier, the key to long-term wellbeing was the ability to remain close to Patrick and in his mother's care because they wanted him to succeed. In Musa's view, proximity and his strategic directing of attention and productive activities to Patrick ensured that he also received the nurturing he needed.

Given the alarming statistics on adult illness and death due to HIV and AIDS in southern Africa, aid workers and government officials frequently lament adult deaths by invoking the children who are left behind. The children in my study were exposed to such discourses daily in the forms of school lessons and radio messages. Throughout the study, the children repeated slogans about the need to care for orphans, and they demonstrated substantial fears about becoming orphans or street children. Take for example Abby's narrative about a drawing of a child sitting on her own and crying. I asked all of the children in my study to offer stories on this and other drawings. All but one child identified the child in the drawing as an orphan. In March 2008, seven months after Abby's mother had initiated TB treatment and at a time when her mother was just beginning to regain strength, Abby offered the following story, linking the child's story with her own experiences:

Here I see the baby crying. Her mother died... Death is very bad, that's why this girl is crying. Even me, it would hurt me very badly if my mother had died when she was sick with TB... Who would take care of me? As to my side, I always pray to God to let my mother take care of me at least up to a stage where I can take care of myself and do the same to my sister and my brother... Not her dying, leaving me at this stage. NO. NO. Because some aunts say: "They are orphans, I will do whatever I want to do with them." That's what happens to orphans. They later become street kids... No one can forget her mother.

Within their discussions, "orphanhood" was constructed as an identity that hinged on social relationships, a lack of belonging, and a removal from recognizable forms of childhood. Even the children who were considered orphans by international definitions because they had lost one or both parents were still fearful of becoming orphans. Recall that Musa's father had died. Musa and the other children who had lost parents did not consider

themselves to be orphans if they had the love and care of an adult, even if such an adult was a grandparent or aunt. Their orphanhood was removed through belonging to households where adults cared for them and engaged in subterfuge to protect them from the stigma associated with parental death (Klaits 2010; Ross 2010). With Patrick and his mother nearby, Musa was not yet an orphan. In a different household, one young girl became so frustrated when relatives removed her from her mother's home that she argued that she and her sister should also get sick with TB so they might be reunited with their mother. The loss of a mother was viewed as more deadly than the loss of health. The shadow side of the illness or death of a parent or advocate is the potential social death of the child.

The children demonstrated that proximity to particular households and adults shaped their identity and facilitated their access to schooling, basic material needs, discipline, and loving adults, and it also carried responsibilities. A good child, they suggested, must act with "good manners," listening and responding to the commands of adults and avoiding behaviors such as lying, skipping school, and stealing food. Giving medicine and the food and water that accompany treatment regimens was one aspect of a child's responsibilities that not only marked them as good children, but became sometimes desperate attempts to ensure the reciprocal provision of resources.

Discussion

The introduction of universal TB treatment in Zambia has saved lives and demonstrated the efficacy of biomedicine. In its implementation in George, DOTS programming has combined the dual notion that TB treatment must be adhered to and that "community" and "family" bear responsibility for adherence. The social side of "following medication" that has arisen under DOTS and within an overburdened health system is part of a larger pharmaceuticalization of public health (Biehl 2005) occurring in Zambia where the state's TB management programs now hinge on providing treatment and outsourcing care to families and communities. We need a richer understanding of how such a shift reconfigures social relations, reproducing inequalities or becoming a tool to redress the harsh conditions produced when poverty and illness combine. Rather than the fault line on which relationships were broken and family members cast out (Biehl 2005), TB treatment, for the children in my study, represented a resource to negotiate belonging at a time when their relationships and futures seemed most fragile.

The ways in which the children utilized adherence models suggests that pharmaceutical resources became indispensable to their efforts to make claims to households, people, identities, and belonging. The children's actions were part of a broader landscape in which community is increasingly experienced and citizenship claims made on the basis of biology and therapy (Nguyen 2005, Petryna 2002, Rose and Novas 2005). However, the children were experiencing belonging and enacting claims not on the basis of their own biology or therapeutic need, but *through* the therapeutic needs of loved ones.

Biomedicine is localized in everyday life, its technologies and categories invoked and contested to make sense of experiences of extreme suffering (Ross 2010) and recast relationships and responsibilities (Biehl 2005). I agree with Biehl and Petryna's assessment that "It is at the intersection of the therapeutic imperative, the biotechnical embrace, and the reason of the market that the intensity of survival becomes visible" (2011: 381). The concept of biotechnical embrace, Good (2001) suggests, implies the affective response associated with biotechnologies, such as TB treatment and protocols for managing TB. In her words, "'embracing and being embraced' fundamentally links contemporary high-technology medicine and bioscience to the wider society" (2001: 399). The children's embrace of TB technologies became evident in their adherence to rules of treatment, their belief in its

efficacy, and the hope it afforded for their futures. TB treatment, because it is so highly effective and requires stringent adherence, shaped their actions and imaginations. However, the term embrace obscures the urgency and desperation in their attempts to sustain life, both social and biological. I suggest, instead, that children were domesticating TB treatment and its rules.

It became clear that the children were neither marginal actors within the national and global emphasis on DOTS, nor were they passive victims of the TB epidemic. As TB treatment has become a domestic project within the context of the state's implementation of DOTS, children have also worked to domesticate TB treatment to gain control over, make sense of, and remedy adverse circumstances. Through actions such as reminding loved ones to take medications, showing themselves as knowledgeable about the rules of the medication, and situating themselves close enough to TB patients to administer medication, the children strategically repurposed TB treatment regimens to reinforce kin relationships and social positions. Carving out a role in TB care became an attempt to shape the care, love, and help available to them. This was not an easy task given the transmissibility of TB and the heightened concerns over and reality of children's risks of infection.

Attention to children's roles in TB treatment regimens exposes the forms of life that are forged at the intersection of public health, DOTS, illness, and childhood. As Ross has argued of belonging in a poor settlement in Cape Town: "a life worthy of the name is created by being dependent on others, and that dependence is precarious" (2010: 205). By considering children's roles in TB treatment, we see not just children's dependence, but how some children nurtured dependence through creating interdependence. The interdependence cultivated by children through TB treatment demonstrates how children engage dominant discourses of global programming, such as DOTS, in resourceful ways that contribute to their sense of belonging to households and kin groups. Such an analysis suggests that the rubric of 'treatment support' inadequately captures the meanings of adherence rules for children. Instead, making adherence possible became imperative to cultivating family and community under conditions where security in relationships and resources were neither assured nor expected.

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