“He is almost like other children”: An Ethnography of Malawi’s National Pediatric HIV Treatment Programme

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
Anthropology
University of Toronto

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Abstract

My dissertation is an ethnographic exploration of what it means to raise a child with HIV in one of the poorest countries in the world. Throughout I follow a small number of children and their caregivers as they engage with a new Global Health Initiative (GHI) to provide free universal access to antiretroviral therapy (ART), or anti-AIDS treatment, for infected children at a government run hospital in rural Northern Malawi. To date very little is known about how the roll-out of pediatric ART in decentralized health settings is progressing. The few studies that exist tend to emphasize access to medicines as the key barrier to treatment, which decontextualizes patients from their social milieu. My project focuses on the clinic-household nexus in order to better understand how historically embedded social relations impact treatment pathways for young children living with HIV. Specifically, I trace how gendered norms within marriage, disease etiologies, the clinical encounter, land tenancy and migration affect diagnosis and long term treatment adherence. My findings indicate that access to and the long term benefits of ART for children are mediated along socioeconomic fault lines. Although ART is an essential component of any HIV/AIDS care and treatment programme, I argue throughout that the distribution of medicines alone is ineffective in the absence of loving caregivers, good living conditions, sustainable food sources or a robust public health care system. My research contributes to academic debates about the mechanisms behind embodied inequalities and calls for a broadened scope beyond the individual patient in the development and implementation of HIV care and treatment services for children living with HIV.
Acknowledgments

Sherry B. Ortner once said that “ethnography of course, means using the self, as much of it as possible, as the instrument of knowing.” In that sense this project was not only an intellectual pursuit but an intensely personal one. The place I call Temwa, which means “love” in the local language chiTumbuka was my home for three years. The people I lived with, cried with when their children died and laughed with while they were bedridden in hospital forever shaped my perspective on life, death and happiness. While I hope that this research benefits each of them in some way, I know with certainty that my perspective on the world has been forever shaped by each of the people who let me into their lives. Tawonga Chomene.

Writing a dissertation is another kind of life transforming experience. The sudden jolt from fieldwork to a solitary writing desk was only possible because of the many people who read drafts, texted encouragement over morning coffee and helped me work through jumbled ideas. A special thank you goes to my supervisor, Holly Wardlow, whose thoughtful and steady commentary since the beginning ensured that fieldwork went smoothly and that the writing eventually ended. My committee members Mark Hunter and Krista Maxwell were also voices in my head that helped me refine my arguments near the end. I also have to thank various faculty members at the University of Toronto who offered valuable insights at critical times including Tania Li, Michael Lambek, Daniel Sellen and Janice Boddy.

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A special thank you also goes to my husband Special Mnkhwamba and my parents Calvin and Patti Sikstrom. Over the years they have each made sacrifices (both in terms of time and money) to make this project possible. I know much of what I did on a daily basis remains a total mystery to them, but for their faith in me and this process, thank you.
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<td>ANC</td>
<td>Antenatal care</td>
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<tr>
<td>ART</td>
<td>Antiretroviral therapy</td>
</tr>
<tr>
<td>CO</td>
<td>Clinical Officer</td>
</tr>
<tr>
<td>GoM</td>
<td>Government of Malawi</td>
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<tr>
<td>HCT</td>
<td>HIV Counselling and Testing</td>
</tr>
<tr>
<td>HCW</td>
<td>Health Care Worker</td>
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<tr>
<td>HSA</td>
<td>Health Surveillance Assistant</td>
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<tr>
<td>IMF</td>
<td>International Monetary Fund</td>
</tr>
<tr>
<td>MCH</td>
<td>Maternal and Child Health</td>
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<tr>
<td>MoH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>NAC</td>
<td>National AIDS Commission</td>
</tr>
<tr>
<td>NGO</td>
<td>Non Governmental Organisation</td>
</tr>
<tr>
<td>OPD</td>
<td>Out Patient Department</td>
</tr>
<tr>
<td>ORT</td>
<td>Oral Rehydration Therapy</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of Mother-to-Child Transmission</td>
</tr>
<tr>
<td>RUTF</td>
<td>Ready to Use Therapeutic Food</td>
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<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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<tr>
<td>TMG</td>
<td>Therapy Management Group</td>
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<tr>
<td>U5</td>
<td>Under Five</td>
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<tr>
<td>UN</td>
<td>United Nations</td>
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<td>UNDP</td>
<td>United Nations Development Program</td>
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<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
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Introduction: “This Disease Ends in Death”

≈ Katherine and Mercy ≈

“Katherine’s grandfather, father and three brothers all died in the last two years,” Mercy explained, when I asked her how she came to know that her five-year-old daughter, Katherine, had HIV. It is May 2009, and a month since we first met Mercy and her five year old daughter Katherine at the HIV clinic at Temwa Rural Hospital. Katherine was one of the first children in Malawi to be enrolled in Malawi’s new national pediatric HIV treatment program; a year earlier she would have died from her HIV-related symptoms, but that day she impishly smiled at me from her mother’s side.

Katherine’s story is typical of the children with HIV that I met while doing 18 months of ethnographic research in Northern Malawi. Like most children with HIV, Katherine became ill before the age of one. Fevers, diarrhea and weight loss all characterised her early childhood. Mercy explained how they would bring Katherine to the hospital each time, and after being prescribed “medicines” [Mercy did not know what kind], Katherine would recover for a while and then fall sick again a few days or a few weeks later.

Around the same time that Katherine was falling sick “now and then,” four of her siblings also died “one by one” over a three year period. During this time, children in Malawi did not have access to HIV care and treatment services so nobody knew what was wrong. As Mercy explained:

Then, they were not testing us [for HIV] when we were pregnant. So we didn’t know what was happening. The doctors were just saying, “this one died of malaria”, “that one died of diarrhea”. “Others” [neighbours, friends, family members] were saying that we were “bewitched” [cursed by a relative out of jealousy], but even at the time I was just wondering if maybe it could be this disease [HIV]. Now I think that they also died of this disease.

Like most families, Mercy only found out she and her daughter Katherine had HIV once her daughter became very sick. A few months before her official diagnosis, Katherine’s symptoms

1 All names and places have been changed.
turned more serious. She started to complain about leg pains; when she tried to walk she would fall down; she had trouble eating; she repeatedly experienced fevers and diarrhea. Mercy and her mother-in-law took Katherine to the district hospital where “the doctor” who examined her found nothing wrong with her legs and sent them home.  

A few weeks later when the problem persisted, they tried the district hospital again and were told that there was nothing wrong with Katherine’s legs and they were sent home again with a prescription for panado [the brand name for paracetemol, a mild analgesic/pain killer].

Around the same time that Katherine was having trouble walking, her father was also very sick. At this time Mercy’s sister-in-law, Katherine’s Ankhazi Esther [her father’s sister] came to stay with them to help look after her brother. Katherine’s Ankhazi Esther suspected that her brother might have HIV, so she advised him to go for a test; when he agreed, she escorted him to the hospital where he tested positive. Mercy cried when he told her the results later that day at home, but she was not surprised:

I knew that maybe we had this disease, when I saw the way he was falling sick and the way our children were dying. But my whole life I was healthy. And I was afraid. To take medicines every day for the rest of my life… I cannot make it.

Mercy’s husband started antiretroviral therapy (ART) two weeks after he tested positive. Unfortunately, he died “before he could even finish one bottle [of the medicines]”, or less than a month later.

A few weeks after his death, Katherine’s Ankhazi Esther intervened again when Katherine stopped walking completely and refused to eat. According to Mercy, she “forced” her to take Katherine for a test after hearing on the radio that children could now take “the medicines” as well. 3 She complied and took her daughter for a test at a health centre not far from

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2 Malawians call most medical staff ‘doctors’, but since the district hospital only had one medical doctor on staff (who did not see patients in the outpatient department) it is unlikely that she was examined by a physician. It is more likely that she was seen by a clinical officer (CO), a mid-level cadre of health care worker with four years of university clinical training and the ability to prescribe medicines.

3It is important to distinguish between an Ankhazi, who is an aunt on the father’s side, and the amama wadoko or the amama walala (young mother or elder mother), since these are aunts belonging to the mother’s side. The distinction is critical here because in this case the involvement of paternal relatives indicates that the child is “owned” by her father’s family, or that he paid lobola (bride wealth) that transfers custody of children to the father’s family. This has two major implications for Mercy. The first is that Katherine’s father’s family can (and
Temwa. Mr. J, the Health Surveillance Assistant (HSA) on duty, a cadre of community health care worker, gave them both a rapid antibody test and told her that they were both positive. Mercy was not surprised about the results, given as she said, “the way we are in our bodies.” Mr. N, the clinical officer at Temwa, “staged” them according to the clinical guidelines established for treatment initiation and determined that they were both eligible to start treatment.\(^4\) After taking “the lessons” [mandated treatment adherence counselling] a few weeks later, Mercy and her daughter both started treatment. This was the same day that we met them for the first time at Temwa Rural Hospital. On that day, I conducted a short interview and then I obtained Mercy’s consent to visit them at home; after she agreed, we decided that the best time to visit would be in a few weeks.\(^5\)

On the agreed upon day for our home visit, my research assistant and I rode my motorbike approximately 10km outside of town to find their village. Early on in my research I was not sure what to expect after a child started ART treatment for the first time. The day we met Katherine, she could barely lift her head to say hello to us. So we were thrilled, and very relieved, when we found Katherine completely transformed and playing outside with her best friend Judy. Katherine greeted us shyly and showed us the miniature brick house she built in the tobacco field next to her house. Miniature houses were used by children of all ages to play *kudimbika*, or “house.” Her role, she told us, was to play at being “a girl.” She put an old margarine container filled with water on top of her head to show me what she means:

\(^4\) According to the national guidelines at this time adults and children could start treatment if they were classified either stage three or four according to a clinical algorithm developed by the World health Organisation (WHO). See Chapter One and Four for more details.

\(^5\) As part of this process, I encouraged families to think about the repercussions of my visit; how would they explain my presence to neighbours and friends? What would they like me to tell people about the purpose of my visit and so on since the child’s HIV status was rarely widely known. In nearly every case we agreed to tell neighbours and friends that I had met them at the hospital for a common childhood illness and that I was coming to see how everyone was doing.
“[As a girl] I draw water!” To tease her a little bit, I asked if she was married to anyone: a common game in kudimbika was for young children to marry each other in elaborate (and noisy) wedding ceremonies. She laughed and laughed, raised her eyebrows (a child’s way of saying yes) and then ran away. Mercy stood near me and watched her daughter run away. Mercy then turned to me and said: “We have a few more days, but no future. This disease ends in death.”

I was shocked by her conviction; the worries I’d had about Katherine’s future had evaporated when I saw how quickly she’d recovered after just a few short weeks on treatment. When I asked Mercy to explain, she highlighted their lack of resources, her own poor health and her certainty that Mercy would never have a “normal life.” She explained:

Her body will never be healthy like her friends. She will never marry, or get educated or have her own children. Maybe she will be a bit better for a few days... but this disease never goes away. We will both die of it. And what happens to her when I die? Who will make sure she takes the medicines and eats good food? No, we cannot make it.

Her mother-in-law and I both tried to encourage her by pointing out how well Katherine was doing after such a short time. While she agreed that Katherine was doing much better, and felt very relieved about this, she remained unconvinced that this would change her fortunes.

Two months later we learned from Ankhazi Esther that Mercy died of her own HIV-related symptoms at home, just a couple of weeks after our home visit. According to Ankhazi Esther, Katherine’s health deteriorated soon after her mother died. Her mother’s relatives claimed that Katherine belonged with them [a dispute over whether the lobola, or bridewealth, which transfers custody of children to the paternal family, was paid in full], and she was taken to live with her amama walala [her mother’s older sister], who, we were told, was very old and believed that because Katherine was so young that it was dangerous for her to take powerful medicines like ART treatment every day for the rest of her life. So after Katherine’s medicines ran out, no one came to collect the next month’s dosage. After a few weeks, Katherine’s health deteriorated rapidly. Ankhazi Esther took Katherine to stay with her when she saw how poorly she was doing. We found all of this out one day when Ankhazi Esther came to the HIV clinic

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6 Caregivers often worried that the medicines were “too strong” for young children (kamwana’s), or children who were weak, an issue I take up in more detail in Chapter Three.
carrying Katherine on her back; Katherine could no longer walk and was unable to even lift her head to greet us.

A few months after we met at the hospital the second time we went to visit Katherine again where she now lived with her Ankhazi Esther, in a village not far from Temwa. We found Katherine outside on the porch chatting with her cousins. Ankhazi Esther took care of eight children in total, Katherine and her brother, as well as six other children who were orphaned after the death of another brother and her own daughter. Ankhazi Esther said that although her own children were grown and married elsewhere, it was her duty to take care of these children as best she could. Although Katherine appeared to be doing better than when we last met at the hospital, she was not out playing with her friends, and was still having trouble walking. Ankhazi Esther was worried; although Katherine was supposed to start Standard One [Grade One] she was still not well enough to attend with her friends. We left them both for the last time after an afternoon spent chatting in the shade of their fallen down kitchen, unsure of what Katherine’s future might hold.

• • • •

My dissertation is an ethnographic exploration of what it means to raise a child with HIV in a resource-poor country like Malawi. In the following pages I introduce you to a small group of children with HIV as they and their families engage with a Global Health Initiative (GHI) to provide free universal access to antiretroviral therapy (ART), or anti-AIDS treatment, for children at a rural hospital in Northern Malawi. Although ART is an essential component of any HIV/AIDS care and treatment programme, I argue throughout that the distribution of medicines alone is ineffective in the absence of loving caregivers, good living conditions, sustainable food sources or a functioning health care system. In short, the benefits of ART for children in Malawi are unevenly distributed along socioeconomic fault lines. While ART resolves many HIV-related symptoms for some, not everyone, for various reasons I discuss, will survive into adulthood on treatment. Katherine’s case study above illustrates my argument. Despite Katherine’s access to free ART, her future is anything but certain. Her story draws attention to the institutional challenges, complex caregiving arrangements and long-term treatment trajectories of children living with HIV. Her story, and many others like it, illustrate how care proceeds amid
uncertainty and scarcity. The children’s stories in this dissertation reveal the unfortunate fact that biomedicine, or what some call “magic bullet” approaches, are always partial solutions. ART, like many biomedical interventions, can simultaneously save lives while exacerbating existing social inequalities (see Livingston 2013; Hamdy 2008 for similar arguments). My dissertation demonstrates that GHIs face many challenges at ensuring universal access to ART and that pharmaceutical interventions alone will not ensure that children with HIV grow up to live long and healthy lives.

The global scale up of ART was a welcome change after more than a decade of treatment denial and neglect (Nguyen 2009; Biehl 2007). However, the original initiative left children behind, revealing what Fassin has called the “politics of life”, or the “evaluation of human beings and the meaning of their existence” at the heart of humanitarian interventions (2007: 500-501). In other words, the humanitarian logic of these interventions, which claim to help all human beings equally and impartially, actually reproduces existing social inequalities in unexpected and sometimes “brutal” ways (see also Ticktin 2006: 34). For example, children with HIV are still half as likely to access free ART as adults, and the life expectancy of those children on treatment is unknown (Hazra et al. 2012; Mills et al. 2011). In effect, while Malawi’s national pediatric treatment program was driven by the desire to minimize treatment disparities between adults and children, the failure to recognize that all human beings are socially embedded within their own households, communities, and nations within the global political economy, has paradoxically resulted in exclusionary practices. This dissertation analyzes the consequences of providing free medicines for children with HIV while leaving untouched the social and economic conditions that lead to new pediatric HIV infections in the first place.

Throughout this dissertation I seek to critically explore how families and clinic staff interpret, negotiate, and implement health policies that are often designed elsewhere with little knowledge about the lives or compelling concerns of their “target audiences.” I am deeply aware of the very real and positive effects that HIV treatment has for infected children and their families. Left untreated, death comes quickly and painfully to an infected child, and it is my hope

7 The implication is that children are considered less valuable and less worth saving than adults. However this contradicts the stated humanitarian logic, which emphasizes the untained value of children because of their innocence of children. I believe this contradiction exists partially because HIV has been constructed as a sexually transmitted infection, and therefore research and drug development for children lags behind developments for adults.
that my research will improve treatment access and prevent treatment delays for infected children. To that end, my dissertation speaks to anthropologists interested in development more generally, as well as the emerging anthropologies of policy, pharmaceuticals and childhood (Hirschfield 2002; Petryna et al. 2008; Shore and Wright 1997, 2011). In addition, individuals engaged in developing and implementing health programmes might learn something about conceptualizing their “target audiences” within the wider social context of competing gender and generational demands at the household level, as well as the importance of class dynamics and mobility at specific health centres. Therefore, following in the footsteps of many people writing in the field of critical medical anthropology, throughout I will keep global structures of inequality in view while not discounting the possibility that Malawi’s paediatric HIV initiative has real, positive effects on children and their caregivers within those structures.

“Temwa is just a bush”: Decentralized HIV care and treatment in rural Northern Malawi

I’m catching a lift to my field site in the back of a Chief’s pick-up truck. I’m stuffed in the back with some of his relatives, my new mattress, pillows, bed frame, office supplies, clothes, lamps, food and a watering can that he helped me buy in Mzuzu where prices are cheaper. Another village headman holds tightly to my laptop bag while five-year-old Beatrice sits patiently on the spare tire in the middle, but gets onto her knees at every stop to look around. The Milky Way floats above my head and the moon is half full, but orangey red. We pass roadside okalas (small wooden shops) lit up with paraffin lanterns and Chinese LED lights, where vendors sell chips, candles, black-market petrol and cheap alcohol in small plastic sachets. I don’t see any cooking fires or villages in the darkness, but we pass some familiar places: Chambo village where I spent four weeks last summer staying with a family while I searched for a field site during preliminary fieldwork; “J. Lo’s Hot Spot” at Enukweni village where my last minibus broke down; the Bowe river just a trickle after a few months with no rains; the bumpy transition from tarmac to dusty dirt road outside Rumphi town; finally “Aunt Henry’s Filling Station” and the two giant makama fruit trees\(^8\), which means we’re almost in Temwa. As we get

\(^8\) As one person said to me: “If you plant a makama your grandchildren will be eating the fruit”, indicating that it took years for the giant palm tree-like fruit trees to produce fruit. They produce a football-sized fruit that people crack open on rocks, divvy up and eat like mangoes.
closer to town I hear Zambian tunes blaring from the local bottle stores and realize it’s that time of the night when nearly all the women have gone home and only the men remain, drinking, chatting and who knows what else. I’ll probably never find out. Dogs howl, the chickens have gone to their homes and tomorrow I’ll start mine.

- Moving Day, September 15, 2008

**Figure 2 Political Map of Malawi**
The refrain “Temwa is just a bush” was told to me repeatedly throughout my fieldwork. Health care workers complained about the lack of running water; teachers griped about government housing shortages; tenants working on tobacco farms compared their Temwa experience to working in the mines in South Africa; and my research assistants (both educated in cities, but from the Northern Region) worried about witchcraft attacks, which they argued proliferated in the “bush.” Bounded by a National Park to the north, a wildlife reserve and Zambia to the west, and acres of dry unfarmed land in Mzimba district to the south, Temwa often did feel like the middle of nowhere – especially after a gruelling three hour journey from the nearest internet cafe in the region’s political and economic capital, Mzuzu, 150km south.

Compared to the surrounding villages, however, Temwa felt like a bustling metropolis with electricity, a secondary school, a police station, franchised shops and a regional transport hub.9 “Town” [pronounced town-y by Malawians] was full of activity during the tobacco harvest season. The dirt road leading to the centre of town was lined with a half dozen brothels and “bottle stores” (bars that sold bottles of Coke, Fanta, Sprite and Carlsberg Green beer). Small one-room establishments with names like “Last Chance Saloon” and “Speak no Evil” drew crowds of men during the tobacco season when money from the tobacco auction floor sales kept the beer flowing. Catchy Zambian tunes assailed the town for months after sunrise, often lulling me to sleep at night during harvest season. Bar owners smuggled in young women from Tanzania for a few months a year to keep men company; the most obvious sign of this trade were the condom wrappers littered on the side of the road on my morning walk to the hospital. The busy market in the centre of town was indistinguishable from any other market in Malawi; shop owners sold tomatoes, potato chips, beans and bicycle parts. Across from the market a small police station overlooked the “Chirabu,” a treed grassy area bordering the town’s football pitch, where a few dozen men gathered daily from sunrise to sunset to drink homemade kachasu (distilled cane sugar) and beer brewed from millet, which was much cheaper than bottled Carlsberg greens. Men sat in groups of two to five in a circle around a brightly coloured plastic bucket, while a woman (the beer brewer) served them by the cup. While I could never join the

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9 For instance, Peace Corps Malawi had a half dozen volunteers living within a 15km radius of Temwa but had never placed a volunteer in town. As Ferguson also notes: Africa is “a patchwork of discontinuous and hierarchically ranked spaces, whose edges are carefully delimited, guarded and enforced’ (2006: 49). In this sense, Temwa falls somewhere in between the ‘rural’ and the ‘urban’.
men during these times without seriously damaging my reputation, I was told by tenant farmers that this was the best way to find work when they first arrived in town.

The Temwa Rural Hospital was in the centre of town, situated between the busy market, the *chirabu*, and the brothels. The hospital itself was unremarkable; only a faded crooked sign at the turnoff to town marked the space as a hospital to outsiders. The hospital consisted of two rectangular brick buildings connected by a covered cement walkway. One building housed the out-patient-department, the pharmacy and the small female and male wards (six beds each). The other had the antenatal clinic, the maternity ward (12 beds), the HIV Testing and Counselling room (HTC) and a room dedicated to the clinics held twice weekly for children under five. Serious cases were referred to the district hospital, which had more comprehensive medical care and one volunteer physician from the United Kingdom (UK). Two long-drop toilets (pit latrines) sat on the Western edge of the hospital’s unfenced grounds while a busy borehole marked the eastern border. Throughout the day the hospital bustled with activity; long lines often extended into the grounds, where kids were busy hunting for mangoes in the trees and collecting water for home from one of Temwa’s three boreholes.  

While Temwa Rural Hospital distributed free ART for children from a room next to the maternity ward (referred to as the “ART clinic” by staff) as part of a larger UNAIDS-sponsored global health initiative (GHI), palpable evidence often associated with GHIs, such as clinical tourists (Wendland 2012), Land Rovers (Closser 2010) and training workshops (Smith 2003; Swidler and Watkins 2006), was scarce. The few noticeable signs of foreign intervention were unobtrusive: two Chinese citizens built a new maternity ward and seven staff houses during my fieldwork (Alden 2007); photographs of “friends from Canada” – or what I soon deduced were World Vision sponsors – were sometimes posted on living room walls; and various “humanitarian goods”[12] funded by global health agencies, such as frozen immunizations in blackout-proof freezers, mosquito nets and ready-to-

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10 The only running water in town was run by a cooperative of farmers; you paid into a fund and they would build pipes to your house from a system that collected water in the surrounding hills. However, most families just collected water at the boreholes (including myself, since the cooperative could not bury the pipes to my house since it was too far away).

11 There were few NGOs working in the area. UNICEF came through occasionally to monitor their vaccination campaigns and their food supplement programme. On behalf of Temwa’s women’s forum I won a $5000 grant from USAID for a peer-tutoring programme at the secondary school. The Norwegian Development Fund also ran a micronutrient project in a few locations around town, and World Vision operated in the area until 2009 when the financial crisis forced them to cancel all their programs in the area.

12 See Redfield (2012) for a discussion on humanitarian goods.
use therapeutic food (RUTF) peanut butter packets, were distributed by health care workers according to standardized treatment protocols and guidelines.

During my research Temwa Rural Hospital served an approximate population of about 31,000 people, (more during the tobacco season) from over 200 different villages of varying size and distance from the hospital. Most of the children on ART lived within walking distance from the hospital (less than 10km one way); however, a few had to travel upwards of 50km a month round-trip to collect their medicines.\(^\text{13}\) Temwa hospital employed one clinical officer (a cadre of health care worker between nurses and physicians) and three nurses in total. The clinical officer spent most of his days seeing patients in the out-patient-department (OPD) while two nurses spent most of their time in the maternity ward delivering babies, with one nurse on duty overnight. Twenty-nine health surveillance assistants (HSAs), a type of community health care worker, ran all of Temwa’s primary health care programs, including vaccinations, under-five clinics, antenatal clinics, HIV testing and counselling and the ART clinic. While small, Temwa was the busiest hospital in the district with over 15,000 OPD visits per year. Eight other rural health centres were widely dispersed throughout the district and rounded out the government-run services available in Rumphi.\(^\text{14}\)

Temwa Rural Hospital presents a compelling microcosm of the intersection between global health interventions and tertiary health care in southern Africa. There, a small team of professional and community health care workers implemented Malawi’s first national pediatric HIV treatment programme in 2008 (see Chapter One for a detailed discussion of this program). Malawi’s national HIV treatment program is mostly funded by the Global Fund to Fight AIDS, Tuberculosis and Malaria (known as the Global Fund), a public-private partnership involving governments, consumer citizens, corporations, private foundations and the pharmaceutical industry (Richey and Ponte 2006; Taylor and Harper 2014). In Malawi, ART is distributed via the public healthcare system, which has free universal access as its mandate and goal (NAF 2005). Treatment guidelines were standardized to reflect best practices at the time and to quickly and efficiently move large numbers of people through the health system. These guidelines were

\(^{13}\) Although my aim was not to evaluate distance in relation to access, it was clear that families closer to the hospital took more advantage of the free services offered there. For example, the further away you got from the hospital, the more likely women were to give birth at home.

\(^{14}\) There was also a not-for-profit run hospital run by Dutch well-wishers not far from Temwa that offered similar services, but for a fee.
largely developed by a team of medical experts at the World Health Organisation (WHO) in Geneva, Switzerland. The guidelines were adopted by the Ministry of Health in Malawi, but their implementation in everyday practice reflects the reality of providing HIV treatment in a public hospital where physicians and vital machines are not present, drugs go in-and-out of stock and families routinely face critical food shortages.

Anthropologists have analysed global health projects from various vantage points, including interstate agencies and NGOs (Bornstein 2005; Justice 1986; Pfeiffer 2004; Mosse 2005), aid workers (Closser 2010; Englund 2006), voluntourists (Mostafanahzed 2014) and their target populations (Hahn and Inhorn 2009; Foley 2008; Castro and Singer 2004; Tawfik and Watkins 2007; Whiteford and Manderson 2000) using the rubric of humanitarianism (Bornstein and Redfield 2011; Fassin and Pandolfi 2010), human rights (Cheney 2007) and development (Ferguson 1994; Li 2007). These perspectives provide valuable insights into why variously positioned actors feel compelled to alleviate suffering and extend charity in different settings.

Public health practitioners have also analysed and measured these projects, but focus almost exclusively on the health outcomes of these projects (Gupta et al. 2011) and on increasing their “efficiency” through health system and health policy reforms (Hanefield 2010; Schwartlander et al. 2011). All of these perspectives go about answering the same question “what do these projects do” in very different ways. However, most of the research on ART programs relies on observations and research conducted on best-practices from specific geographical regions (Galway et al. 2012; Stringer, et al., 2006), better funded providers at district and central hospitals (Bong, et al., 2007), or nongovernmental organizations which provide above average services (MSF 2004; Sauvageot, et al 2010). James Ferguson refers to social and physical spaces where social and economic capital congregates as “enclaved points” within a global network.

However, an important consequence is that very little is known about the places that lie between these points, or what Ferguson refers to as the “abandoned hinterlands,” both in terms of how target populations engage with and understand health interventions designed elsewhere, and also their medical efficacy (2006: 47-50). While Temwa Rural Hospital relies on the transnational organization of funding and institutions to run its HIV/AIDS programmes, the lack of doctors, food, testing technologies and pediatric drug formulations reveals how starkly divided and hierarchically ranked the global health landscape is. Thus, my dissertation contributes to a wider
discussion about how global health interventions unfold within a marginalized social, geographic and economic context.

Although we know very little about how the roll-out of pediatric ART in decentralized government-run health centres is progressing, the information we do have indicates that men, children and migrant populations in resource-poor settings are far less likely to benefit from treatment, although very little is known about the reasons behind these results (Barninghausen 2007; Lima et al. 2009). The few long term studies that we have also indicate that Malawi has one of the lowest ART retention rates in the world, with only 54% of patients who start treatment still on it after five years, which raises important questions about the long term outcomes for children on treatment (UNGASS 2010). This paucity of research on decentralized ART programs is even more striking when you consider that nearly 87% of Malawi’s current population lives in rural areas, where rural health centres and rural hospitals like Temwa represent the standard of care for the vast majority of Malawians – not the often cited specialized treatment centres funded by NGOs or the better funded government central and district hospitals (WHO 2010).

Understanding the empirical reality of ART roll-out in these “abandoned hinterlands” (Ferguson 2006: 49; Das and Poole 2004; Piot 1999) is crucial not only for expanding our understanding of how global health programmes work, but also for ensuring equitable and timely access to life-saving medicines. Thus, my dissertation is both an anthropology of global health, which is less concerned with a specific project’s effectiveness than with “its messy, conjunctural effects” (Li 2005:101), and critical medical anthropology, which seeks to document and contextualize the effectiveness of health services with the explicit aim of improving them (Pfeiffer and Nichter 2008).

My Research Trajectory

I spent 2004-2005 doing research for an organisation in Malawi interested in food security and child nutrition. As part of this work I interviewed mothers who had young children with an illness they called moto, a syndrome with a number of symptoms, including severe coughs, fever, diarrhea and weight loss. While at the time nurses at the hospital insisted that “moto was really malnutrition,” I later became convinced that the reported rise in its frequency was related to undiagnosed cases of HIV in children (Sikstrom et al. 2010). What really intrigued me as an anthropologist was how people imbued moto with meaning: most attributed their child’s illness
to social dysfunction within their villages or to “promiscuous behaviour”\(^{15}\) by the child’s parents or youth in the village. These depictions evoked Evans-Pritchard’s (1936) classic quandary for biomedicine: its inability to resolve “the why me and why now” questions surrounding misfortune. I also became interested in how moto became a target of public health intervention by the nearby hospital after our research “revealed” to the hospital staff that grandparents were treating moto with herbal remedies. Medical personnel called all the grandparents together for a workshop at the hospital to “tell them” not to do it anymore. They were concerned that herbal remedies could introduce dangerous pathogens from unsafe drinking water to the children. While this “behaviour change” workshop was met with scepticism by the attendees, it left a lasting impression on me.\(^{16}\) How were families’ health strategies for sick children shaped by the various global health policies that filtered into their lives through government hospitals or mobile clinics that transmitted this information via health care workers to rural villagers?\(^{17}\)

In July 2007 I returned to Malawi as a PhD student to conduct preliminary research on child health, food security and health strategies for malnourished children with two broad questions in mind: how was childhood illness understood and experienced and how were global health interventions targeting child survival working in practice? As part of this process I met with a number of government and NGO employees to discuss my research interests and ask for the input of local experts. I focused my efforts on Northern Malawi; I was motivated to stay in the North because I had already gained some fluency with the language in the region, chiTumbuka. A few weeks into my trip I met Mrs. M, the AIDS programme coordinator at a Northern district hospital. She mentioned in passing that they were very busy that day because her staff was being trained by Baylor (Baylor International Pediatric HIV Initiative) in new testing and treatment guidelines for children with HIV; Malawi, she told me, was “rolling out” a national treatment programme for children in the next few months. Mrs. M had conflicted

\(^{15}\) “Promiscuity” in this context means “beyond the bounds of acceptable behaviour” and includes marital infidelity as well as sex between husband and wife while the mother is still breastfeeding.

\(^{16}\) Hampshire et al. (2009) also discuss a similar disconnect between humanitarian organisations and their target population during a food crisis in Niger. Whereas humanitarian organisations targeted vulnerable children under five for food supplementation, families felt the need to balance the risks to a single child with the need to preserve the long term livelihood of multiple family members. Thus, rather than provide food supplements to a single child, these were shared equally among all members.

\(^{17}\) The term “health strategies” is informed by Lock and Kaufert’s emphasis on the pragmatism of women’s responses to biomedical interventions, “where women will use whatever biomedicine can provide in pursuit of her own goals”, resulting in a complex mixture of selective resistance and selective compliance (1998:7).
feelings about the new program. On the one hand she felt that it “would help a lot of children” and that children had been excluded from treatment programs for “too long.” On the other, she had doubts that people “in the rural areas” would be very interested in putting their children on life-long treatment regimens in light of other pressing concerns, such as finding enough food to eat. I was intrigued, and told her that if they would support me I would come back in a year to do research on this new program. She agreed, as long as I secured the support of local Chiefs and the District Health Officer (which I did).

At that time, researchers had begun to examine ART disparities in access and treatment success along gender and geographical lines (Makombe et al. 2006), but I felt that seasonal rural-rural migration of farm workers and their children remained a severely overlooked factor affecting equitable access to HIV treatment (Barnighausen 2007; Lima et al. 2009). I knew from my previous work in Malawi that the district was a popular destination for seasonal migrant labourers. I also knew that food insecurity altered breastfeeding and infant-feeding practices, so I wondered how it might influence health-seeking practices for HIV-infected infants (Bezner Kerr 2005; Bezner Kerr et al. 2007, 2008; Sikstrom 2007). With these issues in mind I asked Mrs. M how she thought tenant farmers would see this new program. She suspected that tenants would struggle to put their children on ART. In her words: “They are so poor! No food to eat, living in terrible conditions. If you are interested in tenants you should go to Temwa. They have thousands of tenants there, and the hospital has even more visitors than us here at the district hospital.”

After our meeting I left the hospital and quite literally ran into a former Peace Corps volunteer that I had been friendly with in 2004. Emily was back in Malawi on a short contract, and, fortunately for me, she was now living in a village just outside Temwa and could introduce me to the health staff at the hospital. The next morning, I made my way to Temwa for the very first time. Over the following week Emily took the time to show me the area and introduce me to hospital staff, village Chiefs, People Living with HIV/AIDS (PLWHA) support groups and various members of the community involved in tobacco farming. These early introductions helped me refine my research questions and methodology. With Emily’s support (she was fluent in chiTumbuka) I secured permission from the traditional authority to work in the area, and the support of the Rural Hospital for my project as long as the Ministry of Health agreed. I left with
a few P.O. Box addresses in my pocket and a promise that I would return in a year to start my research.

In July 2008 I returned to Malawi and made the 750km journey from Lilongwe, Malawi’s capital city, to Temwa. Armed only with a letter that promised housing from a local Chief named “Chief Kaluwa”, I made the long dusty and uncomfortable journey by taxi, bus, minibus and finally pick-up truck. It takes two days to travel from Lilongwe to Temwa. The first day is spent on a bus to reach the Northern Region’s capital, Mzuzu. From there you catch a minibus for the second leg of the journey. After an hour or two you arrive in Rumphi “boma”, the political and economic hub of the district. This is where the district hospital is located. Foreigners were not very common this far north, and the minibus conductors always assumed that I was either a tourist or a Peace Corps volunteer, since there were at least a half dozen living in the area. They often shouted: “Mzungu, Njobvu, Njobvu!” (White person, white person! Elephant park this way!). I usually shook my head and told them that I am not going to the park, but that I was looking for the pick-up truck that would take me to Temwa. On my first day back in 2008, the conductor scrunched up his face in confusion and then declared: “Ahh! Doctor!!” which was a very common assumption. However, as part of my research ethics guidelines, I was not able to tell anyone publicly that I was doing research on children with HIV. As I was a very visible member of a small community, health care workers were worried that potentially damaging rumors would surround every family I met with. So, I told the
minibus conductor: “I’m a student doing research on child health, such as understanding how tenants find food.”

Malawians were often pleased by this declaration, but not always; many also felt that research by foreigners was an inherently extractive exercise, one that benefitted the foreigner (in wages and prestige) but not Malawians. On this particular day, the conductor was pleased. He escorted me to the one-ton truck waiting to fill up under the shade of a jacaranda tree. I threw my bag in, climbed up over the side using the tire as a ladder and sat myself down on a bag of maize with two other ladies. After a two hour wait, where we snacked on boiled peanuts and some bananas, just when I thought they could not possibly cram in another person, two more men jumped in and the conductor finally rapped the top of the cab and shouted “Tiyeni!” (Let’s go) to the driver. Squished into the back with two dozen farmers (I counted 23, not including almost as many children), fertilizer, 50kg bags of sugar and baskets of tomatoes, a few men got out to give us a running start. A few minutes outside of town the conductor asked for our money (200MK, or 1.50$CAD); I knew from my time in Malawi that to ask before everyone was settled would be considered very rude. For the next hour we lurched the last 20km leg of the journey to Temwa; the ladies covered their heads to protect their hair and eyes from the dry season dust, but I enjoyed the breeze after the hours in the stagnant air. Plumes of smoke from burning fields dotted the landscape; farmers were burning the fields to get ready for planting. Without any crops obstructing my view, I could see everything clearly. Goats frolicked alongside the road; tenant farmers carried watering cans, on their way to water their tobacco nurseries; and temporary bamboo houses were spread throughout the landscape: it all reminded me that tobacco season was imminent.

After an hour or so we turned right onto another dirt road. We were in Temwa. Brick houses, mostly owned by tobacco estate owners were on our left and on our right some government houses for local civil servants. Jacaranda trees (not yet in bloom) lined the short road to the “center” of town; the “bus stop” was across from regional post office. Farmers World, a
popular agricultural franchise selling farm equipment, fertilizer and seed, stood opposite two rows of small wooden shops selling hardware supplies, ice water, beans, rice, chips, watering cans and over-the-counter medicines for coughs and colds. Trucks loaded with tobacco lined the road to town; last year’s harvest was still being sold at the auction floors in Mzuzu. I recognized Chief Kaluwa in the crowd right away; he was easy to find because he was wearing his black “crown” (a sort of black turban denoting his Chiefly status). He greeted me warmly, but with bad news: the house he had found for me was not ready for anyone to live in. The owner of the house had a lucrative business transporting tobacco from the villages to town, but his vehicle had recently been in an accident, and he had decided to spend his money on repairs instead of finishing his house for me to rent. Temwa had no lodges or guest houses, so, with nowhere to go, Chief Kaluwa suggested that I stay with him and his family in the interim.

The first four months with Chief Kaluwa, his wife, their four children, two orphaned nieces and his sister-in-law in a small village six km outside of town was a welcome interlude while I waited for ethics clearance from the Malawian National Health Sciences Research Committee (NHSRC) from the Ministry of Health. Although we agreed from the outset that I would not write about their lives, staying in their home, eating and socializing with them and their children was enormously helpful. To occupy myself I spent a lot of time trying to learn about the history of the area, and improved my chiTumbuka. Chief Kaluwa’s children humoured me for months, showing me their games and how they found food on their own. Our everyday interactions with their tenants’ children living in an old shed nearby helped me understand the world through their eyes. I also had extended conversations with my host family about childhood (what makes a child good, what makes a child bad), gender dynamics in marriage (a subject Kaluwa was deeply committed to after becoming a “born again” Christian), childcare and child health. Faith healing ceremonies by American pastors on their TV powered by a diesel generator sometimes rounded out our evenings, but mostly we sat chatting about life in Malawi in their living room lit by a single solar powered light bulb. As a former tobacco estate manager, Chief Kaluwa also helped me secure valuable contacts in the area, and he became a key source of information about the history of tobacco and tobacco farming practices in general. I
also spent a lot of time travelling to Lilongwe to work through the ethics process with the Ministry of Health. Aided by Chief Kaluwa’s generosity, and his status as both a Chief and respected community member, I secured a house not far from the hospital four months later in November 2008.

**The Political and Economic Context: Northern Malawi**

Malawi is a long, narrow and relatively small, landlocked country in sub-Saharan Africa. It is bordered to the north and northeast by Tanzania; to the east, south, and southwest by Mozambique; and to the west by Zambia. The Rift Valley spans the length of the country and encompasses Lake Malawi, which extends along the eastern border for 475 kilometres (NSO and ORC Macro 2005:1). Malawi, with a culturally and linguistically diverse population of nearly 15 million people (NSO 2010), is divided into three regions - Northern, Central, and Southern - as well as 28 districts (see Figure 2). Temwa Rural Hospital is located in the “Tumbuka heartland” of Northern Malawi, Rumphi District. Tumbuka is a Bantu language minority group spoken by less than 10% of Malawi’s population and also in small numbers in northern Zambia and southern Tanzania (MDHS 2010). Although Rumphi district was largely composed of Tumbuka-speaking peoples during my fieldwork, large numbers of rural-rural migrants from Central, Southern and further North in Malawi, as well as small numbers of refugees from Burundi, Somalia and the Congo, worked in the area, either as farm labourers or self-employed entrepreneurs. The Chewa are Malawi’s largest ethnic and linguistic group, making up close to 70 percent of the population. The rest of the population is composed of the Yao, Sena, Lomwe, Tonga, Nkhonde, Ngoni, Senga, Nyakyusa, and Lambya, as well as very small numbers of people of Asian and European descent (NSO 2002:62; Tew 1950). English and ChiChewa are Malawi’s national languages. Malawians are mostly Christian (80 percent), with smaller groups of practicing Muslims (13 percent), mostly among the Yao in southern Malawi (NSO 2002:63).

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18 I speak French, so I was on friendly terms with many of the foreigners living in Temwa. In mid-2009 the police conducted a night raid on Temwa’s market, arresting a dozen foreign nationals; rumours that a Burundian family was murdered by an angry mob for selling children’s body parts also circulated around this time. I contacted a representative at UNHCR at this time, but we could not confirm the case.

19 Archaeologists and oral historians estimate that Malawi was occupied by ancestors of its present-day inhabitants in waves of migration between the 13th and 19th centuries (Ott 2000:151-153). For the Tumbuka, a general consensus is that successive in-migrations of slave traders and Ngoni pastoralists from South Africa and Tanzania significantly altered Tumbuka kinship systems. Historically, the Tumbuka had a matrilineal system similar to those
While there are many similarities between the different regions in Malawi, the Northern Region is distinct in a number of important ways. A geographical divide based on ethnic group in Malawi is very strong, and political favouritism towards the Central and Southern Regions since independence exacerbates this tension (see for example Kaspin 1995, Osei-Hewedi 1998; Posner 2004). The ethnic regionalism in Malawi dates back to the colonial period, when “Divide and rule was to be the British policy” and when the Colonial government and missionary interventions favoured the North (Vail and White 1989: 164). However, since Malawi’s Independence from British rule in 1964, President Kamuzu Banda emphasised his own Chewa identity, and began what has been seen as an “attack” upon the north (Vail and White 1989: 183). This, along with the abolition of chiTumbuka as a national language in 1968, fosters feelings of neglect to this day. Nevertheless, colonial favouritism towards Northerners is reflected in a number of current demographic and health indicators, which show that poverty levels are less acute in Northern Malawi than in either the Central or Southern Regions (McCracken 1997; MDHS 2010). For example, according to the most recent statistics available, the percentage of children in Malawi who suffer from poor nutrition is almost 10% lower in Rumphi than the national average (39% versus national average of 47%). Also, less than 9% of the individuals living in the North have no education, versus nearly 27% of all people in the South (NSO 2004). Significantly, the estimated adult HIV prevalence rate is much lower in Northern Malawi (6.6%) than in southern Malawi (14.5%), which is likely a reflection of high prevalence rates in urban centres (MDHS 2010). These differences play out in interesting ways at Temwa Rural Hospital, an issue I take up in more detail in Chapter Five.

Many of the differences between Northern and Central/Southern Malawi are attributable to the early influence of the colonial powers, who institutionalized two different kinship systems in Malawi (Englund 1998, 1999, 2002; Peters 2002, 2007; Tew 1950). Unlike the Southern region, where land is passed from mother to daughter, customary land is passed through sons in the North, and wives move to their husband’s village after marriage, where they often take up

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20 This tension was exacerbated during my research when President Bingu wa Mutharika, who was from Southern Malawi, placed quotas on the number of students who could be selected to university from the Northern region.
residence with their in-laws (Peters 1997). 21 This has important implications for the health strategies for sick children, including the household allocation of resources, the care of orphaned children and the residence of children after their parents’ divorce (Poulin 2005; Reniers 2003; Schatz 2005). Marriage among the Tumbuka also ideally involves the transfer of bridewealth, called a “lobola”, from the husband’s family to the woman’s family to compensate them for the loss of her companionship and labour and to make the children born of that marriage full members of the husband’s family (Munthali 2002). 22 If a woman’s husband dies, or she divorces, when she remarries she is often required to leave her children with her former husband’s kin, usually the mother-in-law or, in some cases, the sister-in-law. 23 Demographic data also indicate that despite a decline in recent years, Rumphi district still has the highest rates of polygamy in the country at 24% of all marriages compared to just 5% in the Southern region (MDHS 2010). All of these factors have important implications for the care of HIV positive children, which I discuss in more detail throughout.

While labour and caretaking practices are strictly divided by age and gender among both the Tumbuka (located primarily in the north) and the Chewa (located primarily in the south), these arrangements result in different health strategies for sick children. For example, Kennedy and Peters (1992) argue that children’s nutritional status in female-headed households in Southern Malawi is significantly better than in higher income male-headed households, whereas Bezner-Kerr et. al. (2011) found the complete opposite in Northern Malawi. This indicates that the gendered and generational organization of households, which varies largely by ethnic group, has consequences for child health. Married women from both groups are also responsible for most agricultural labor, caring for sick relatives and for performing short-term work in the informal sector for either cash or food, and they are more likely to be paid less for their labour (Bezner Kerr 2005; Bryceson 2002; Tawfik and Poulin 2012; Whiteside 2000). Men, on the

21 There are few historical or contemporary ethnographies of Northern Malawi. For the few exceptions that I am aware of see Friedsen (1996) on Vimbuza healing rituals among the Tumbuka; Soko (2002); Classen (2013) and Poulin (2007).
22 A practice called “lobola” (sometimes referred to as ilobola in some contexts) is widely practiced throughout Malawi, Zambia, South Africa, Botswana, Zimbabwe, Lesotho and Swaziland, but the actual details around the exchange vary widely (Mvududu 2002; Roalkvam 2006). While in some places the exchange is mostly made up of cattle, in Malawi today the exchange of lobola between the wife-givers and the wife-takers often occurs in stages over many years and in cash or goods (Vail and White 1989).
23 For instance, during an orphan care study I coordinated with the Ekwendeni Hospital AIDS program in 2005, many children staying in grandmother-headed households had mothers who had remarried and moved elsewhere.
other hand, are responsible for obtaining cash, through formal or informal labour schemes, to pay school fees, although they are also involved in some agricultural activities, such as building the “gafas,” which are used to dry tobacco, and applying fertilizer to crops. In Northern Malawi the paternal grandmother makes most major decisions regarding a child’s health, (Bezner Kerr 2005, 2007), while in Central and Southern Malawi the maternal grandmother or mother’s brother is more likely to play this role.\(^{24}\) The care of children by siblings is extremely widespread, especially when women are working in the fields or gathering firewood and water. More specifically, children ages five to 11, usually girls, regularly carry, cook for and play with their siblings who are as young as a month old (Ansell et al. 2006; Gottlieb 2004; Hampshire et al. 2009; Levine et al. 1994).

Rumphi district is also unique within the Northern region. It is the centre of a large-scale tobacco industry, ranging from large plantation-style farms to small-scale production by smallholder farmers. Since tobacco is an extremely labour intensive crop, it draws thousands of migrant farmers from poorer regions of the country every year (Blackie and Conroy 2006; Takane 2005).\(^{25}\) The Center for Tobacco Control Research and Education (2006) estimates that there are nearly 2 million Malawians working directly in the tobacco industry in Malawi, and that nearly 80,000 are children less than 14 years old.\(^{26}\) In particular, many Tumbuka landowners (both smallholder and plantation owners) employ tenant farmers from all over the country for eight to ten months per year. Tenants tend to consist of a small family group (husband, wife and children under five) and rarely include older children or extended kin, which has obvious

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\(^{24}\) Among the Tumbuka the gendered division of labour is widely joked about, and groups of men and woman often debate whether women work harder than men. In one instance, this debate ended in riotous laughter when one man declared: “You are wrong! We men work harder, because aren’t we the ones who dig the graves?”

\(^{25}\) Tobacco, sugar and tea represent approximately 80 percent of Malawi’s export earnings, with tobacco accounting for 70 percent of foreign exchange earnings and about 37% of the gross domestic product (GDP) (Conroy and Sachs 2006; Harrigan 2003). Large-scale tobacco plantations dominate the Temwa area, and crop diversification remains limited, exposing the region to exogenous shocks such as collapsing commodity prices and rising fuel prices (Conroy et al. 2006). Tobacco farming also increases household vulnerability to food insecurity since tobacco is more profitable than competing food crops, and reduces soil quality through erosion and tree-felling (Nichter and Kendall 1991). More recently, tobacco prices and production levels have declined under pressure from the anti-smoking lobby, but Malawi has not made any progress in promoting crops to replace its primary export earner (ARB 2007).

\(^{26}\) From my observations, children did work on the tobacco farms, but according to my informants they only did age-appropriate tasks, such as “sewing” tobacco. Tenants’ children were far less likely to attend school, but this was for a variety of reasons, including the fact that most tenants did not speak the language of instruction (chiTumbuka), the stigma faced by tenants’ children in school, the poor quality of schools in tenant-dominated areas (i.e. a one room grass building), and the fact that many tenants did not value education as much as the Tumbuka.
implications for sick children. They are particularly vulnerable to food insecurity since they rely on landowners to provide all food and medical supplies (see Chapter Five for more details).\textsuperscript{27} Therefore, another motivation for choosing Temwa as a field site is that while research shows disparities in ART access along gender and socio-economic lines, seasonal rural-rural migration of farm workers and their children remains an overlooked factor affecting equitable access to HIV treatment (Barnighausen 2007).

Despite distinct differences between various ethnic groups, HIV/AIDS, high rates of food insecurity, customary land tenure reforms, intermarriage, wage labour, seasonal migration and a long history of living side-by-side have continuously stimulated change to create more fluid forms of household composition and social relations (see also Levy 2007). Missionization, colonization, economic change, and increased migration may have accelerated cultural change, but ethnographers have shown that the cultures of Malawi, as elsewhere, were never static (see, for example, Mair 1951; Ott 2000; Phiri 1983). The dynamic nature of many of these cultural practices was evident in many ways in my research. For example, intermarriage among different ethnic groups was very common, and single young tenant farmers often married Tumbuka women. Although technically this would make them both landless, in every case I encountered they were able to secure land in the wife’s home village.\textsuperscript{28} Many tenant farmers from Southern Malawi also stated that one of their main motivations for finding work in the North was because they wanted to avoid living with their wives’ families, as is customary in the south. As one man said: “Ahh… No! To have your in-laws asking you where you’ve been or seeing how many beers you’ve taken? It is better we come here and then I can feel free.” Many men in Northern Malawi are also too poor to provide a lobola, and therefore women are increasingly retaining custody of their children after a divorce or the death of their husbands, which is one of the main reasons that most of the children I worked with lived in their mother’s home villages (see

\textsuperscript{27} Significantly, I was also told that most landowners pay male migrant workers only and rely on them to share their earnings with their family. I was told that a lot of this money ends up being spent on alcohol, and it often is a catalyst for arguments and divorces within households. However, whenever I suggested that landowners should divide the payment between men and women equally, nearly every woman felt that this would lead to divorce.\textsuperscript{28} However, the Chikuyalamatembe framed this as a growing problem, and is therefore likely to become less common as land quality and availability dwindles. It is also unclear whether this practice is a reflection of land policy reforms by the Malawian government that favour bilateral inheritance (see for example Peters and Kambewa 2007).
Illness and death in productive adult members due to HIV/AIDS has also had a significant impact on household composition and the ability of households to mobilize resources, creating what de Waal and Whiteside (2003) have famously called a “new variant famine.”

Also, young women, who are often the primary caregivers for children, are also dying earlier and faster than men, which has major implications for household composition and caregiver arrangements. These and other examples indicate that land inheritance and caregiving arrangements are much more flexible in practice. I discuss in more detail below how Janzen’s (1978) concept of the “therapy management group” helps us understand these dynamics.

**Theoretical Orientations: Key concepts**

Four key concepts inform the arguments and analyses in this dissertation – policy, the pharmaceutical imaginary, therapy management groups and childhood. While the relevant literature surrounding each concept is woven throughout every chapter, the following sections provide a brief grounding of the key arguments and literature from each area. The section on policy and policymaking highlights how global health interventions design and implement standardized health programs for diverse contexts. The main point is that these programs are ostensibly designed to maximize efficiency, yet their universality produces exclusionary

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29 Levirate marriage customs and polygamy are also declining because they are the targets of HIV/AIDS prevention interventions since, from a public health perspective, they increase the transmission of HIV (Reiners 2008). During my research UNICEF supported a “Stop Harmful Cultural Practices” campaign: [http://www.unmalawi.org/newsroom/press_release/unicef_stop_child_abuse_facts29jun07.html](http://www.unmalawi.org/newsroom/press_release/unicef_stop_child_abuse_facts29jun07.html).

The flexibility of cultural practices has particular importance in health development and HIV intervention, where cultures have too often been viewed as static and rigid. The fight for health and against HIV has too often been cast as a fight against culture (for critiques of this approach see Fassin 2001; Gausset 2001; Hunt 1996; MacDonald 1996; Oppong and Kalipeni 2004; Sacks 1996; Schiller et al. 1994; Schoepf 1995; Schoeph 2004; Treichler 1999; Watney 1989; Wardlow 2002; Wilton 1997). Such an approach often fails to recognize that cultural practices are flexible and people open to change if health providers suggest compelling modifications. Policymakers also fail to recognize that it is unsafe aspects of cultural practices that create risk of HIV infection, not the practices themselves. For example, levirate marriage itself is not dangerous, but marrying someone with HIV is. Moreover, focusing on cultural practices diverts attention from other explanations for high prevalence and regional variation in HIV infection (Oppong and Kalipeni 2004). Policymakers often look to culture as an explanation for why people are not taking up health promotion, rather than focusing on structural barriers that may impede individual capacity (Fassin 2001; Farmer 2008). I present this discourse not to deemphasize cultural beliefs and practices, but to problematize the reification of culture in global health interventions.

30 They argue that the HIV/AIDS epidemic is distinct from other food crises since it diverts valuable labour away from food production to the care of sick of household members and that it alters the overall age and sex ratios within a population (Hosegood et al. 2005; van Blerk and Ansell 2007).
practices. The discussion of pharmaceutical imaginaries highlights three key points: the importance of recognizing that the current emphasis on pharmaceutical intervention is particular to our current historical period, that the therapeutic efficacy of pharmaceuticals is mediated through the relational aspects of health and healing, and, lastly, that the imaginary often obfuscates valid problems with ART undermining treatment outcomes for children. The section on families and households argues that these terms do not adequately represent the fluid and dynamic nature of childcare arrangements in Malawi, and that the concept of therapy management groups provides a better methodological tool to capture the nature of these arrangements. Finally, the section on childhood emphasizes the fact children and caregiving are conceived of differently from setting to setting and that these conceptions shape caregivers’ health strategies for sick children.

**Pharmaceutical Governance: Policy Implementation in Malawi**

The World Health Organisation (2013) estimates that more than 10 million people are now on ART worldwide.\(^{31}\) Unprecedented alliances among AIDS activists, governments, international agencies, philanthropic foundations and the pharmaceutical industry made this possible (Biehl 2008; Nguyen 2009). Following World AIDS Vancouver in 1996, highly active antiretroviral therapy (HAART, or ART) became the standard of care for adults living with HIV (Nguyen 2007; Crane 2013; Colvin 2014). From this point onwards the HIV/AIDS treatment landscape changed dramatically. In 2000, access to HIV treatment around the world became framed as a global humanitarian emergency; the right to treatment was increasingly understood as a “moral imperative” by the global health community (MOH 2005: 13; Biehl 2008; Nguyen 2009). Arguments that “Africans” could not adhere to lifelong treatment regimens, that treatment would be unaffordable, that it would take scarce resources from prevention programmes, and that it could not be effectively delivered by struggling health systems were brushed away by a “humanitarian juggernaut” consisting of non-governmental organisations, foreign donor governments, universities, research institutes, churches, pharmaceutical firms and even the US military (Nguyen 2009: 196-197). An influx of cash after the creation of the Global Fund to treat

AIDS, Malaria and Tuberculosis in 2002 propelled governments around the world to make ambitious plans to “scale-up” or “roll-out” free antiretroviral treatment (Kenworthy et al. 2014). The emphasis on treating AIDS pharmaceutically on such a massive scale draws attention to the importance of studying population health in relation to the world system (Marcus 1998); yet as ethnographers we study people-in-places, which presents both theoretical and methodological challenges, since what constitutes “the local” in the context of globalization is contested (Ong and Collier 2005; Janes and Corbett 2009: 168-69). My research on GHIs targeting children with HIV/AIDS at one Rural Hospital (of the thousands throughout Sub-Saharan Africa deploying similar interventions) elucidates the importance of drawing attention to the tensions and exchanges between the global policy making sphere, where medical standards and norms are set, and both the hospitals and clinics where individuals implement these new programs, and their target populations who are expected to adhere to them.

The growing research on policy by anthropologists reveals how larger processes of governance, power and social change are shaping our world today. This research has been heavily influenced by Foucault’s later work on governmentality (see Shore and Wright 1997, 2008; Rose 1999; Foucault 1978). Foucault developed this idea to examine transformations in State power through the eighteenth and nineteenth centuries in Europe. He argues that the pre-modern State exercised rule through the power invested in the Sovereign to kill or to let live, whereas the modern state employs new, less obvious ways of controlling populations and governing the conduct of individuals. This “governmentalization” of the State intervenes in the lives of its citizens through bureaucratic practices, such as the development and implementation of policies in realms as varied as economics, education and public health. As Cruikshank illustrates so effectively in her research of post-welfare state governance in the U.S., these approaches are often instruments of governance that rely on the voluntary compliance of citizens, rather than any strict enforcement through law or punishment. In 1989 she started to notice that most of the garbage dumpsters in her neighbourhood were locked, which prevented many of the poor and homeless from scavenging for food. She set out to find out what reasons, laws or policies lay behind the dumpster lockups but to her surprise she could not find a single authority or official policy. Yet the new dumpster lock up policy had a number of major consequences. For one, it forced the poor to either steal or seek out more institutionalized forms of charity and support that subjected them further to governmental interventions. She concludes that
“democratic modes of governance and social scientific ways of knowing (re)produce citizens who are capable of governing themselves, of acting in their own interests” (1999:3).

Governmentality approaches to policy have raised important questions about how diffuse forms of power regulate populations, often foreclosing the possibility of effective resistance to them since their workings are often imperceptible. Unlike Cruikshank’s example, however, the global health policies guiding GHIs that target adults and children with HIV are made by policymakers under the authority of global health institutions, national governments and corporations. These policies are informed by knowledge that is generated by highly codified and institutionalized procedures, such as legal interpretations or evidence from scientific studies in economics, medicine, engineering and so on (Lambert 2005). A defining feature of policy is that it delineates a resolution to a problem, often across time and space (Shore and Wright 1997:3).

For example, the HIV/AIDS policies implemented in Malawi are developed by experts in Geneva, Switzerland to be implemented transnationally over a set period of time, often in five year increments. They are designed to “make live” while also creating new forms of “responsibilized citizens” responsive to mostly patient-led, rather than provider-initiated, health interventions. In other words, policies are meant to lengthen life expectancies and create new forms of personhood, ideally the kinds of patients who “optimize” their health by making good choices (i.e. avoid “risky” sex). Thus, governmental approaches to pharmaceutical governance work in tandem with more traditional forms of centralized power (see also Marsland and Prince 2012). In light of this, my research on Malawi’s national pediatric HIV treatment programmes raises a series of interrelated questions: How do policy makers imagine the subjects or targets of their initiatives and interventions? In what ways are they hoping to regulate their conduct? And how do the subjects of these interventions engage with this new policy?

There is a range of approaches in anthropology that I draw on to examine how health policy as a governmental technique articulates with local perspectives and realities in very specific ways. Within many of these paradigms, health policies often fail to achieve their stated goals and produce unanticipated consequences because they are prone to “overlook[ing] the complex social fields in which they are situated” (Adams and Pigg 2005:21). Most of these

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32 For instance, in 2006 a diarrhea outbreak killed 400 children in Botswana, after a new public health policy mandated the free distribution of infant formula to prevent infant HIV infection from mothers’ breast milk, effectively reversing gains made by child survival experts in reducing mortality from this common, preventable illness (Creek et al. 2007).
studies have been critical, focusing on the dangers of policy shifts, policy gaps, lack of local responsiveness, and neglect of important social and political contexts, which either produce or ignore health inequities and vulnerabilities (Castro and Singer 2004; Farmer 1992; Justice 2000; Tawfik and Watkins 2012; Schoepf, et al. 2000; Whiteford and Manderson 2000; Waterston 1997). For example, Winch found that political and social divisions within a medium-sized fishing community in Tanzania led to different rates of retreatment for insecticide-treated mosquito nets between local residents and migrants working in the area. Older established men in this context found their authority threatened by the influx of government employees, migrants and externally funded global health interventions providing new “better” ways of behaving. Subsequently retreatment rates were much lower among local residents who resisted imported health messages (1999: 58-60).

Others emphasize that the primary aim of health policy is not to improve health, but to leverage political support and solidify partnerships between a range of transnational, international and national institutions. In this scenario, policy is both a rationalizing political discourse concealing hidden purposes of bureaucratic power and a means to enmesh emerging (or untouched) economies into the global economy, which has instrumental effects (Ferguson 1994; Mosse 2005, 2004; Poku and Whiteside 2004; Scott 2000; Sparke 2009). As this statement by the President of Becton Dickinson & Co illustrates:

Of course we want to help eradicate neonatal tetanus, but we also want to stimulate the use of non-reusable injection devices, and to build relationships with ministries of health that might buy other products from us as their economies develop (in Buse and Walt 2002:53).

As Stefan Ecks (2008) similarly argues, corporate donations of anti-cancer medicines to poor countries is part of a larger global pricing strategy by the pharmaceutical industry to protect their profits in North America and Europe (see also Alden 2007; Shretta et al. 2001). Research has also highlighted how global health policies limit the autonomy of national governments to develop locally relevant solutions (Buse and Walt 2002; Okuonzi and MacRae 1995; Peterson 2001; Reich 2002). These perspectives offer valuable insight into policy as an important technology of governance used to regulate and manage populations (Foucault 2008; Scheper-Hughes and Lock 1987). However, as Shore and Wright point out, policies are not just
documents that constrain or direct individuals’ actions, they are also reflections of the social worlds they aim to regulate (2011: 1-4). Policies are never blindly and easily adopted wholesale by those who are meant to deploy them; rather, their implementation is often a “messy free-for-all in which processes are often uncontrollable and results uncertain” (Mosse and Lewis 2006:9).

Anthropologists therefore have also shown the ways that policy is *productive*; that is, it has the ability to organize people and ideas in new ways. For example, Kingfisher and Goldsmith (2001) show how neoliberal work policies in New Zealand and the United States forge new subjectivities among their target populations, in this case, unemployed women looking for work. In her research with HIV positive individuals in Tanzania, Beckmann (2012) also found that individuals are becoming “responsibilized patient-consumers” through HIV counseling, which emphasizes self-care to ensure good health. Through this transformation some patients come to feel that good health is the reward for good behavior instead of the product of systemic inequalities. Others have also shown how health policies help consolidate power and authority for some, while providing leverage for “regime change” for others (Shore and Wright 2011: 7-8).

For example, Helen Lambert argues that the current emphasis on using evidence-based medicine (EBM) to formulate health policies and hospital protocols strips physicians of their authority by devaluing their clinical expertise and judgment and relocating it in the hands of epidemiologists (2006: 2634-5). While research has shown that policies are often very effective at engulfing the contestation that always surrounds their design and implementation, the subjects of these interventions are able to question, to differing degrees, the way they are being constructed and the ways they contest and redefine the policies that are acting upon them (Kugelberg 2012; Muller 2012; O’Malley 1996; Pero 2012). All of these perspectives consider what happens when policies migrate into new settings and acquire new “social lives” (Appadurai 1986). Collectively they provide significant analytical leverage; my research is informed by and contributes to this literature by considering peoples’ lived experiences with Malawi’s pediatric HIV treatment program, showing how they engage with and impact the social life of a policy.

To shed light on both the instrumental and productive dynamics of policy implementation Sally Engle Merry (2006) and others have “mapped the middle.”

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33 For excellent examples of studies that examine policy implementation from the perspective of intermediaries see Englund (2006) on the role of Malawian activists and foreign NGO workers who mobilize human rights discourses for their own ends – specifically to distinguish themselves from the “less privileged” or poorest Malawians. Walley (2005) also demonstrates how the micropolitics amongst NGO workers and national park
paid particular attention to intermediary agents, or those individuals who reside between policymakers and target populations, such as health care workers, who often act as gatekeepers, interpreting and selectively implementing policy that they had no part in designing. For example, Wardlow (2012) examined how the work of one AIDS awareness workshop facilitator in Papua New Guinea hybridized the “script” developed by policymakers to explain the problem of AIDS in a way that was meaningful and effective for her and the workshop attendees. In Malawi, Angotti (2010) also found that HIV counselors altered the rules regarding consent, confidentiality and counseling to reduce the harm they saw arising from them (see also Butt 2011). More radically, Bogdan-Lovis and Sousa (2006) demonstrate how some health policies are actually derivatives of already established clinical practices rather than the product of any rational amalgamation of scientific evidence. For example, they demonstrate that although a growing body of evidence supports a midwifery model of care for pregnant women in the US (over an obstetrician supported, technology intensive model), the institutional authority accorded to physicians prevents any policy changes. As Wardlow also points out (2012:408), policies are lost in translation as they travel across space and time; their fidelity cannot hold up to the incongruities between how policies are imagined to work and the reality on the ground, which compels actors to improvise. While Malawi’s national pediatric HIV treatment programme is less contested than some policies described elsewhere, the lack of resources at tertiary health care settings, the fluidity of household dynamics and ambiguities embedded in the policy surrounding the “social criteria for eligibility” provide obstacles to implementation, as discussed in Chapters Three, Four and Five.

The Global Pharmaceutical Imaginary: Health and Healing in an Unjust World

I experienced a sense of dread anytime families asked me how long their children would live on ART. Questions like, “can this one become a child?” or “will this one grow up?” were impossible to answer, not only because I have no medical training, but also because the long-term medical efficacy of adult-dose split tablet regimens for children who start treatment in resource-poor settings with limited food resources is still largely unknown (Mills et al., 2012). employees in Tanzania had a significant impact on policy implementation. See also Wilce (1995) on health messages and biomedical encounters in Bangladesh. 

34 See also Wendland (2010) and Livingston (2013) on improvisation and medicine.
Yet, access to free ART has transformed the practice of global health by raising billions of dollars for the sole purpose of ensuring universal access to these medicines (Brandt 2013). Within this global imaginary, spearheaded by activists, UN agencies, grassroots organisations, prominent NGOs and the media, ART “saves lives” by transforming a once deadly disease into a manageable, chronic condition (Mattes 2014; McGrath et al. 2014; Hardon and Moyer 2014). Also, within this imaginary the benefits of treatment go beyond saving individual lives; the efficacy of the medicines will also “end AIDS” altogether by preventing new infections and will lift “Africa” out of poverty by preventing early deaths among productive household members (see for example Sachs et al. 2004). Thus, I use the concept of the pharmaceutical imaginary to contrast the ways that ART programmes are imagined to work in their target communities by the global ART assemblage, with the everyday experience of growing up with HIV in Malawi.

An imaginary is defined as the “ways that people imagine their social existence, how they fit together with others, how things go on between them and their fellows, the expectations that are normally met, and the deeper normative notions and images that underlie these expectations” (Taylor 2002: 106; Gaonkar 2002). Imaginaries are also aspirational, inviting and sometimes coercing people to live “as if” imagined eventualities were inevitable or at least probable (Appadurai 1996: 31). Mary-Jo Delvecchio Good developed this concept further to analyse how the affective and imaginative dimensions of the “medical imaginary” wraps physicians, patients and the public in a “biotechnical embrace” (2001: 397). In other words, the medical imaginary constitutes a particular (biotechnical) approach to health and healing, which feels desirable, natural and modern (Curtis 2002; Foucault 2003). Recently Calhoun has also used the idea of the “emergency imaginary” to explore how the concepts of “humanitarian” and “emergency” have come together to shape a way of understanding humanitarian problems around the world, from the Rwandan genocide to the December 2004 tsunami (2010: 30-35). As he points out, suffering is not new, nor is there any evidence that there is more suffering now than in earlier eras, but how we imagine the way the world should be has changed, and therefore our responses to

suffering have also changed. My dissertation focuses on a particular “pharmaceuticalized”
response to suffering at a tertiary health care setting in Northern Malawi (Biehl 2007).

My theorization of the pharmaceutical imaginary draws on recent research in
anthropology on the social life of medicines. The social lives of medicines approach reminds us
that medicines are substances with the power to transform living organisms in a multitude of
ways both physiological and social (Whyte et al. 2010). Research by medical anthropologists and
others shows clearly that pharmaceutical efficacy is much more multi-faceted than the simple
equation: ingest and heal. Medicines can injure as well as heal, with most having a wide range of
possible adverse side effects (Etkin 1992; Foley 2006); they are valuable commodities with
political, economic and social significance (Pollock 2013); and they have “social lives” that are
critical to healing (Moerman 2002). Inspired by Appadurai’s (1986) “social life of things,” this
perspective emphasizes how the social significance of medicines changes as they circulate
through different social and health-service contexts (Whyte et al. 2000). Drawing on these
findings, I argue that there is a consequential gap between how policymakers imagine ART
working in a direct and unmediated way on target populations, and how anthropologists
understand social relations to have a powerfully mediating impact on healing. Accordingly, I
develop the concept of the “pharmaceutical imaginary” to explore this disparity.

I use the idea of the “pharmaceutical imaginary” to highlight how increasingly
“pharmaceuticalized” global health initiatives are becoming. Joao Biehl, for example, argues that
public health has been “pharmaceuticalized” as “access to pharmaceuticals” has superseded
public health care models of prevention and care (Biehl 2006; 222-224; Bell and Figert 2012;
Dew et al. 2014;). Access to pharmaceuticals is increasingly imagined to be the solution to a
range of social, political and economic problems, from AIDS-based stigma (Campbell et al.
2011), to poverty (Sachs et al. 2004) to alleviating family tensions and social dysfunction on
First Nations reserves in Manitoba, Canada (Oldani 2009). What I call the “pharmaceutical
imaginary,” therefore, implies an optimistic story of the many possibilities of ART (to save life,
transform social lives, end poverty, save a continent) that eclipses alternative stories that might
raise questions about the ability of GHIs to achieve “universal access” as well as about the
effectiveness or safety of treatment for children in the long term. In that sense the pharmaceutical
imaginary refers to the policymaker’s a-social, decontextualized somewhat utopian assumptions
about how medicines work. The pharmaceutical imaginary raises a number of important
questions that are relevant for the processes of designing, implementing and adhering to an ART program in Northern Malawi.

Anthropological research on health and healing in particular is helpful for unpacking some of the inherent failings of the pharmaceutical imaginary. Research in diverse contexts demonstrates that healing is not only a biological process, but an interactive, collective response to illness and social suffering (Petryna and Lakoff 2008; Kleinman 1988). Claude Levi-Strauss’s classic essay “The Sorcerer and his Magic” provides insights into this dynamic. Levi-Strauss recounts the story of Quesalid, an apprentice who is initially skeptical of his ability to heal, since he uses some sleight-of-hand to produce a piece of bloody down as a stand-in for the affliction affecting his patients. However, Quesalid later realizes that it is his ability to manipulate social expectations that endows him with magical gifts; he “did not become a great shaman because he cured his patients: he cured his patients because he had become a great shaman” (1963: 50). By focusing the community’s attention on a physical object, he was able to instill confidence in his patients and the wider community that he was able to remove the affliction. Pharmaceuticals work the same way to some extent; their “thingness” is what makes them powerful symbols of healing, yet the actual mechanisms through which medicines produce their effects are mediated through the meanings attached to them.

Research on the “meaning response” highlights how belief in the efficacy of a medicine can effect real physiological healing. More commonly known as “the placebo effect” when the response is positive and the “nocebo effect” when the effects are undesirable, multiple studies highlight how therapeutic efficacy is impacted by the meanings attached to medicines and the quality of the social interactions between patient and healer (Moerman 2002: 472; Hahn 1997; Scheper-Hughes and Lock 1998). For example, research shows that both the colour of the pills and the amount taken lead to different physiological responses cross-culturally (Bledsoe and Goubaud 1985; Etkin et al. 1990). Research also shows that a healer’s costume (the white coat, stethoscope hanging around the neck) and his or her relative enthusiasm for the proposed treatment all influence the therapeutic outcomes of a range of biomedical interventions, including pharmaceuticals and surgery (Blumhagen 1979; Ruehman et al. 2005; Blasi et al. 2001). The demand for specific pharmaceutical regimens is also mediated through local ethnophysiologies, or local perceptions of bodily functioning and well-being. For example, Langwick (2007) argues that caregivers seek out biomedical treatment for sick children with
malaria symptoms only after visiting a traditional healer because the method of administering the medicines (injections) is considered dangerous and likely to bring about *degedege*, an illness capable of killing the child (see also DeBessa 2006; Caruth 2014; Geissler 1998). I discuss how the meaning response in Malawi is mediated through local ethnophysologies and the pharmaceutical imaginary in more detail in Chapter Three and Six.

These findings have important implications for Malawi’s ART roll-out. While the global pharmaceutical imaginary considers ART a “life-saving” miracle drug that can transform a once deadly disease into a manageable chronic condition, the reception of ARTs in different contexts is more varied. Mattes (2014), for example, shows how elusive “normal life” remained for patients on treatment in Tanzania because of structural factors limiting patients’ access to nutritious foods (see also Hunleth 2013; Kalafonos 2010). Schumaker and Bond (2008) also argue that while most Zambians have positive feelings towards ART, they were less certain about the long term therapeutic efficacy of treatment given their own socio-economic circumstances, such as their ability to pay for transport to the hospital every month. The toxic side effects of treatment, such as fat-redistribution (lipodystrophy), gastrointestinal and liver problems are all known to undermine long term health outcomes (van der Geest et al. 2006). My findings add to the small, but growing literature about what it means to grow up on ART (see Bernays et al. 2015 for a recent example).

Margaret Lock’s (1986) research on menopause in Japan also provides insight into healing as a bio-cultural process. She argues against a universal body to point out how cultural practices, such as the value placed on exercise and eating nutrient-rich foods, has resulted in not only a different phenomenological experience of menopause in Japan but also a physiological one. One of her main contributions is to argue that standardized medical practices that fail to pay attention these “local biologies” might not only be less effective, but in some cases dangerous. Hamdy (2013) also uses the concept of local biologies to highlight how structural factors, such as access to water, food, and health care, lead to different rates of kidney disease among economic classes in Egypt. Recently, Livingston (2013) highlights how the epidemiological make-up of the cancer epidemic in Botswana, a large percentage of cancers being viral, are an unintended consequence of free ART programmes. I draw heavily on these insights further in Chapter Six, where I discuss the roll-out of free ART for children in a food-insecure and under-resourced context.
Anthropological insights also draw attention to the ways medicines work on and between those who are ill and those who are prescribing or administering treatment; in other words, medicines have social as well as therapeutic efficacy (see Whyte et al. 2002: 23). Smith and Mbakwem (2007) introduce the concept of “life projects” to highlight how treatment adherence among HIV positive people in Nigeria cannot be understood in only biological terms; marital and childbearing aspirations often trump global health recommendations in this context. Patients on ART are well aware of the importance of strict observance of treatment protocols and the danger to themselves and others if they have unprotected sex. However, these risks are overridden by the fact that unprotected sex is a marker of trust, signals a willingness to procreate and therefore signals a desire for marriage (2007: S38). In a similar example in the Gambia, Bledsoe (2004) notes that policymakers incorrectly interpreted the uptake of oral contraceptives as a sign of “unmet need” for fertility control; rather, she argues that women in the Gambia use contraceptives to have as many children as possible by giving their bodies a “rest” before getting pregnant again. Oldani (2009) also argues that physicians prescribe a psychotropic drug called Ritalin to aboriginal children in Manitoba based on their interpretations of life on reserves as an “oasis of chaos”; thus, for physicians, the imagined potential of Ritalin goes beyond its purely physiological effects. In the Philippines, Hardon (1987) explains that women over-medicate their children with Western pharmaceuticals in order to publicly demonstrate their social role as a “good mother” within their communities. Empirical evidence shows that physicians often prescribe inappropriate or unnecessary medicines to meet their patients’ expectations or to compensate for a lack of resources (Paredes et al. 1996; Stivers 2002; Stivers et al. 2003). These wide-ranging cases all suggest that adherence to pediatric ART drug regimens cannot be automatically regarded as a marker of program success; rather, it indicates that the individual or individuals caring for HIV-infected children have reasons for ensuring that the children take the medicines in the ways indicated by the prescriber. In other words, individuals may adhere to medical protocols for reasons that have little to do with why the prescriber told them they should adhere, and thus success rates do not necessarily mean that patients share the same pharmaceutical imaginary as those designing the programme from afar.

Complex encounters with previous and ongoing global health interventions also shape the way populations understand and seek care. Palmer et al. (2014), for instance, argue that the legacy of fragmented, donor-driven vertical health programmes in South Sudan has profoundly
and differentially shaped access to health care for ethnic minorities: while internally displaced Dinka populations were receptive to patient-led approaches to sleeping sickness case detection, returning Madi minorities were not, despite having higher rates of infection. They show how Dinka populations actively sought out testing because it reflected their own personal and political aspirations for improved access to healthcare after years of struggle. The Madi, on the other hand, experienced the transition from provider-initiated approaches typical of the refugee camp in Uganda where they spent many years to the patient-led approaches fostered at their local clinic as a kind of withdrawal of services, since testing was now much harder to access.

Historical encounters with coercive health interventions have also led to widespread resistance to new pharmaceutical interventions and vaccination campaigns in various contexts (see for example Briggs 2002; Feldman-Savelsberg et al. 2000; Greenough 1995). The language used to explain and promote health interventions can also dramatically shape how differently positioned groups receive them. Nations and Monte (1996), for example, note that a cholera-control campaign in Brazil replicated racist tropes about poor marginalized populations, leading to widespread distrust and resistance to the campaign. Malawians also have a long and varied history with innumerable health interventions from the colonial period to the present. While missionaries were mostly concerned with illnesses that affected colonial civil servants or the British military, there was a growing interest in “tropical diseases” from the early 1900s onwards (McElhinny 2005; Packard 1989). The smallpox eradication initiative in Malawi, the first global health initiative to take hold there in the late 1960s, was largely accomplished with the use of “small-pox police” who had the authority to vaccinate and imprison individuals against their wills (Vaughn 1991). Thus, it should not come as a surprise that not everyone I talked to embraced the idea of untested, life-long pharmaceutical intervention for their HIV positive children. Historical, economic and political circumstances specific to Northern Malawi shape both the meaning of and therapeutic efficacy of ART treatment. In this way, adherence to, or the rejection of, pharmaceutical intervention is not only about the therapeutic efficacy of the drugs, but also depends on how families and health care workers understand and engage with the therapies prescribed to HIV infected children. In sum, although a global assemblage of policymakers, activists and health experts has successfully produced a pharmaceutical imaginary in which universal access and patient compliance will have myriad positive outcomes, the Temwa families who participated in my research did not, for the most part, share this imaginary.
Their imagined futures with ART were more cautious, and even pessimistic, and were informed by complex relations with kin, landlords, spouses and health care workers.

Families and Households: The Permanent Ambiguity of Therapy Management Groups

“The visitor kills the snake” – Tumbuka proverb

Therapy management – or the diagnosis of illness and the selection and evaluation of treatments – is a fluid process negotiated among socially embedded persons (Janzen 1987). The concept of the therapy management group (TMG) – that is, the group of people who participate in the often contested process of therapy management – is an underused methodological tool that can help researchers and service delivery organisations contextualize caregiving arrangements within specific contexts over time. Although making a distinction between the concept of the “household” and the “therapy management group” may seem purely academic, the concept helps us avoid preconceived or static assumptions about what households are and helps us to highlight instead the permanent ambiguity of many child care arrangements. Hunter (2010:13) defines a “household” as “a group of people who share significant elements of life, from remittances to daily meals.... More than one household can live in a single dwelling, and households can stretch between homes in different locations.” While this concept is helpful for understanding how households work as economic units spaced over different geographical regions, this definition excludes a number of people who become significantly involved in resolving serious child health issues but are not part of a child’s household. The proverb of “the visitor who kills the snake,” for example, was regularly told to me during many of my home visits during fieldwork. The logic of this proverb as it was explained to me is that an outsider can often see and intervene into a problem or “family issue” and resolve it in a way that “insiders” cannot, either due to a lack of resources or because of social norms regulating how people from different social locations (men and women, young and old) should communicate with each other.36

36 This proverb was often told to me by an elder man after I had helped a family in some small way, either by referring them to nutrition services at the hospital, providing cloth for school uniforms or providing some small food items.
The fluid nature of a child’s TMG becomes very salient in the case of HIV positive children who often develop severe, and very visible HIV-related symptoms that prompt interference by friends, neighbours and concerned community members. While policy makers have tended to overstate the stability of household compositions in order to develop standardized health interventions, my research demonstrates that an oversimplification of household variability obscures, rather than illuminates, the fluid composition of therapy management groups and may impede the early diagnosis of the many children who live in non-standardized and poorly understood kinship networks. This is particularly important since HIV diagnosis in children is a process, lasting months, and sometimes years, when, over time, children are cared for by shifting TMGs as individual members move for work, parents die or child care arrangements are altered by their parents’ divorce. Therefore, I argue that defining “household” in this context in a way that could be useful for policy makers might be impossible and instead suggest the use of “therapy management group” to allow for more ambiguous, fluid and sometimes temporary (i.e. including tenants) care networks for sick children.

Although the concept of the TMG originated in the analysis of the therapeutic trajectories for adults in a wide range of cultural and disease contexts (Janzen 1978; also Heilman and Witztum 1994; Hirsch 2007; Nichter 2002; Tolhurst, et al. 2008), arguably the concept is particularly significant for understanding pediatric illnesses since children typically have little control over their own treatment, and their health outcomes are thus largely dependent on the negotiations of adult actors around them. To highlight the complexity of these dynamics consider the child care arrangements of children whose mothers remarried. For instance, Rhoda, a mother of 10 year old Fanny, sent her daughter to live with her asibweni (Rhoda’s mother’s older brother) nearby when she remarried, but still oversaw the majority of her daughter’s pharmaceutical care on a daily basis although her extended kin networks provided food,

37 In rare cases of child neglect, witchcraft or abuse therapy management groups also included external authority figures such as village chiefs, police officers or religious leaders. For instance, if a child is severely malnourished a village chief may choose to remove that child from the family and place him or her with social services and the child may eventually be adopted by another family. During my fieldwork I was also told about many cases of children allegedly being trained by senior witches, or children who in the night time took other children to graveyards to train them how to be witches. These cases often took years to resolve and they involved sing’anga’s (traditional healers) first, and over time, families would sometimes consult with religious leaders from Pentecostal churches. Therefore, serious neglect or disease associated with witchcraft was also likely to reconstitute the therapy management group to include community members with considerable authority over the course of a child’s treatment trajectory and child care arrangements.
homework supervision and Fanny contributed to household and agricultural chores at her asibwenti’s. Therefore, although Fanny was not living with her mother, her mother was the one who monitored her ART regimen with health care workers and oversaw her treatment adherence. As I have shown, a child’s TMGs is very flexible over the course of their lifetime for a variety of reasons. Even seemingly small changes in the composition of the TMG, such as the addition of an older female relative like a mother-in-law, can have a significant impact by, for example, restricting a mother’s ability to make decisions freely about her child’s health (Bezner Kerr 2008). Alternatively, some mothers gain crucial support for opposing senior male household members who prioritize other crucial investments, such as purchasing fertilizer, over paying for transport to take a sick child to the hospital. Therefore, the primary contribution of the concept of the TMG is that it helps us avoid preconceived or static assumptions about what childcare looks like in specific geographical or cultural settings and to highlight instead their fluidity and potentially contested nature over time. This concept helps us avoid unwarranted assumptions about the nature of people’s intimate or caregiving arrangements. The concept also draws our attention to how non-household members become involved in health strategies for sick children. These issues are very salient for HIV positive children, since the advanced signs of infection are often severe and visible, drawing the attention of concerned traditional healers, village Chiefs, police officers, neighbours, religious leaders and employers. Landowners employing migrant workers often take on the role of “grandparents” and in some cases will even move a very sick child into their own house, taking over all childcare activities.

Broadening our understanding of childcare beyond “households” or “family” to a larger network of people also provides insights into processes of negotiation within and between different interest groups. In Malawi when a child’s mother or father dies, a series of negotiations often takes place between the child’s paternal and maternal kin to settle child custody issues, as seen in Katherine’s case at the beginning of this Introduction. Since more than half of the children on treatment in my sample had lost one or both parents prior to their diagnosis, understanding how healthcare strategies are organised and by whom is crucial for contextualizing long term health outcomes of HIV positive children. By employing the concept of the TMG to understand how various caregivers engage with the therapies prescribed to HIV-infected children over time, my dissertation provides an analysis of the long-term challenges to successful paediatric ART treatment.
The composition of a child’s TMG at the time of an HIV diagnosis and ART treatment initiation also helps us understand who has the authority to negotiate key health strategies for sick children. As Table 1 illustrates, TMG characteristics varied considerably. First, in nearly every case, children were living in multigenerational households (86%) where either paternal or maternal grandparents were involved significantly in decision-making around children’s health. The only exceptions were the five tenant families who had children on treatment; none of these children had older relatives involved in their care, since they were all left in home villages to take care of the land and the older children. Second, because ideal kinship practices among the Tumbuka are patrilineal, it is striking that more than half of the children on treatment were living with their mother’s kin. This arrangement derived from a range of circumstances including the death of the father or a divorce. Regardless of the precipitating causes, the arrangement itself has important implications for children’s long term adherence to ART since, as they move into adolescence, they are less likely to have access to land and school fees. Finally, very few children had both parents involved in their care (23%), since most fathers were either dead or had remarried elsewhere prior to the child’s diagnosis. The lack of paternal involvement in HIV treatment initiation also raises important questions about the role of gendered household dynamics within intimate partnerships and how they shape health strategies for sick children. Therefore, certain therapy management group compositions are more conducive to early paediatric HIV diagnosis (such as the presence of older grandparents), while others might cause delays (such as the presence of a father or a boss). Understanding how these dynamics work is discussed throughout my dissertation.

<table>
<thead>
<tr>
<th>Table 1: Therapy Management Group Characteristics for Children on Treatment (N=35)</th>
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<tbody>
<tr>
<td>living in multigenerational households</td>
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<tr>
<td>living with mother’s kin</td>
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<tr>
<td>living with both mother and father</td>
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<tr>
<td>primary caregiver was a grandparent</td>
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<td>polygymous household</td>
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"The Anthropology of Childhood: Agency, efficacy and the meaning of illness"

Today, as never before, the “State of the Worlds’ Children” is a matter of intense public scrutiny, and child health and mortality outcomes are used as universal indicators of international and national developmental success (UNICEF 2014). Images of children suffering as child soldiers, street children, or as victims of abuse, neglect, or poverty have been deployed to represent global political economic disparities, international and national policy failures and the danger of corrupt, undemocratic governments (Stephens 1995; Scheper-Hughes and Sargent 1998). To borrow Liisa Malkki’s term, children are “pure victims”: blameless, helpless and the ideal worthy subject for international assistance (1996: 378). In this sense, “children are meaningful creatures in virtually all societies” (Hirschfeld 2002:613), and their health and wellbeing have somehow become indices of the “state of the world” in general. Yet, for nearly a decade, children with HIV were left to die, untreated, and their deaths unrecorded (Robbins 2006). As Paula Treichler (1987) argued almost three decades ago, HIV is an “epidemic of signification.” By this she meant that unscientific assumptions about how HIV is transmitted influence science and policy (see also Hinterberger 2013; Patton 2002). Public health discourse has defined HIV primarily as a sexually transmitted infection, and, since there is a widely held belief that children are non-sexual beings, very little effort went into preventing or treating infections in children. Thus, my dissertation explores how concepts of children and childhood lead to or prevent the early diagnosis and treatment of children living with HIV.

Pediatric HIV is a crucial area of study since it underscores the tensions between conceptions of children as developing beings who are vulnerable and in need of protection, and children as agents in their own right, capable of interpreting their worlds and acting on them (Bluebond-Langer and Korbin 2007). The health and wellbeing of children also provides

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38 See McElhinny (2005) and Hunt (1999) on the early evolution of worldwide attempts to fight infant mortality. Currently, children’s rights are enshrined in the Convention on the Rights of the Child (CRC), which is the first legally binding international instrument that is a “universally agreed set of non-negotiable standards and obligations” for children. In 1989, the CRC set out the basic human rights that children everywhere have: the right to survival; to develop to the fullest; to protection from harmful influences, abuse and exploitation; and to participate fully in family, cultural and social life. [http://www.unicef.org/crc/](http://www.unicef.org/crc/), accessed May 21, 2008. Malawi signed this agreement in 1989.
valuable insight into relations *between* adults (Stephens 1995). For instance, in many places, the mother is responsible for maintaining and restoring her child’s health, and a child’s ill health may result in a serious loss of a mother’s social standing (Amunyuzu 1998; Richards 2004[1932]). Critically, HIV is a disease that children get *from* their mother, either in utero, at birth or during breastfeeding, and, therefore, a diagnosis of HIV in a child potentially raises uncomfortable questions about maternal responsibility and blame. Children with AIDS, in particular, invoke powerful discourses of blame and social discord that often reinforce and reproduce already constituted social hierarchies, such as gender, color and class (Schoepf 2001:338).

Anthropologists have also demonstrated that there is great cross-cultural variation in conceptualizations of infants and children, and these studies emphasize that local conceptualizations of childhood impact child rearing practices in unpredictable ways (Levine et al. 1994; Gottlieb 2004). However, international health institutions categorize children according to universal standards, which emphasize age categories. For instance, according to these guidelines, infants are defined as children aged zero to one year, and a child is aged one to five years. However, among the Tumbuka in Northern Malawi, emic categorizations of children differ from global standards. In particular, the Tumbuka have three main categories. The first, called “Bonda,” refers to newborns (1-2 weeks old); the second is called “kamwana”, which means “small child” and refers to both small infants and children less than five; finally, there is a “mwana”, which is a fully grown child. Mwanas are different from kamwanas because they “understand” things; for example, they will no longer run in fear of the “mzungu” (white person), run around naked or cry unnecessarily. These conceptualizations also shape the meaning assigned to an illness, and, in many cases, childhood illnesses are blamed on social fissures at the household or community levels (Evans-Pritchard 1980; Green 1999; Howard and

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39 In Northern Alberta, I also noted that teenage girls had babies as a strategy to both attain adulthood and align themselves with men who disproportionately benefit from the oil boom in a gendered labour market (Sikstrom 2000).

40 In Malawi, contradictions between international and local definitions of infants are most commonly evident in child survival initiatives promoting exclusive breastfeeding. For instance, global health recommendations are that women breastfeed their children exclusively until the baby is six months old, whereas Malawians emphasize behavioural cues such as ‘the baby is sitting up and active’, which often occurs around four months of age, and therefore suggests that Malawian concepts of childhood agency may play a key role in child care practices and decision-making. For the purposes of this study I worked with children from one month old until they transitioned into “youths” or “yamatas” (see Classen 2013).
Millard 1997). For instance, Mabilia (2005) demonstrates that the Wagogo of Tanzania attribute the most serious cases of childhood diarrhea to violations of the post-partum abstinence taboos by the mother and father. Similar findings in Malawi suggest that increases in child mortality and morbidity lead to increased gender and generational conflicts within households. As one older woman stated in a workshop: “Our children did not used to die so often… It is because you young women do not respect the old ways, you are busy giving in to your husbands; that is the cause of the problem” (Bezner-Kerr 2005:111; see also Mphande 2004).

Contradictory interpretations of child deaths also underscore the tensions in the concept of childhood; children are viewed simultaneously as “appendages to society” or “adults in the making” (Hirschfeld 2002:613-14), as well as agents who contribute to their own health and well-being, even from a very young age (Bluebond-Langer and Korbin 2007; Cheney 2007; Hecht 1998; Briggs 1998). For instance, anthropological studies have shown that varying conceptualizations of childhood agency and vulnerability alter nutrition and feeding practices (Engle et al. 1996; Fouts et al. 2005), caretaking arrangements (Engle and Breaux 1997; Weisner and Gallimore 1977; Gottlieb 2004; Hewlett et al. 1998) and health seeking practices (Amunyuzu 1998). Moreover, these practices often vary by class (Dyhouse 1978; Kusserow 2004) and gender (Nieunhuys 1994; Hadley et al. 2008). Scheper-Hughes (1997) also argues that children in poverty-stricken Brazil are viewed as agents of their own deaths and denied medical treatment if they do not exhibit a sufficient “will to live”, whereas Einasdottir (2004) argues that child deaths in Guinea-Bissau are attributed to outside forces, such as sorcery or

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41. During preliminary research (2004-2005 and 2007) I was also told about a deadly, chronic form of childhood diarrhea called *chingwenya* that was caused by inappropriate sexual conduct within the household or the community. Assigning causality to sexual transgressions also had important ramifications for treatment choices, since a child diagnosed with *chingwenya* was not taken to a health centre.

42. In Malawi, ambivalences around children with AIDS are filtered through the Church, a site of lively debates about the place and meaning of the HIV infected child in communities. For instance, Jen Levy (personal communication) witnessed a debate amongst religious leaders who were alternatively arguing that HIV infected children were “paying for the sins of their fathers” versus worthy of love and treatment according to the adage “Love thy neighbor.”

43. For instance, mothers in Italy pinch the nose of female babies who suckle too vigorously while breastfeeding. Also, Morton (1996) argues that young boys in Tonga are also more likely to gather fruit because they are more mobile than girls. Bezner Kerr et al. (2007) noted that the types of food given to young children were directly related to local beliefs about the size of a children’s intestines and their ability to appropriately digest certain foods (see also Mandala 2004, on the differential access to the different parts of a chicken according to gender and age).
However, pediatric HIV remains poorly researched by social scientists. My research is situated within a particular historical moment when new diagnostic technologies and treatment regimens have made pediatric HIV visible and knowable for the first time. Therefore, my dissertation adds to the small but growing literature on children and HIV by considering how conceptualizations of childhood influence health strategies for sick children.

**Among the Walking Wounded: Research Methodology**

My ethnographic narrative employs a “follow the policy” approach and considers the social life of the paediatric initiative in different social contexts, starting with Temwa Rural Hospital and ending with the children themselves (Marcus 1995; Appadarai 1986). In each context, I explore the social relations and power dynamics that shape health strategies for sick children, resulting in a mixture of selective resistance and selective compliance (Lock and Kaufert 1998). Ethnographic case studies throughout highlight the ways that people in each of these contexts interact with this new policy and the effects it has had on their lives. The social relations I describe explain why children are far less likely to access ART than adults, and outlines potential challenges to improving treatment for children as countries adopt the newest WHO (2013) recommendations to treat children pre-symptomatically. I consider children as agents, and throughout I draw attention to their social worlds and daily activities so that readers can consider the ways that they, no matter how old they are, might engage with the policy themselves.

I conducted research in Temwa from April 2009 to December 2010. I had originally intended to “follow the policy” to the policymaking sphere, including the Baylor International Paediatric AIDS Initiatives (BIPAI) offices in Lilongwe. The aim of this approach was to cross-cut the dichotomies such as the “local” and the “global” by elucidating the intersections and disjunctures between different sites (Ferguson 1986; Justice 1986; Tsing 1993). However, after I arrived in June 2008 the global financial crisis led to budgetary restraints and programme cancellations for major donors throughout Malawi (see Chapter 2). The result is that BIPAI restricted their activities to four health centres in and around Lilongwe and cancelled their

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44 See also Jolivet (1997) and Oaks (1994) who illustrate that many illnesses among women in Japan are attributed to malevolent aborted fetuses seeking out retribution on their parents. In contrast, human embryos in the North America stem cell debates are often accorded “primordial” or magical powers to heal bodies (Sikstrom 2002).
original plans to carry out capacity building with health care workers throughout Malawi. Therefore, the challenge became to delve into the unique perspectives of people who were the targets of the new paediatric HIV treatment intervention, while linking their experiences to global health policy more generally (Walsh 2004; Moniruzaman 2012). Accordingly, I did not follow the methods of a multi-sited ethnography, but chose to explore a localized ethnography of a global health policy by focusing on one rural hospital’s catchment area. This approach sheds light on how target populations, and the health care workers trained to implement the new initiative, interpret, reinvent and make use of global health policies designed with little understanding of their unique context.

My primary research objective, to explore why children are far less likely to access HIV treatment services than adults, presented substantial methodological challenges. In particular, how could I access children with HIV before they are diagnosed to understand why their parents delay testing or what symptoms prompt early treatment? And how do you find children whose caregivers might be avoiding HIV treatment for reasons of their own? These issues were compounded by the fact that most people keep their HIV status and their child’s HIV status secret from everyone but very close family members, making it nearly impossible, and sometimes unethical, to locate and identify HIV positive children in everyday settings. While over time I came to recognize certain symptoms, such as oral thrush or a very fussy child with a puffy face as indicating possible HIV infection, there was no way to know for sure without a test. This is especially true in Malawi, where HIV infected and uninfected children both suffer from high rates of mortality and morbidity.\(^{45}\) To address some of these challenges my fieldwork consisted of periods of systematically planned collection of data, on the one hand, and a continuous private participation in daily life, on the other. My intent in presenting a detailed discussion of this two-pronged approach is to satisfy both ethnographers and applied social scientists who have different criteria for evaluating the generalizability and validity of research

\(^{45}\) Six common childhood illnesses account for more than 80% of hospital admissions in children with symptomatic HIV (DeBaets et al. 2007). These include: respiratory infections, persistent diarrhea, malnutrition, malaria, anemia and meningitis (Vetter et al. 1996; Bobat et al. 1998; Emodi and Okofor 1998; Amadi et al. 2001). Significantly, respiratory infections and diarrheal diseases are also the leading causes of mortality in uninfected children under 5, with about eight million deaths worldwide each year (WGWCH 2002; Black et al. 2003). Singer and Scott’s (2003) syndemic concept is useful here, since it refers to the concentration in a population of two or more diseases or health conditions that have some level of biological interaction that magnifies the negative health effects of one or more of the comorbid diseases or health conditions.
findings (see Hirsch 2003). I also hope it serves to highlight the challenges faced by ethnographers who wish to make both theoretical and practical contributions to understanding and responding to global health issues (Singer 1998) while highlighting how critical sustained informal participation in daily life is to contextualizing health strategies for sick children.

Formal data collection combined quantitative and qualitative methods to explore health strategies for sick children more broadly. The data were obtained through participant observation, longitudinal interviews with therapy management groups caring for HIV positive children, home visits and interviews with key informants who had specialized knowledge about child health, the political economy of the region and paediatric HIV. Since very little qualitative research has been done on the few pediatric HIV treatment programs that exist, the methodological framework for this research built on recent anthropological work on adult ART treatment programs (Hirsch 2007; Smith and Mbakwem 2007; Nguyen 2003, 2007), as well as studies of child health, illness and nutrition (Gottlieb 2004; Kamat 2006; Castle 1994; Hardman 2001; Hirschfeld 2002; Amuyunzu-Nyamongo and Nyamongo 2006). I also divided my research into three phases: Phase 1 (formative), Phase 2 (recruitment) and Phase 3 (extended case studies) to capture the ways that material constraints, such as seasonal food shortages, migration patterns and workloads, impact health strategies.

During Phase 1 (April 2009-July 2009) I concentrated my research efforts in Temwa’s catchment area trying to understand the political economy of the region (see Chapter 5). The first step was to select representative village areas for field visits with Health Surveillance Assistants (HSAs). After consultations with them, we selected four village areas, Somba, Batala, Kapenta, and Usipa, for field visits. On these visits I accompanied HSAs on their routine village visits, which included activities such as post-natal care, village inspection and mobile clinics for children under-five. HSAs and village chiefs also helped me recruit 42 landowners and tenant farmers to discuss food security, health strategies for sick children, migration patterns and household dynamics affecting health care decision making. These interviews provided vital background information about the political economy of the region, while simultaneously allowing me to observe hospital staff in their daily tasks.

During Phase 2 (August 2009-May 2010), I recruited children with HIV on ART for longitudinal interviews and repeat home visits. The most reliable way to access HIV positive children was to identify and recruit them after they were diagnosed with HIV at Temwa Rural
Hospital. In total, 33 therapy management groups caring for 35 children with HIV were recruited from the HTC and ART clinic with the help of hospital staff. A health care worker would tell the primary caregiver about my research first and send them over to talk me in the room next door. Two additional children were recruited using the informal methods outlined below. Only one mother declined to participate in the research (her daughter died a month after we first talked), and I suspect it was because her husband was a very prominent man in town whom I knew personally. In one other case I could not interview the child because she was under 15 years old and I could not get the permission of a guardian since she came to the clinic alone. When I started my research in April 2009, Temwa had 27 children on treatment, and by the time I finished there were 38 children on treatment. Therefore, the 35 children I recruited, with the exception of one refusal, is an almost total sample of the children on treatment between March 2009 and August 2010. However, based on estimates from the Ministry of Health, which show that only 23% of the children in need of treatment were getting it at that time (Makwiza et al. 2006), I estimate that there were at least another 150 children in the area not on treatment who needed to be (UNGASS 2010; UNAIDS 2010).

After I had informed potential participants about the purpose of the research and any risks they might incur for participating, I would conduct, with the help of one of my two research assistants, a semi-structured interview in the language of their choice (either chiTumbuka or chiChewa). During the first interview at the hospital, which lasted between 25 minutes and an hour or more, I would ask caregivers about how they found out the child in their care had HIV, why they decided to start him or her on treatment, any disagreements about that decision and what they felt about the child’s future. We also discussed the challenges they faced in giving the medicines every day, whom they had disclosed the child’s HIV status to and why, and who helped them with childcare when they were busy or sick. At the end of the first interview I would ask for informed consent to do a follow-up visit in the next couple of weeks at their home to talk to them again as well as other members of the therapy management group.

I did home visits with all but one of the 33 households at least once in the months that followed, usually by motorbike, but sometimes by pickup truck (spending the night), bicycle or by foot. I did not visit one family because we could not find the house according to the directions we were given and we never saw the child again; neighbours informed us that they had rented land in another area outside Temwa’s catchment area. One tenant farmer initially did not give us
permission to visit her at home because she was afraid her boss would terminate her employment if he found out she had HIV. She felt that if he knew she had HIV he would be worried that she might die while in his employment, obligating him to pay to send her body back to her family, a very expensive process. However, as soon as the farming season was done she asked us to come and visit her, where she and her son lived in the landowner’s kitchen detached from the main house. The purpose of the follow-up home visits was to get a better sense of the family’s socioeconomic status (house structure, food security, access to water and so on) and to observe and better understand gendered and intergenerational household dynamics.

Topics discussed formally and informally with participants included: stigma experienced by households with HIV positive children; religious practice and how this shaped therapy choices; the symptoms noticed by family members, the steps they took to deal with the illness, whom they consulted, the treatments they tried, and their evaluation of the treatments and side effects; experiences with HIV diagnosis and disclosure; interactions with clinic staff; how they interpreted the illness in the context of high child morbidity and mortality rates from other causes in the community; and what their next steps were to be in terms of treatment follow-up (including alternative approaches such as traditional healers). I also inquired about relations of power and conflicts within the therapy management group, and how these shaped therapy choices; household coping strategies for food insecurity; and medication practices. Life histories were also gathered to elicit migration patterns, work histories and marriage history (Scheper-Hughes 1997). The children on treatment ranged between the ages of 10 months and 14 years, but most were less than five years old. As Table 1 above illustrates, therapy management group characteristics varied considerably.

As I spent more and more time in the ART clinic I started to notice how few children were brought in for HIV testing when they were 18 months old, that is, when rapid antibody tests were considered effective in infants. By the time most were diagnosed at Temwa nearly all were already very sick from HIV-related symptoms. To address this unexpected issue, six months into my research I started doing interviews with caregivers who had “HIV-exposed infants.” An HIV exposed infant is a child whose mother has HIV and could pass the virus onto their child, but the child is too young for his HIV status to be determined with a rapid antibody test. Unlike the families with HIV positive children on treatment, I did not follow these children to their home villages since I expected to see them again if and when the child tested positive for HIV.
Therefore, what happens during this critical time still remains a poorly understood issue, which will only become more important as paediatric HIV treatment programmes push for earlier treatment initiation of infected infants.

To ensure that these individual experiences can be used to make relevant analytical conclusions, I also supervised two surveys at Temwa Rural Hospital conducted by Health Surveillance Assistants (HSAs). At the height of the tobacco season (March 2009) and again in the post-harvest season (August 2009) we administered a short survey (15-30 minutes), using a combination of pre-coded and open ended questions to capture specific childcare practices and child health indicators for children under five (n=460). This survey was modeled on the WHO’s Integrated Management of Childhood Illness (IMCI) guidelines (WHO 2000; Webb 2006; Moursi et al. 2008), but was modified according to Phase 1 findings. The survey asked whether the child had experienced any illness episodes in the previous week, and if so, whether the type and amount of food, breast milk, or liquids increased, and the range of health related services used (i.e. hospital, traditional healer, over-the-counter medications, and herbal infusions). The survey also asked who the key decision maker was for each action, and it included short demographic variables to capture the composition of the therapy management group and the livelihood strategy (i.e. tenant vs. landowning family). I also gathered food security indicators to analyse the impact of seasonal food shortages and workloads on child care practices (Ruel and Arimond 2003). To that end the survey included a short dietary diversity survey (DDS) and anthropometric data (child’s height and weight) to measure levels of food security in and around Temwa.\(^\text{46}\) This was conducted once during the tobacco season and then again during the post-harvest season to capture seasonal food availability since estimates are that between 70-85% of households in Malawi run out of food every year (Kaida 2000). The DDS is a rapid, user-friendly tool to measure changes in dietary quality at the household and individual level (FAO 2007; Hoddintott 2001; Hatloy et al. 2000; Steyn et al. 2006; Kennedy et al. 2007). Although these scores do not capture how food is shared within therapy management groups, such as men getting the best quality meat, this information was helpful for ascertaining differing levels of food security between tenants and landowning families in particular.\(^\text{47}\)

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\(^{46}\) I referred all children with severe malnutrition to UNICEF’s malnutrition clinic held on Friday mornings. I also gave each family who participated in the survey 1kg of soya beans.

\(^{47}\) The biggest finding from this survey was that levels of food security between tenants and landowners was not that different. However, a class of farmers renting land were very vulnerable to food insecurity.
During Phase three, (June 2010-December 2010) I focused the majority of my time on four extended case studies. The extended case studies were done to contextualize ART “adherence” and “non-compliance” further by conducting additional home visits with a subset of the children on treatment. To maximize the generalizability, and therefore the potential applicability, of ethnographic studies, I selected four therapy management groups across three pre-determined social axises: migration status, food security status and composition of the therapy management group (see Hirsch 2003 for an explanation of systematic sampling). The composition of each therapy management group varied widely and changed over time due to deaths, divorce or migration. Therefore, the children were selected to represent the range in diversity of TMGs in terms of the primary caregiver (grandmother, sibling, and mother), status of the father (divorced, polygamous, dead, caregiver) livelihood strategy (tenant, landowner, and entrepreneur), gender (boys and girls) and age (two children under five and two under the age of two). These extended case studies gave me more time with each family and insight into how variations in the TMG could lead to treatment delays or interruptions in treatment.

Near the end of my research I also conducted a series of key informant interviews from a range of social contexts. I interviewed three religious leaders from the town’s most prominent churches, two traditional healers, two tobacco estate owners and six grandparents known for their knowledge of childhood illnesses. At Temwa I interviewed a half dozen health care workers involved in the pediatric HIV treatment program as well as two HIV/AIDS programme coordinators for the district hospital. These interviews helped me understand programme limitations from the viewpoint of both programme implementers and health care workers.

I conducted all of the interviews along with one of two research assistants in either chiTumbuka (the local language) or chiChewa (the national language mostly spoken by tenants). Interviews were recorded, translated and transcribed using a computer by assistants at my home during the day. I selected my research assistants, Maggie and Lennie, in consultation with staff at the hospital and after I conducted a dozen interviews with interested candidates. Maggie and Lennie were also mothers with young children and we discussed family dynamics and child health for hours over the course of my research. I use their real names throughout this thesis at their request.

For the duration of my fieldwork I combined the more formal methods outlined above (semi-structured interviews, surveys) with more ethnographic data collection methods. In
particular, for the entirety of my fieldwork I spent at least two days a week conducting participant observation at Temwa Rural Hospital. I focused my attention on pediatric HIV “entry points” identified in Malawi’s national HIV treatment guidelines, such as the ART clinic, the HIV testing clinic, outpatient department and the under-five child health clinics (MOH 2006). In addition to these twice-weekly observations I also spent time observing immunizations, child health days, mobile clinics and “village inspections” by HSAs. Participant observation of interactions between patients and health care workers was crucial for understanding how the structure and culture of biomedicine impeded early diagnosis for marginalized children with HIV. For example, interview data with healthcare workers on their self-reported practices rarely matched up with what I observed day-to-day. Getting ethics clearance from the Ministry of Health, while necessary, also created a whole set of problems for me with the healthcare workers at the hospital. While I tried hard to reassure them that their identities would remain confidential and that I would not report any information that could put their jobs at risk, many were never absolutely candid with me, and some lied to me about their daily activities. They knew that I was ultimately accountable to the Ministry and that I was under an ethical obligation to report my findings to the Ministry at the end of fieldwork. Moreover, while I have changed informants’ names to mask their identities, it is possible for those involved to recognize themselves and their coworkers. However, nearly all of the key health care workers at Temwa that I make reference to in this dissertation are no longer there; most have been transferred to other health centres, while a few others have moved onto other positions within the Ministry of Health or in the NGO sector. As a result, the interviews I conducted with health care workers are useful in the sense that they tell me what health care workers are supposed to do, whereas more ethnographic methods, such as participant observation at the hospital, told me more about what they really did on a daily basis (see also Closser 2008: 19).

Home visits were also a valuable source of information about the challenges faced everyday by families raising children with HIV. I often spent whole afternoons with each family doing small household chores (shelling maize, sewing tobacco) while chatting with many members of the child’s therapy management group, including neighbours, employers and

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48 “Voluntary Counselling and Testing” was renamed to “HIV counselling and testing” in 2009 to better reflect the turn from ‘voluntary testing’ to the routinization of HIV testing during hospital admissions, out-patient visits and antenatal care (Agnotti et al. 2010).

49 Tobacco leaves are stitched together so that they can be hung up to dry over bamboo poles.
grandparents. I witnessed arguments between in-laws, neighbours dropping off food, tenants negotiating their payments, children hunting for birds, mothers selling vegetables to get transport money to the hospital and other activities that provided insight into the child’s relationship to his or her broader community. For example, one girl’s uncle arrived one day very drunk and started shouting at his sister that she was too much trouble for him because she had HIV and that he had his own family to support. Many of these observations also provided insight into the daily challenges of trying to raise a child with HIV. The child’s living conditions, such as the type of housing (mud versus brick, for example), furnishings (some furniture versus none), the crops (tobacco farmers or labourers) and the level of social support surrounding for the child (the presence of grandparents, uncles, aunts) were much more tangible in person than in an interview. Therefore, although during home visits we did not always talk extensively about the child’s HIV status or their treatment regimen, they were helpful for understanding the family’s broader social support network, conflicts with other family members, and also how the children themselves interacted with their siblings and friends.

Although home visits were invaluable, there were limits on my ability to participate in village life outside of Temwa. I had originally planned to do home-stays with a small number of families who had children with HIV, but high levels of food insecurity and poor living conditions made that impossible. Although it is customary for Malawians to feed visitors, very few families were able to offer me any food on my visits. This problem was particularly acute during the “hungry season” (January-February for landowners; May-August for tenants) when most families were only eating one meal a day. I was very conscious of this pressure and made every effort to visit families in the afternoons after lunch and before dinner so that families would not feel embarrassed or feel pressured to give me food they needed. To offset any possible costs of having me in their home I brought small cash food items from town (sugar, beans, cooking oil, juice) and occasionally cloth for school uniforms or second hand clothes donated by my research assistants. I also started carrying Oral Rehydration Therapy Salts with me from the hospital, after I realized how prevalent chronic diarrhea was among caregivers and the children with HIV. In a few cases, we had to travel very long distances to get to the homes (30km), but because of the poor living conditions (one room bamboo houses for six people for example) we would arrange ahead of time to sleep with various members of my research assistant’s family, who somehow seemed to be everywhere.
In addition to my research activities I also participated in the daily life of the community. Since I am a certified English as a Second Language Teacher (CELTA) I volunteered at the local primary school one afternoon a week for the duration of my fieldwork. The 20 or so kids who became my regular students helped broaden my understanding of children and childhood more generally. Through these activities I recruited two more children with HIV who were attending the Temwa Rural Hospital on their own to get medicines and therefore too young for me to interview without a guardian’s consent. My landlord also gave me two acres of farmland in his home village. For two years I grew maize, the local staple crop, which gave me a whole new appreciation for the problems associated with labour shortages. For example, a quarter of my crop was eaten one year by termites because I could not find anyone to weed it on time. Temwa was my home as well as my research site; I made friends, attended funerals, ate in people’s homes, chatted with my neighbors, had people over for birthday parties, watched local football matches and argued with my landlord about the rent. In a few cases people came to ask me to intervene on their behalf in personal family matters. For example, one youth asked me to advise her mother to get an HIV test because she did not feel she had the authority to do so. In these ways I came to understand how HIV diagnosis in children is a messy, lengthy affair often involving many people.

Research Limitations

While my research provides insight into why so many children are diagnosed too late to benefit fully from ART, and why some children fall out of treatment, I also think the challenges to early diagnosis that I identify – such as gendered and intergenerational household dynamics, an overemphasis on standardized treatment guidelines and a poor understanding on the part of policy makers of the everyday realities in rural, resource-poor settings – are likely much more serious and consequential impediments than they might appear in this dissertation. The reader should bear in mind that most of the children I write about were eventually enrolled into Temwa’s treatment programme; however, epidemiological forecasting suggests that for every child enrolled at Temwa, three more died before they were ever even diagnosed with HIV. In other words, while the children I studied managed to find their way into treatment despite the

50 Estimates at the time of my research were that 23% of the children in need of treatment accessed it; hence the ⅓ ratio cited here (UNAIDS 2010).
many challenges, most HIV-positive children do not, and thus most die without HIV ever having been diagnosed. This issue became even more apparent when I realized that I saw very few women who tested positive during antenatal care bringing their children back for HIV testing at 18 months. An important addendum to my research, then, would be to study post-partum HIV-positive mothers (and their households and TMGs) in order to better understand why they do or do not return to have their children tested, though the design of such a study would have to be very carefully conceptualized in order to minimize the influence of the researcher on a mother’s (or the TMG’s) decision-making (i.e. asking a mother why she did not return for testing would probably make her more likely to return).

**Outline of the Thesis**

This dissertation follows a small group of children with HIV as they are diagnosed and then initiate ART over a two year period from 2008-2010. In Chapter One I begin by discussing the origins, design and implementation of Malawi’s first national pediatric HIV treatment programme. In particular, I discuss how global health standards were adjusted to facilitate universal access to ART in decentralized settings like Temwa Rural Hospital where doctors, laboratories and pediatric formulations were absent. I conclude by considering how recent revisions to Malawi’s national treatment guidelines fail to address many of the concerns around treatment access and adherence that my dissertation identifies.

Chapters Two and Three explore why so many children are tested for HIV months after they first exhibit dangerous symptoms. In Chapter Two I explore how opt-out testing strategies, which are designed to help identify HIV positive children before they become too sick to benefit from treatment, puts married women in the awkward position of trying to encourage their husbands to go for an HIV test with them together after they test positive. I argue that the design and implementation of this policy often fails to consider the ways that knowledge flows within multigenerational households. I highlight how it is neither necessary nor strategically advantageous for some women to disclose their HIV status to their husbands “straight out”. Instead, I show how grandparents often play pivotal roles at ensuring timely HIV tests for sick children and suggest that HIV programming draw on their role as “secret keepers” to prevent treatment delays. In Chapter Three I consider how “failed sociality”, or caregivers’ concerns
about the long term efficacy of ART treatment linked to the precarity of everyday life in Malawi, were linked to treatment delays. These findings suggest that ART roll-out without any additional social and nutritional support will likely have a limited impact on the long term health and happiness of children living with HIV.

Chapters Four and Five move away from factors that affect HIV testing and treatment uptake for children at the household level to consider the clinical encounter at Temwa Rural Hospital. In Chapter Four I consider how the bureaucratic need to certify that each child is eligible for treatment, through standardized testing and rigid staging criteria often end up excluding many children who require immediate assistance. In Chapter Five I explore in depth how these criteria end up excluding the most economically and socially marginalized patients, or tenant farmers working on tobacco farms in the Northern region. Combined these chapters indicate that a “one size fits all” approach to policymaking and ART roll-out will not result in universal access to care and treatment and often prevents health care workers from offering relief from suffering in many cases.

Finally in Chapter Six I consider the long term futures of children living with HIV. Since I did my research during the early years of the programme, when few children had been on treatment for more than a year or two in most of the country, these results are preliminary. However, they suggest that in the future barriers to long term treatment adherence will include growing independence into adolescence, the death of caregivers, chronic food insecurity and the long term toxic side effects of ART. Many of the children I worked with also showed signs of developmental and/or physical disabilities that were impacting their ability to go to school, work on their farms and attain independence in adulthood. These findings suggest that rather than defining program success as “universal access” we should also consider both the quality of life and long term treatment outcomes for children growing up with HIV.
Chapter 1: “Building a Ship as it Sails”: Pediatric HIV in Policy

For the first time since the beginning of the AIDS epidemic, we have a historic opportunity to lay the groundwork to achieve zero new infections, zero discrimination and zero AIDS-related deaths.

- UNAIDS Treatment 2015 Report

The goal of an AIDS-free generation may be ambitious, but it is possible with the knowledge and interventions we have right now. And that is something we’ve never been able to say without qualification before. Imagine what the world will look like when we succeed.

- U.S. Secretary of State Hillary Rodham Clinton, November 8, 2011

We believe by 2015 children everywhere can be born free of HIV and their mothers remain alive.

- Global Plan Towards the elimination of new HIV infections in children by 2015

Global Context of Pediatric HIV

Worldwide there are an estimated 3.2 million children aged 0-14 infected with HIV, but nearly all of these children (90%) live in Sub-Saharan Africa (UNAIDS 2013). Most children are infected with HIV during pregnancy, during delivery or through breastfeeding (UNAIDS 2013). Effective methods to prevent maternal-to-child transmission (PMTCT), such as HIV testing during pregnancy, c-sections, replacement feeding (instead of breastfeeding) and pharmaceutical intervention during pregnancy and at birth have virtually eliminated pediatric HIV in developed countries (Lewis and Donovan 2009). In contrast, an estimated 300,000 children are newly infected with HIV every year in developing countries (UNAIDS 2013). Recent research shows that simple pharmaceutical interventions, such as single dose nevirapine (sdNVP) during delivery, ART for pregnant and breastfeeding mothers, as well as infant prophylaxis for six weeks after birth, can reduce transmission rates to less than 5%. This treatment is collectively referred to as Option B+ (Ahmed et al. 2013; WHO 2006, 2009). Recently global health
interventions (GHIs) have reemphasized the importance of preventing new HIV infections in children. *The Global Plan Towards the Elimination of New Infections*, a public-private partnership spearheaded by UNAIDS and USAID, aims to reduce transmission rates in 22 “priority countries”51 (that is countries with the highest numbers of HIV positive pregnant women) by 90% by the end of 2015.52 These efforts have made significant progress; globally the number of new infections per year are nearly half of what they were at their peak in 2003 (570,000) (Kim et al. 2013; WHO 2011). However, only a few priority countries are on track to reach the global target by 2015.53 Malawi, for example, faces a number of challenges that make the prevention of new pediatric HIV cases unlikely: PMTCT programs remain underfunded and are not fully integrated into antenatal programs (Price et al. 2014); health systems are overburdened and understaffed; and breastfeeding remains the only feasible option to prevent malnutrition when most families lack the resources that would make replacement feeding safe and effective, such as clean drinking water and nutritious complementary foods (Lewis and Donovan 2009; Wettstein et al. 2012). Recent research in Malawi also indicates that between 20-30% of the pregnant women who enroll in Malawi’s new PMTCT program stop treatment within a year (Tweya et al. 2014). Despite notable progress in the last decade to reduce new infections, understanding why children are still underrepresented in HIV treatment programs is critical since significant numbers of children are still being infected with HIV.

**Child Health and Pediatric HIV in Malawi**

Pediatric HIV is just one of Malawi’s many pressing health priorities. Malawi has one of the highest adult HIV prevalence rates in the world at 10.8% (UNICEF 2014). Malawi is also one of the poorest countries in the world and ranked 174th out of 187 according to the Human Development Index (Human Development Report 2014); nearly 1 out of every 10 children dies

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51 Priority countries are: Angola, Botswana, Burundi, Cameroon, Chad, Cote d'Ivoire, Democratic Republic of the Congo, Ethiopia, Ghana, India, Kenya, Lesotho, Malawi, Mozambique, Namibia, Nigeria, South Africa, Swaziland, Uganda, United Republic of Tanzania, Zambia, Zimbabwe (UNAIDS 2013). Notable exclusions in countries with poor PMTCT coverage include: Papua New Guinea, South Sudan, Guinea, Guinea-Bissau, Eritrea, Djibouti, Benin, Burkina Faso, Congo, Gabon.


53 Botswana as an estimated HIV transmission rate of 4%, with antiretroviral coverage of nearly 93% among pregnant women. Malawi has made moderate reductions; estimated transmission rates in 2011 were 25% (1/4 children born to HIV positive mothers get HIV) (UNAIDS 2013).
before the age of five.\textsuperscript{54} Common causes of death are neonatal conditions, pneumonia, diarrhea, malaria and HIV/AIDS (MDHS 2010). Efforts to reduce child mortality (Millennium Development Goal #4) have been very effective in recent years, but are being hampered by new HIV infections in infants and rising rates of child malnutrition, which is the leading underlying cause of most childhood deaths (Black et al. 2003, 2008; Horton 2008). Thus, while pediatric HIV is a significant cause of child morbidity and mortality in Malawi (Garenne and Gakusi 2006; Marston et al. 2005), there are other competing health concerns, especially high rates of malnutrition, and high levels of poverty, that draw human and health resources (see Table 3; GOM 2005; NAF 2009).

In Malawi an estimated 180,000 children under 14 have HIV, and more than 30,000 infants and children are infected every year (UNAIDS 2013). Without any treatment children with HIV face a bleak and short-lived future: half die by their second birthday and a full three-quarters die by the time they reach the age of five (DeBaets et al. 2007; Newell et al. 2004). Pediatric HIV is a “hidden epidemic;”\textsuperscript{55} by this I mean that despite recent efforts to improve HIV prevention and treatment services, most infected children still die before the age of two, with their deaths left undiagnosed and attributed to other common childhood illnesses such as diarrhea or respiratory infections (Taha et al. 2000). Although estimated HIV treatment rates for children have risen since the launch of Malawi’s national ART programme, from a miniscule 5% at the end of 2004 to 36% by the end of 2013, treatment rates remain far below current global targets. Without major investments in Malawi’s public health care system, Malawi is unlikely to meet the “Zero new infections by 2015” target established by UNAIDS in 2011.\textsuperscript{56}

\textsuperscript{54} The Under Five Mortality Rate (U5MR) for Malawi in 2013 was 68 deaths out of every 1000 live births, or 0.7 deaths out of every ten children; while this seems high it represents a significant reduction over the last two decades. In 1990 the U5MR was 245 deaths for every 1000 live births (UNICEF 2015).

\textsuperscript{55} Biehl (2005) used the term ‘hidden epidemic’ to refer to the unrecorded HIV deaths amongst Brazil’s poorest and most marginalized. I use it here to refer to a similar invisibility in pediatric HIV/AIDS deaths.

\textsuperscript{56} In June 2015 the WHO announced that Cuba was the first country in the world to eliminate mother-to-child transmission, which is defined as less than 2% of children whose mothers have HIV are born with the virus (http://www.who.int/features/2015/born-hiv-free/en/, accessed July 10, 2015.)
TABLE 2: Child Health Statistics for Malawi (UNICEF 2014) 57

<table>
<thead>
<tr>
<th>% of Total Child Population</th>
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<tbody>
<tr>
<td>Proportion of population &gt;15 years of age (%)</td>
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<tr>
<td>Immunization coverage</td>
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<tr>
<td>Infants with low birth weight</td>
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<tr>
<td>Underweight (moderate and severe)</td>
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<tr>
<td>Stunted growth</td>
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<tr>
<td>Child Mortality Rate (0-5 years)</td>
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<tr>
<td>HIV/AIDS prevalence (0-10 years)</td>
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<tr>
<td>Child deaths due to HIV/AIDS</td>
</tr>
<tr>
<td>Children in need receiving ART treatment</td>
</tr>
</tbody>
</table>

Multi-Bi Financing and Global Health Governance

Understanding Malawi’s national pediatric HIV treatment program requires a look at the organizations that created it: the Government of Malawi and the plethora of donor agencies that make it possible. Their sometimes contradictory goals, funding and accountability structures have determined how the programme was designed and implemented in Malawi. In the late 1970s, Judith Justice noted that while Nepal’s Integrated Community Health Program was funded by at least 15 different organisations, the vast majority of the funding was derived from the public sector (1984:24-35). However, the landscape of global health has changed significantly in the last two decades (Brown et al. 2006; Cohen 2006; Brandt 2013). Along with the more traditional multilateral and bilateral sources of funding available for national treatment programmes, new funding structures, sometimes called “multi-bi financing,” have entered the scene, accompanied by their own expectations and goals (Sridhar 2012). Multilateral funding refers to monies given to an organization that involves two or more governments or institutions, the prime example being the World Health Organisation (WHO), the major United Nations

agency for health. Bilateral funding refers to monies given from one government or institution to another such as the President’s Emergency Plan for Aids Relief (PEFFAR). Multi-bi financing refers to the practice of donors choosing to route funding earmarked for specific projects (such as HIV/AIDS) through multilateral agencies and to the emergence of new public-private multi-stakeholder initiatives, such as the Global Fund for to Fight AIDS, Tuberculosis and Malaria.

The Global Fund was launched in 2002, following the endorsement of the UN general Assembly Special Session on HIV/AIDS (UNGASS) in June 2001. It emerged as a result of much public health activism, the support of Microsoft founder and philanthropist Bill Gates, an impassioned plea by the then UN Secretary General Kofi Annan for the creation of a “war chest” to fight HIV/AIDS, and, to some extent, the convergence of US foreign policy and security interests in global health (McCoy et al. 2012; Taylor and Harper 2014). The Global Fund was heralded as an innovative response to perceived failures in “big aid”; its supporters claimed it could make aid more effective by bringing “‘hard nosed’ strategy, performance metrics, innovative financing models and increased control of grantee decision making to philanthropy and development” (McGoey 2014: 111; Rogerson et al. 2004). The Global Fund is the world’s largest Global Public Private Partnership (GPPP), and brings a wide set of stakeholders that include the UN, government donors, private foundations, big business, civil society and individual donors together into a single structure (Sridar 2012; Taylor and Harper 2013). As the largest single contributor for HIV/AIDS treatment in Sub-Saharan Africa, the Global Fund has significantly transformed the global health agenda (Brandt 2013). While the injection of funds is welcomed, some caveats are worth considering. The Global Fund, with its narrow disease-based focus, raises important questions about the costs and benefits of vertical programmes compared to comprehensive and integrated health care (Fidler 2008; Taylor and Harper 2013; Walt and Buse 2000); about the trade-offs between needing to urgently expand coverage of life-saving services and needing to build sustainable and robust health systems for the future (Biesma et al. 2009; Nguyen 2009); and about the relative ability of recipient countries to use aid for their specific needs (Okuonzi and MacRae 1997; Shretta et al. 2000; Stuckler et al. 2011). Understanding how major shifts in the global health policy sphere influence HIV treatment programmes in specific locales is a central theme of my dissertation.
A Brief History of Malawi’s ART Program

Malawi’s national HIV treatment program is supported by a bewildering array of international donors, but there are two major players: the Global Fund and the WHO (see Figure Seven. The Global Fund and the WHO are marked by significant differences in their governance structures and in their strategies to alleviate the burden of HIV/AIDS. The main role of the WHO in Malawi is to provide technical support and act as a normalizing agent, by setting global norms and standards. To that end, the WHO produces and distributes HIV treatment guidelines to help national governments develop relevant, evidence-based policy frameworks (WHO 2009; Walt and Buse 2000). While headquartered in Geneva, the WHO has a regional office that coordinates with national governments to develop national health policies. The WHO formulates their health policies at the Annual World Health Assembly, which is attended by delegates from all 191 member states (Walt and Buse 2000). The Global Fund on the other hand, has no in-country presence and very little representation of recipient countries either on governing boards, or on technical, advisory or grant-giving committees (Walt and Buse 2000). Unlike the narrowly defined disease-focused mandate of the Global Fund (“to attract and disperse additional resources to prevent and treat HIV/AIDS, TB and malaria”), the WHO has a broad mandate (“the attainment by all people of the highest possible level of health”). While the WHO (and its affiliated UN agencies) was once the leader in global health, their ability to direct and influence policy is currently in flux as new and powerful players such as the Global Fund flex their financial muscle (Brown et al. 2006).

58 Other UN agencies, such as UNAIDS, which shares office space with the WHO in Geneva, and (The United Nations Children’s Fund) in New York City, also monitor global HIV/AIDS epidemiological trends and advocate for a comprehensive and coordinated global response to HIV/AIDS. UNICEF launched their “Unite for Children: United Against AIDS” campaign in 2005, to raise awareness about the neglect of children worldwide in national treatment programmes and to provide a framework for improving their inclusion http://www.unicef.org/media/media_29500.html, accessed December 4, 2014.

59 Calestous Juma, international aid expert at Harvard University stated that WHO’s failure to stop the ebola epidemic in West Africa has been “catastrophic”, highlighting how little actual power the WHO has to mobilize resources on it’s own http://www.cbc.ca/thecurrent/episode/2014/11/20/will-band-aids-christmas-single-really-help-fight-ebola/, accessed November 20, 2014.
Rounds 1 and 2 of Malawi’s national HIV treatment scale up plan (2004-2005; 2006-2010) were funded by initial grants from the Global Fund with technical support provided by the WHO (and affiliated UN agencies UNAIDS and UNICEF). The advent of multi-bi financing in global health has had a significant impact on priority setting and policy making efforts in recipient countries. For example, the Global Fund provides nearly all of the funding for Malawi’s HIV test kits and ART medicines (see Table 3). Although the Global Fund’s actual presence in Malawi is non-existent, their adoption of “performance-based” funding mechanisms, whereby

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60 The “3x5” initiative covered 2003-2005; from 2005-2010 it was the ; in 2011 the UN Political Declaration on HIV/AIDS set a global target of 15million adults and children on treatment by 2015;
funds are released as certain targets as met, has profound implications for the “scale up” of HIV treatment programs and their long term sustainability.

In November 2009 and December 2010 Malawi’s application to the Global Fund was rejected on the basis that Malawi’s proposed amendments (in line with the WHO’s amended treatment guidelines) were “too ambitious”, since they would have required significant health and human resources (MSF 2009). The original proposal focused heavily on tackling transmission of HIV from mother to child by providing lifelong HIV/AIDS treatment to all HIV-positive pregnant women. They had also planned to spend more to retain health workers and scale up voluntary male circumcision to help slow down the spread of HIV.64 These plans were considered too audacious by the Global Fund and Malawi was advised to scale back their intentions.

The suspension of funds to Uganda in 2005 because of some high level mismanagement also highlights how these financing structures are likely to benefit countries judged to have “good policy environments” (Shakow 2006).65 Yet the poorest countries often need support to establish good policy environments, highlighting how “the fallacy of the level playing field” overlooks the unequal power relationships inherent in these new “partnership” arrangements (Sidibe et al. 2006a, 2006b; Whiteford and Manderson 2000). Due to persistent economic constraints, Malawi remains almost entirely dependent on external funding for its HIV/AIDS response. In 2011, UNAIDS reported that the Government of Malawi (GOM) only funds 1% of the country’s HIV/AIDS programming. Thus, within this new multi-stakeholder regime where financing flows towards countries that produce results, inequalities between countries are amplified, putting the most affected countries at even greater disadvantage.

Table 3: Major Sources of Funding for Malawi’s national treatment programme (2003-2014)

<table>
<thead>
<tr>
<th>Source</th>
<th>Funding (millions)</th>
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<tbody>
<tr>
<td>Global Fund 61</td>
<td>670</td>
</tr>
<tr>
<td>PEPFAR 62</td>
<td>166</td>
</tr>
<tr>
<td>World Bank 63</td>
<td>145</td>
</tr>
<tr>
<td>WHO</td>
<td>Unknown</td>
</tr>
</tbody>
</table>

65 A “good policy environment” is characterized by, for example, the rule of law, an open and regulated financial system, human rights protection (see Walt and Buse 2000: 168; Okuonozi and MacRae 1997).
The organisation of Malawi’s national treatment program reflects current trends in global health that value partnership and collaboration (see also Closser 2010: 48-50). Officially, the Government of Malawi (GOM) is responsible for organising and coordinating the HIV response within the country via the National AIDS Framework (GOM 2009). The President of Malawi is the ultimate authority for Malawi’s National AIDS strategy; he or she is the Minister responsible for developing Malawi’s official National AIDS Framework with donors, the Ministry of Nutrition and HIV/AIDS, as well as representatives from the National AIDS Commission (NAC) (GOM 2009). The GOM established the NAC in 2001 with funding from the World Bank’s Multiple Country AIDS Program, which focused on building capacity and HIV/AIDS prevention to coordinate “a multi-sectoral approach” to the HIV/AIDS epidemic (Gorgens-Albino et al. 2007; Ooman et al. 2007). The main aim of the NAC is to develop national HIV/AIDS treatment guidelines with technical support from the WHO (and other partners) and then to coordinate, implement and supervise it in each of Malawi’s twenty-eight districts. The NAC is also responsible for securing funds for the national programme and coordinating with all donor agencies within and outside Malawi. Figure eight depicts a spaghetti like squiggle of lines connecting dozens of bubbles that represent the national implementation of Malawi’s ART program; it connects a diverse array of “partners” from the private and public sectors, while also including community and faith based organisations (see also Buse and Walt 1997; Cohen 2006). The overall effect is quite dizzying and highlights how the Global Fund’s vision to be a simple financial tool has resulted instead in “mushrooming bureaucracies” in recipient countries who have to keep up with the partnership and performance-based funding criteria of their major donor in order to keep their national treatment program running (Mtonya et al. 2005; Taylor and Harper 2014).

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66 The Board is made up of individuals appointed by the President as well as various stakeholders including, business leaders, people living with HIV/AIDS, youth and faith based organisations (NAF 2009).

At the district level, all government health activities fall under the supervision of the District Health Officer (DHO). The DHO is directly accountable to the district and national level authorities, but has no contact at all with the WHO or the Global Fund. The District AIDS Coordinator, who organises the training of health care workers and the day-to-day implementation of the national treatment program, reports directly to the DHO but has no official relationship with district or national level authorities (see Figure Nine). Health care workers at both rural and district hospitals compile data that is sent to the Ministry of Health, who then collate it and submit it to the NAC for review. The Ministry of Health also carries out quarterly inspections of district HIV treatment centres, but to my knowledge district-level officials never visited Temwa during two years of my research, and representatives from USAID visited Temwa once. While the health care workers I spoke to did not know for sure what the consequences would be for failing to meet projected treatment targets, they unanimously felt that they would be
“labelled as bad” and that either the hospital would lose funding or they would be transferred to a less desirable location (i.e. rural health centre) or demoted. Part of the reason that they could only speculate about the repercussions of failing to meet government targets was that Temwa Rural Hospital performed better than many other rural hospitals or health centres in the country. Many also connected any district level failures to the withdrawal of financial support by Malawi’s major donors.\(^6\) Thus, in many ways health care workers felt that they and the patients at Temwa were responsible for ensuring that the national treatment programme was funded for many years to come. In this way the onus to succeed is placed on the targets of Malawi’s national treatment roll-out and the health care workers who administer it, rather than on those responsible for the design and implementation of the programme at the national or international level.

**Figure 9: Malawi’s National ART Program at the District Level**

As part of a larger Global Health Intervention (GHI), Malawi’s national treatment program was remarkably similar to other HIV treatment programs around the world in its design and implementation strategies (Biesma et al. 2009). This fact highlights how difficult it is for

\(^6\) During my research GTZ and other donors froze their funding because of controversy surrounding the deportation of a British diplomat, and the lack of transparency around aid funding. These topics were widely debated by Malawians, many of whom found the “conditionalities” tied into aid unacceptable.
Malawi, which is almost entirely dependent on foreign aid for its national treatment program, to resist or modify global health recommendations even for its own benefit (see also Okuonozi and Macrae 1997). A good example of how this problem manifests itself in Malawi is the persistent disconnect between the Global Fund’s definition of “Populations at Risk” and those who are most likely to have HIV in Malawi. For example, the Global Fund identifies men who have sex with men, injection drug users, transgendered individuals and commercial sex workers as key populations at risk. However, in Malawi, HIV is a generalized epidemic, which means that most new infections occur within long term relationships (Epstein and Morris 2011; Hirsch and Wardlow 2009; Lagarde et al. 2001; Morris and Kretzschmar 1997; Morris et al. 2013; Padian and Manian 2011); injection drug users are non-existent. While commercial sex workers have extremely high HIV rates (estimated at 70%), there are other occupational groups with HIV rates more than double the national average, such police officers and teachers, yet very little is known about the social determinants of HIV transmission that lead to these high rates (see for example Sikstrom 2010). Thus, the Global Fund’s persistent focus on standardized risk categories and performance measures prevents national governments like Malawi from tailoring their interventions to the epidemiological realities of their context. I expand this argument further in Chapter Five, where I examine in more detail the systematic exclusion of tenant farmers, or rural-rural seasonal farm workers, from HIV/AIDS treatment programs.

**Health Care Delivery in Malawi: Decentralized HIV Care and Treatment**

The vast majority of the Malawians on HIV treatment (87%) obtain access to HIV treatment services through a government or mission-run rural health centre or hospital, like Temwa. Malawi’s Ministry of Health is responsible for 62% of the health services in the country, with another 37% are provided by the Christian Health Association of Malawi (CHAM). Malawi’s public health care system has three separate tiers (primary, secondary and tertiary

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69 The Global Funds most recent strategy for 2014-2017 to address key populations recognizes that the key populations they focus on may not match up with the vulnerable populations in specific contexts, such as street children, people with disabilities and miners. Therefore the “Global Fund’s new funding model directs resources to priority services where needs are greatest in order to achieve impact” (The Global Fund 2014: 6), but what this will actually look like in practice is unclear.

care), which are all linked by a referral system (WHO 2009). Most patients enter into care at the tertiary level, which includes manned and unmanned health posts, community based outreach (mobile clinics), urban and rural health centres and rural hospitals, like Temwa. There was nothing remarkable or extraordinary about Temwa rural hospital; it was neither a great nor a bad hospital. It has been offering a variety of free health services for three decades, including vaccinations, malaria treatment and antenatal care. However, it did not have many of the services most Canadians would expect to find in a hospital; there was no running water, no doctor, and aside from a microscope to do malaria tests there were no x-ray or laboratory technologies on site. If a patient’s condition was considered critical they were referred to the next level of the health care system. Secondary level care is provided by district hospitals that are located in all of Malawi’s 28 districts. These hospitals are equipped to provide all of the same basic services as the tertiary level hospitals as well as a few more including x-ray facilities, an operating theatre (small surgeries, c-sections) and a laboratory (WHO 2009). The top tier of care is provided by central hospitals located in major urban areas (Mzuzu, Lilongwe and Blantyre), and they offer more specialized treatment including some cancer treatment, burn units, eye exams and so on.

Results from Round 1 (2004-2005) of the national HIV treatment programme demonstrated that good health outcomes for patients with HIV could be achieved in resource-poor contexts like Malawi and also that universal access to ART was possible (Bemelmans, et al. 2010). This encouraged Malawi (and their donors) to “decentralize” HIV care and treatment services to larger tertiary tier health centres and rural hospitals (Round 2 – 2006-2008), and later to small rural health centres and health posts (Round 3 – 2008-2010). Temwa Rural Hospital, as one of the larger tertiary health centres in Northern Malawi, started distributing free ART treatment to adults in Round 2 of Malawi’s national scale up plan (MOH 2005; MOH 2004-2009). At present, Malawi’s estimated HIV treatment rates have risen by over 2500% in less than 10 years (UNGASS 2012). The dramatic increase in the use of ART therapy was a welcome development after years of treatment denial and neglect. Prior to transformations in global policy making that made treatment affordable for countries like Malawi, families and health systems were collapsing under the burden caused by HIV/AIDS. In 2005, 14% of all children in Malawi were orphans (Wolf 2013); the public health system was on the verge of collapse due to critical human resource shortages (MOH 2007b); and high mortality and morbidity rates among adults
resulted in a “new variant famine” (de Waal and Whiteside 2003), which refers to the fact that productive members of the household in HIV/AIDS affected regions are too ill to farm or have died, reducing the viability of farming livelihoods and increasing the vulnerability to external shocks, such as droughts. However, mass treatment programmes have also been criticized for “cannibalizing” other health services (Nguyen 2009), and for producing their own “anti-politics” (Ferguson 1994; Fisher 1997). By this I mean that international donors and the government of Malawi are depicted as mere instruments for implementing health policies and engineering behaviour change (Taylor and Harper 2013). Some argue that new therapeutic regimes have deflected attention from the broader social conditions of HIV infection and the long term survival of those already infected (see for example Biehl, 2007; Hunsmann 2013; Kalafonos 2010; Marsland 2012). My dissertation contributes to the wider discussion about the ambiguous side effects and unintended consequences of mass HIV treatment programs.

Rapid scale up at decentralized tertiary health centres was accomplished through a number of health service adaptations, including task shifting to compensate for the lack of trained medical personnel and the simplification or standardization of protocols for testing and treatment (Bemelmens et al. 2010). Task shifting entails the delegation of certain medical responsibilities to less specialized health care workers (Callaghan et al. 2010). With the shortage of doctors in Malawi, paramedical clinical officers, medical assistants and nurses were trained to manage and deliver ART. The HIV unit of Malawi and selected partners developed a 5-day training model and a certification of competence linked to a formal examination. Successful candidates then proceeded with a two week practical clinical attachment at an experienced ART site (Bemelmens et al. 2007). At Temwa, the clinical officer and one of the three nurses on staff were certified by the MoH to provide ART. In decentralized settings like Temwa, health surveillance assistants (HSAs) also played a critical role in HIV testing and treatment services. HSAs were initially created as a community cadre responsible for preventative activities and organizing disease outbreak response during the smallpox eradication campaign (Nyirenda and Flikke 2012). HSAs, as a minimum requirement have a Junior Certificate of Education (JCE, or the equivalent of a Canadian Grade 10 education). To become an HSA they participate in a 10-week basic training offered by the Ministry of Health (MoH). Some HSAs opt to take an additional three-week training to become certified by the MoH to conduct HIV testing and counselling (HTC), and ART adherence counselling (Libamba et al. 2007).
The ability of lower-cadre health personnel to administer and monitor a rapid scale-up of ART was facilitated by a standardized approach to testing, delivery and adherence monitoring (Libamba et al. 2007). According to Malawi’s ARV scale-up plan (2006-2010), this approach had four essential components. First, every eligible patient received the same medicine; a generic fixed-dose combination treatment with stavudine, lamivudine and nevirapine, delivered free of charge. Second, to qualify for treatment every patient had to be referred from HIV testing centres (HTC) for clinical staging by a trained clinical officer; patients who were staged as either “stage 3 or 4” according to the clinical guidelines were eligible for treatment. Eligible patients and their guardians were then required to attend a group counselling session where the principles of ART and the importance of adherence were described. Third, patients were followed up with on a monthly basis, with only one clinical criterion (weight gain or side effects usually) used to judge treatment progress. Fourth, there was a standardized system for registering, monitoring and evaluating all ART sites on a quarterly basis (see also Libamba et al. 2007). Although I discuss in more detail the limitations of a standardized approach at Temwa throughout this dissertation (see chapter four in particular for more details), these strategies overall have been very effective in many ways at supporting increased access to ART in resource-limited settings like Malawi (see for example Ferradini et al. 2011: 206). However, poor retention rates and treatment disparities between adults and children in particular highlight the limitations of this approach.

Malawi’s Pediatric HIV Treatment Guidelines (2006-2010)

One of the major challenges facing HIV treatment scale-up programs worldwide has been the underrepresentation of children in treatment programs. To account for these discrepancies, most public health literature cites numerous technical and logistical complications, ranging from the lack of affordable pediatric ART drug formulations, and a lack of training and experience among overworked health care personnel, to the lack of diagnostic testing technologies that would work in resource-limited settings (Ministry of Health, Malawi 2006; Bong et al. 2007). In 2006, the WHO developed their first comprehensive pediatric HIV treatment guidelines to address these challenges.\(^{71}\) They were designed for senior policy makers involved in the planning of national HIV care strategies for children in resource-limited settings. These guidelines were

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\(^{71}\) Children were included in their first ART guidelines in 2004 designed for adults (WHO 2004).
based on the recommendations of a “Technical Reference Group” that met in Geneva in 2005 (see for example Mitchell 2002). While the explicit aim of the guidelines was to simplify and standardize testing and treatment protocols for children to ensure universal access, the expert working group was also supposed to avoid “the use of substandard protocols that compromise the outcomes of individual patients” and rely “on the best available scientific evidence” – such as randomized controlled trials, observational cohort data and “expert opinion” – if those things were not available (WHO 2006: 2–5). While this was a laudable goal, the report acknowledges the limitations of this approach by noting that many national programs would have to compromise their quality of care to make up for technical and operational deficiencies. For example, to accommodate the “restricted infrastructure in different levels of the health system” they “tier” their recommendations “to facilitate HIV care and treatment in a variety of locations” (WHO 2006: 58). Thus, the guidelines present a set of “preferred” testing and treatment guidelines along with acceptable alternatives intended for tertiary health care settings with limited technical and financial resources like Temwa.

Malawi’s national pediatric HIV testing and treatment guidelines, developed in 2006 after the release of the WHO report, were “tiered” in three significant ways (MOH 2006; UNAIDS 2005; Rollins 2006). First, a major challenge for tertiary health care settings is that standard rapid antibody tests used for adults do not work in infants since maternal antibodies pass through the placenta in utero, which results in false positive results until approximately 18 months of age (TECS 1988). However, PCR, or virological testing, which can ascertain an infant’s status from birth, is only available at district and central hospitals. Thus, children at Temwa could not be tested for HIV until they were at least 18 months old. This has tragic consequences for many, since HIV disease progression in children is much faster than it is in adults; one-third of infected infants die before their first birthday (Newell et al. 2004).

Although HIV treatment for children was first introduced in 1997, a second major challenge was that there were no affordable or practical treatment regimens suitable for children in resource-limited settings (Lewis and Donovan 2009). For example, the few pediatric regimens
available at that time required refrigeration and had complicated dosing constraints. The WHO noted that this problem was “urgent” and would require “a separate process to consult with the Pharmaceutical Industry” (WHO 2006: 2). In the interim they noted that new evidence suggested that good health outcomes could be achieved if children took the same generic, fixed-dose combination (FDC) treatment as adults (see also Bong et al. 2006). In practice, that meant that during my research caregivers “split” the tablets meant for adults into either halves, or quarters depending on the child’s weight (see Figure 11). Although researchers characterised this development as “less than ideal”, since it could lead to under or overdosing, which could both be dangerous and lead to treatment resistance later in life, without treatment death was certain (Bong et al. 2006). I discuss the implications of this approach in more detail in Chapter Six.

A third adaptation was based on the shortage of CD4 count machines throughout Malawi (see Figure 12). Our immune systems are comprised of various types of cells including CD4 cells, which are a type of white blood cell that moves throughout the body, helping to identify and destroy harmful bacteria and viruses. A CD4 count helps to indicate the strength of our immune system and, for people with HIV, the stage of infection. According to the 2006 WHO guidelines (adopted by Malawi), a child with HIV was eligible to begin ART when his/her CD4 count fell below 1500-200 depending on age. However, from 2008-2010, there were only 42 CD4 count machines in all of Malawi (UNGASS 2010). Since these machines were not (and are still not) available in tertiary health care settings, the WHO developed a set of clinical criteria to help health care workers determine a child’s eligibility for treatment (Chimbwadira et al. 2012). An imperfect tool, their effectiveness is undermined by a number of factors, including: high rates of mortality and morbidity in both HIV infected and uninfected children, which makes it difficult for family members and health care workers to distinguish between HIV infected and uninfected children; and overworked health
care workers who do not have time or skill to give thorough exams.\textsuperscript{72} For example, according to these criteria, nearly every child who visited Temwa should have been given an HIV test, which is both expensive and impractical with the limited resources available. Moreover, research demonstrates that clinical symptoms are not a reliable method for detecting viral loads in children (Shearer et al. 1997). Thus, the timing of treatment initiation at tertiary health care settings is often very delayed, increasing the chances of early infant deaths and limiting the overall efficacy of ART in children (see Chapter Four for more details).

Pediatric HIV treatment programs worldwide are also impacted by serious ideological conflicts that ultimately limit their ability to raise funds and institutional support. For many, scaling up ART programs for children seems “inefficient” when there are proven methods to prevent mother-to-child transmission (PMTCT) (WHO 2009: 2). Efforts to scale-up PMTCT programs are still hampered by significant policy, financing and institutional barriers (Druce and Nolan 2007; Manzi et al. 2005).\textsuperscript{73} Even though PMTCT services have improved since 2010, I argue that contrary to what policymakers imagine PMTCT programs are not the most likely entry point into HIV treatment services for children. HIV disease progression is much quicker in children than it is in adults; therefore, in many cases, the child is often the canary in the coal mine, since while they are usually the last in a family to get infected they are often the first to become significantly unwell, an issue I take up in more detail in Chapter Three. Also, while most women are tested for HIV during pregnancy, a negative result does not mean that her child is not at risk of getting HIV. For example, the latency period between infection and the ability to confirm a diagnosis suggests that testing only during pregnancy is insufficient for capturing all children at risk of HIV exposure. Moreover, an estimated 1.9% of women become HIV infected while they are breastfeeding (Lockman and Creek 2009; Moodley et al. 2009; Mbivzo et al 2009); and since most women in Malawi breastfeed for more than two years, there is a long

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\textsuperscript{72} For instance, six common childhood illnesses account for more than 80\% of hospital admissions in children with symptomatic HIV (DeBaets et al. 2007). These include: respiratory infections, persistent diarrhea, malnutrition, malaria, anemia and meningitis (Amadi et al. 2001; Fassinou et al. 2004; Taha et al. 2000). Significantly, respiratory infections and diarrheal diseases are also the leading causes of mortality in uninfected children under 5, with about eight million deaths worldwide each year (Black et al. 2003). Singer and Scott’s (2003) syndemic concept is useful here, since it refers to the concentration of two or more diseases or health conditions in a population in that have some level of biological interaction that magnifies the negative health effects of one or more of the comorbid diseases or health conditions.

\textsuperscript{73} Manzi et al. (2005) state that rural programs in Malawi are experiencing progressive losses-to-follow up rates; six months after birth fewer than 20\% of the HIV infected mothers were still in the program. This is partially because a large portion (29\%) of the births in Malawi take place in the home or with a traditional birth attendant (12\%).
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period where a child could become infected after the window into PMTCT care has passed, which is only during pregnancy. However, without major investments in broader public health care initiatives children will continue to get HIV. Thus, rather than rely on PMTCT programs to identify children with HIV, I suggest that pediatric HIV care and treatment services should be integrated into maternal and child health activities, such as the annual child health days or at the time of vaccination.

Malawi’s Revised Pediatric HIV Treatment Guidelines (2010-Present)

A challenge for anthropologists doing research on HIV/AIDS is how quickly the science and global health recommendations evolve. Our emphasis on long term immersion in a single place does not lend itself to quick turnovers of complex data. For example, up until the end of my research in December 2010, mothers with HIV were told to stop breastfeeding when their child was six months old; however, in 2009 the WHO released “Rapid Advice: infant feeding in the context of HIV” which amended these earlier recommendations to encourage women to breastfeed until at least a year based on new evidence and programmatic experience. The WHO has also revised their pediatric HIV treatment guidelines twice since 2006; in 2010 and again in 2013. Most of the changes in these new recommendations reflect a growing awareness that the earlier a child starts treatment the better their health outcomes will be. However, key changes, such as new recommendations that all pregnant and breastfeeding women should receive ART, still emphasize the prevention of new pediatric HIV infections, rather than the identification of children who have already been infected. Although these are significant improvements that will prevent many new pediatric HIV infections, the actual practice of identifying and treating infected children has changed very little at decentralized settings. For example, while growing evidence shows that early treatment initiation is best, decentralized treatment centres still do not have access to early diagnostic tools or CD4 machines.

There are some notable exceptions that will impact the health outcomes of children living with HIV. During my research children did not have access to pediatric formulas. As I discuss in Chapter Six, this has long term implications for their health. However, by mid-2010 children with HIV in Malawi were being transitioned onto pediatric formulations. Although these treatment regimens were the same formulation as the adult medications (lamivudine, stavudine, nevirapine) they are more sensitive to a child’s weight and dosing requirements, reducing the
chances of treatment resistance (Kashuba et al. 2010). Another significant improvement is that all children under two (in 2010) and under five (2013) now qualify for ART whatever stage of their HIV infection. However, this will make little difference for children in decentralized settings, since a definitive HIV positive test cannot be determined before they are 18 months old, and by then nearly half of all children with HIV are already dead (Ginsburg et al. 2006; Little et al. 2007). Also, for reasons I discuss in more details in Chapters Three and Four, clinical guidelines used to make presumptive diagnoses of children with HIV in decentralized settings are not that effective in settings with busy health care workers and high morbidity rates among uninfected children. Thus, while these are both welcome changes, they are unlikely to address most of the challenges I outline in this thesis, such as long term health outcomes of undernourished children on treatment (Chapter Six), the exclusion of vulnerable groups from treatment (Chapter Five), household dynamics that delay treatment initiation (Chapter Three) and weak health systems (Chapter Four). Of note as well is that the immediate implementation of all of the WHO’s recommendations is not possible in Malawi, which continues to grapple with financing shortfalls, acute health care worker shortages and competing health priorities (Walensky et al 2010).

“Building a Ship as it Sails”: Confronting Policy Roll Back in Malawi

We are meeting at a time of crisis. We face a fuel crisis, a food crisis, a severe financial crisis, and climate that has begun to change in ominous ways. All of these crises have global causes and global consequences. All have profound, and profoundly unfair, consequences for health. Let me be very clear at the start. The health sector had no say when the policies responsible for these crises were made. But health bears the brunt.

- Dr. Margaret Chan, Director-General, World Health Organisation, October 24, 2008

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74 In July 2011, the policy changed again, and children were started on tenofoir, which is associated with fewer toxic side effects (Price et al. 2014).

Funding crises and shortfalls threaten ongoing HIV care and treatment programs. The 2008 Global Financial Crisis, as well as recent funding shortfalls due to unmet pledges at the Global Fund, have halted, and in some cases reversed, gains made in treatment access over the last decade (MSF 2009; UNAIDS and the World Bank 2009; Taylor and Harper 2014; David 2014; Zaracostas 2012). In particular, the Global Fund reduced their funding pledges by 10% in both Rounds 8 (November 2008) and Rounds 9 (November 2009) of their funding commitments.76 While the Global Fund was supposed to be worth $10 billion a year, by 2008 they had only raised $3 billion/year, much less than they anticipated they would need to achieve universal access (ITPC 2010). Many other donors, both public and private, were also impacted by the financial crisis, which reduced the overall scale and impact of Malawi’s national HIV treatment scale up plan (MSF 2009).77 When Malawi developed their ART scale-up plan for 2006-2010, the goal was to ensure universal access (defined as 80% coverage of those in need) by the end of 2010. However, by mid-2008 Malawi was already grappling with the impact of the financial crisis, and by the end of the year officials from the NAC met to revise the national treatment guidelines in line with the new budget constraints (UNAIDS and the World Bank 2009; HIV unit, MoH, 2008, 2009; MSF 2009). At Temwa Rural Hospital, the impact of the scale-back was tangible; drug stock-outs, reagent shortages, stagnating enrollment rates, and declining enthusiasm among patients and health care workers alike permeated the hospital.

ART drug stock outs in Malawi were less acute than in some contexts (see for example David 2014 on the Central Africa Republic), but by the end of 2009 Malawi was facing critical ART drug shortages (HIV Unit, MoH 2009). During my research these stock outs only led to treatment interruptions once at Temwa; in this instance patients were given only two weeks (rather than one month) of their treatment in a single visit. To prevent treatment disruptions, health care workers however did ration ART by reducing the number of new patients who enrolled into treatment for the first time. While this ensured treatment continuity for those already on treatment, some patients who qualified for treatment were told to wait until the shortage was less acute. As I have already pointed out, treatment delays for children are

77 For example, BIPAI, the public-private initiative offering technical support to Malawi on its pediatric HIV treatment programme scaled back their efforts significantly; at present they work in Kamuzu central hospital, four health centres in Lilongwe and conduct outreach throughout the country. [http://www.bipai.org/Malawi/](http://www.bipai.org/Malawi/), accessed April 29, 2015.

particularly deadly, since they progress to advanced disease much more quickly than adults (Fassinou et al. 2004). During this time Temwa also ran out of rapid testing kits and routinely turned away patients away who requested HIV tests. I vividly remember a very pregnant woman who came to the HTC room one morning to “protect her baby from HIV” only to be sent home. Second line drugs, for those who develop severe side effects or exhibit resistance to the standard first line treatment, were not available in Malawi. Also, while HIV exposed children were supposed to take antibiotic prophylaxis for the prevention of opportunistic infections, none of the children I worked with had continuous access to these medications (see also ITPC 2010). As David argues, these “stock outs of life-saving medications raised the possibility of ‘killing’ within a biopolitics of ‘making live’” (2014: 146). They also raise unanswered questions about the conflicting interests of private investment in public health initiatives (see also Walt and Buse 2000; McGoey 2014), as well as the long term sustainability of Malawi’s national ART programme, which is entirely reliant on donor funding.

The Global Financial Crisis, which erupted in the final four months of 2008, also had staggering echo effects for those already on treatment. Transport costs due to a parallel energy crisis doubled nearly every month, making it harder for those families furthest away from the hospital to collect their medicines (Fidler 2008; Hardon et al. 2007). Rising fuel prices and petroleum-based inputs into food production (i.e. fertilizer) and distribution (i.e. moving tobacco to the auction floors in Mzuzu) also increased dramatically, both reducing food production in Malawi and forcing food prices to skyrocket (FAO 2008; Oxfam 2008). For example, in less than six months the cost of a bag of sugar doubled. Political instability within Malawi also resulted in the suspension of many government services since the government was no longer able to pay many of its employees, such as teachers and some health care workers; fuel shortages halted transportation altogether for days at a time (Cammack 2012). By the end of my fieldwork “transitional funding plans” were put in place and the shock of the scale-back was less visceral. However, severe fiscal austerity policies in major donor countries is putting future funding in jeopardy. On November 22, 2011 the Global Fund cancelled the 11th round of funding proposals and announced that it would only fund essential services for ongoing programs until their conclusion in 2014 (Zaracostas 2012). They are currently facing a $2billion budget shortfall to maintain the programs they have, let alone help countries like Malawi implement the WHO’s
newest ART guidelines released in 2013. The health care workers, officials and patients I spoke to were used to the vagaries of shifting global health priorities. Most felt that Malawi would be unlikely to maintain a free national treatment programme indefinitely. Mr. L, an HIV/AIDS program director, noted when I asked him what he thought of Malawi’s plans to scale up HIV treatment in 2008: “It’s like we’re building a ship as it sails.” As the funding crisis persists, with no apparent long-term solution emerging, their suspicions are worth considering.

**Conclusion**

Malawi’s national ART program is almost entirely dependent on foreign aid to function. The result is an “unruly ménage” of external ideas and initiatives that enforce unrealistic targets and prevent the development of locally relevant solutions (Buse and Walt 1997: 449). Performance-based funding measures popular with the Global Fund enforce these targets through punitive measures (by suspending funding), reifying health inequalities between countries, which will ultimately disadvantage the countries like Malawi with weak health systems. While standardized procedures and protocols enabled the rapid scale-up of much needed medicines during a decade’s long crisis, it is unlikely that such an approach will ensure universal access. To reach vulnerable populations, such as infants, children, teachers and migrant farmer workers, Malawi needs to develop more nuanced approaches that address the complex social and structural barriers to care.

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Chapter 2: “There was no love there”: Secrecy, Intimacy and HIV Disclosure

At Temwa Rural Hospital the HIV counselling and testing clinic (HCT) opened up onto a dusty yard in the middle of town. Right in the middle of the yard was a busy borehole, one of three that provided free water for almost ten thousand residents in and around town. At any given time at least a dozen women and children were there collecting water. Across the road, and visible from the clinic doors, was the busy town market, a half dozen hospital staff houses and a number of “bottle stores” or local pubs. Twice a week the clinic offered antenatal counseling (ANC) and HIV testing for pregnant women as part of the Government of Malawi’s Prevention of Mother to Child Transmission services (PMTCT). On this particular day, Mrs. M, one of the three nurses at Temwa, stood in front of a large group of very pregnant women and counselled them about HIV and pregnancy. She explained how babies got HIV from their mothers and the steps they should take to prevent it. She told them that if they tested positive they needed “to go see the Doctor [clinical officer]" so that he can decide if you are ready to start ‘the medicines’ [ART treatment].” After that, she advised them: “your baby could also get HIV at birth or from breastfeeding. To stop this you must give birth at the hospital where we will give you some “drops” to protect the baby…. Your baby can also get HIV from breastfeeding, so we are telling mothers to stop breastfeeding when the baby is six months old, and can start eating food… But sometimes the baby still gets HIV, even if you do all of these things, so you need to bring them back here when they are 18months old so they can also have a test and if they are ready they will also start the medicines.”

After group counselling these women waited in a long line that snaked around the building for their HIV test. Mr. M, an experienced health surveillance assistant (HSA) was in charge of testing. As was his habit, he called in four or five women at a time, pricked each of their fingers and lined the small strips of paper along the edge of a sink. While they waited for the tell-tale double lines to appear showing that none or all of them were HIV positive, he wrote each of their names, gender and village down in a black ledger that in a quiet moment he would later use to compile reports meant for the Ministry of Health. While they waited, many of the

79 Malawians refer to clinical officers, a cadre of health care worker similar to a nurse practitioner, as “doctors”. Although they are very skilled health care workers, they are not trained physicians.
women looked off into space, shifting from foot to foot. After the results were in he dismissed some of the women with a brief “you’re negative,” which left two women in the room. Before dismissing these women he advised them: “You should encourage your husbands to come together with you to be tested as well since there is a chance that he also has this disease.” Few, if any, questions were asked during these encounters.

I could not help but raise my eyebrows at this familiar scene; these procedures were so different from The Ministry of Health’s “counselling session guidelines” pasted to the wall above the desk where I sat nearby. These guidelines emphasized the importance of confidential, one-on-one interactions with their clients, directed them to ask probing questions and give emotional support (see Figure 13).

When I wondered out loud why what I observed was so different from what was posted on the wall, Mr. M insisted that “nowadays HIV is not such a secret thing.” Mr. M’s reply reflected his interpretation of international and national policy shifts at that time (see also Agnotti 2010; Butt 2009). International organizations recommended that countries like Malawi with generalized epidemics move away from client-initiated or voluntary counselling and testing (VCT) to provider-initiated approaches, referred to as either “routine”, “diagnostic” or “opt-out” testing strategies (WHO 2007). The protocol is simple: all patients visiting a health care centre for antenatal care (ANC) are informed that they will be tested for HIV unless they explicitly refuse.80 From the perspective of public health experts, routine HIV testing is the gateway to universal access to HIV prevention, care and treatment services (UNAIDS 2004; WHO 2007).81 Routine testing may also, “with a little luck… sound the death

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80 The policy for opt-out testing of pregnant women was introduced in 2003, but not implemented until 2005, and even then its roll-out has been uneven across the country (Weir et al. 2008: 96).
81 Testing for HIV first became available in Malawi in the mid-1990s but was only accessible at private hospitals and research hospitals. In 2003 testing was expanded to central and district hospitals and by 2004 testing was slowly becoming available at some rural hospitals and health centers. At the same time Malawi significantly expanded their prevention of mother-to-child transmission services (PMTCT), namely by offering HIV testing during antenatal care and to a lesser extent, the provision of prophylaxis to the mother, the child, or both (Agnotti et al. 2011).
knell for HIV exceptionalism” (Wynia 2006: 5). HIV exceptionalism is the idea that because of HIV-related stigma an HIV diagnosis is very different from any other diagnosis and must therefore be handled with exceptional confidentiality protections (Bayer and Edington 2009; April 2010).

Routine testing in Malawi has significantly increased the number of pregnant women being tested for HIV. In 2003, less than half of the pregnant women in Malawi went for HIV testing, but, after routine testing was introduced, the percentage of women tested shot up to 99% (Weir et al. 2008: 95-96). However, the effects of the policy on HIV-related stigma are less clear; some research indicates routine testing has adverse consequences for a small number of women (15-20%), including divorce, abandonment, domestic violence and the avoidance of ANC services all together (Hardon et al. 2011; Maman et al. 2006).\(^8^2\) For example, in one community in southern Malawi, abandonment following HIV disclosure by pregnant women was so high that the community called the PMTCT service “the divorce program” (Njunga and Blystad 2010). Also, although routine testing is successful at reducing perinatal transmission rates, that is, HIV transmission at birth by providing prophylaxis (“drops”) (Sununu et al. 2014), we have no idea if routine testing of pregnant women has any effect on the timing of an HIV diagnosis for children or if it improves their access to treatment. As policy makers continue to promote routine HIV testing during pregnancy as the gateway into HIV care and treatment services for infected children, my research asks two interrelated questions: How do the women who are the targets of these new testing strategies negotiate HIV disclosure with their intimate partners? And does routine testing during pregnancy impact the timing of ART for infants and children infected with HIV?

“Prick my finger, it will show that I am innocent”: The paradox of secrets

After the early morning antenatal clinic rush, something happened for the first time: a husband and wife came in to have an HIV test together. They came into the clinic where I was waiting to meet with Fanny and Robert after they got their medicines. They left the door open and knelt down in front of me; as usual I was mistaken for the doctor. The wife

\(^{82}\) The research on adverse effects is varied but indicates that divorce, domestic violence and the avoidance of biomedical health services during pregnancy have resulted from this policy shift (see Obermeyer et al. 2013 for a review). Anecdotally I was also told by some hospital staff that routine testing discouraged some women from coming for ANC services; however, I could not confirm this, since if you asked someone why they did not go to the hospital for ANC services they often cited work obligations at home or transport problems.
was really, really, angry. Before I could tell them that I was not a doctor she started to explain their situation. Apparently, her husband wasn’t coming home some nights; sleeping in bottle stores [pubs] and the wife was certain he was having an affair with another woman. After all this, the husband interjected to protest his innocence: “prick my finger!” He said holding out his index finger to me: “It will show that I am innocent [HIV negative].”

(Fieldnotes, February 26, 2009)

In line with the larger policy shift towards provider initiated testing, government officials came to Temwa in 2009, repainted the clinic door and renamed the “VCT clinic” (formerly the voluntary counselling and testing) the “HCT clinic” (HIV counselling and testing) to deemphasize the voluntary aspect of testing. To facilitate the routinization of HIV testing and disclosure at Temwa, health care workers also began to systematically ignore confidentiality protocols, by testing *en masse*, leaving the door to the clinic open during testing, shouting out HIV statuses across the room, and discussing patient files in front of other people. As part of this process health care workers also began to place a heavy emphasis on HIV disclosure to intimate partners. Yet, when I asked health care workers about the challenges they saw facing the early diagnosis and treatment of children with HIV, they often described how difficult it was for them to get married couples to come for testing together - so difficult, in fact, that in two years I only saw one married couple come in for a test together. However, rather than encouraging women to disclose their HIV status to their partners, health care workers advised them to encourage their husbands to come with them for a test at the hospital. The idea behind this approach is that women can pretend they do not know their status so the couple can “discover” their HIV status together. As Mr. G, another health care worker at the district hospital explained to me: “It is very difficult for them [women] to tell their husbands… Very difficult [shaking his head]… so we encourage them to come together with their husbands. That way they can find out together. That is how we deal with the problem.” Research on barriers to HIV disclosure to date has often

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83 This is not the case in other, more urbanized parts of Malawi. For example, while doing contract work with Theatre for a Change (TfAC) at teacher training colleges in urban centres in Malawi I did witness couples going for HIV tests together. In interviews, many considered HIV testing what I would call a “rite of passage” in a relationship signalling a transition from casual dating to more serious intentions. Some Churches around the same time were also promoting HIV testing for couples before marriage; often if the couples were sero-discordant they could not be married in the Church. These dynamics were not present in Temwa at all, except among the few young professionals working as teachers or health care workers in the area.
focused on HIV-related stigma or psychosocial factors that occur at the individual level which limit truth-telling (Maughan-Brown 2009; Obermeyer and Osborn 2007; van Lettow et al. 2012; UNAIDS 2007). My argument is different. I argue instead that secrecy and truth-telling are socially produced; that is I consider how gendered and intergenerational dynamics regulate how and with whom secrets should be shared. It is my contention that social hierarchies shape practices of secrecy and disclosure within households and that these influence the timing of pediatric HIV diagnosis and treatment uptake.

My findings indicate that HIV disclosure is a social process in which a person living with HIV carefully discloses their status to some people and not others. For one, patterns of HIV disclosure between husbands and wives in Malawi vary according to the stability of the relationship and the presence of “grandparents” nearby. While fear of HIV related stigma did influence HIV-disclosure to friends, neighbours and the wider community, it was not the defining feature of non-disclosure practices between husbands and wives (see also Lugalla et al. 2012). The women I spoke to were very selective about whom they chose to tell their status and often opted to disclose to supportive parents and/or grandparents first. For those women in long-term stable relationships with shared children, their husbands as well (Conroy 2014; Desgrees-du-Lou et al. 2008; Hejaoka 2009). However, non-disclosure between intimate partners did significantly impact the timing of HIV diagnosis for infected children. My research indicates that nearly all children diagnosed with HIV at Temwa were diagnosed immediately after the loss of their fathers, either from divorce or death. Sometimes a husband’s death arises from AIDS-related illnesses and his death reinforced the idea that his wife and child needed to be tested. More often a wife suspected she and her child/children had HIV but felt unable to seek testing for fear of jeopardizing the marriage. The loss of a father from either of these two factors freed women to seek out HIV testing and treatment for themselves and their children, often with the encouragement of their extended family. For some children non-disclosure between their parents resulted in significant delays, and, in at least two cases that I know of firsthand, their untimely deaths from HIV-related symptoms. One two year old boy died two weeks after he started treatment, but months after he developed serious HIV-related symptoms. It turned out that both parents knew their HIV status the whole time, but never discussed their status with each other, which ultimately contributed to his early death. In this chapter, I explain how this happens and what it means for pediatric HIV treatment programs.
Although most research on HIV disclosure has focused on the dynamics between intimate partners, my research indicates positive HIV disclosure processes in this context often involve alternate generations, or “the grandparents” (*agogo*). Grandparents were often able to successfully mediate HIV disclosure between married couples by advising one or both of them to go for an HIV test; they were also in many cases the driving force behind an HIV diagnosis for a sick child. This intergenerational HIV disclosure process reflects an established truth that elders are wise and able to guide others, as well as the continued relevance of older generations in Malawi. While some researchers have argued that the authority and importance of grandparents is being undermined by widespread social change, which makes their experience and knowledge seem irrelevant, (see for example van der Geest 2004), my findings suggest the opposite. Rather, grandparents are reasserting their role as trusted advisors and confidantes by drawing on their widely accepted authority and inserting themselves into the disclosure process and obtaining HIV diagnosis for infected children, often without parental consent. The implications for PMTCT and HIV care and treatment programmes are substantial. Rather than pushing pregnant women to disclose their HIV status to their husbands first or involve them directly in PMTCT programmes, policy makers need to consider the social hierarchies that govern truth-telling and silence in this context. My findings indicate that there are many instances where involving “grandparents” is both morally appropriate and more likely to lead to timely HIV treatment initiation for infected children and their parents.

To examine these issues I draw on classic anthropological questions around secrecy and kinship in Africa. There are a range of approaches to the study of secrecy in anthropology. One of the most influential approaches by Bellman (1984) emphasized the communicative aspects of secrecy in everyday life by focusing on how concealed information was revealed and to whom.

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84 The concept of grandparents (*agogo*) in Malawi is classificatory and used broadly in everyday life to refer to interactions between first and third generations. When informants refer to “the grandparents” they are talking about their parents’-parents’ generation in a very broad sense. Most people make little distinction between their biological and “other” grandparents and there is no difference between grandparents on the mothers or fathers side, except in terms of who can claim “ownership” in the event of the death of one or both parents (see also van der Geest 2004: 48). However, when I talk about a specific child and his or her “grandparents” I am talking about the specific relationship between that child and his or her grandparent, or his mother’s or father’s parent.

85 Murphy (1980) makes a similar argument about grandparents in Liberia. He argues that grandparents used secret knowledge to both legitimize their authority over younger generations and to “manipulate the important decisions affecting the community” (1980: 203).

86 Piot (1993: 534) argues that there are four theories of secrecy in Africa: the structural-functionalist (Fulton 1972; Little 1949, 1966; Watkins 1943), Marxist (Murphy 1980), Freudian (Ottenberg 1989) and semiotic (Bellman 1984).
According to Bellman (1984) the “paradox of secrets” is that they are meant to be told (see also Taussig 1999). In some cases secrets should be told to a select few while in other cases secrets are more like knowledge that everyone is aware of, but only a select few can speculate on or use. In all cases a secret is not a piece of information that only one person knows. Thus, routine, provider initiated HIV testing of nearly all pregnant women in Malawi constitutes a secret that must be told. For instance, health care workers encourage women to bring their husbands to the clinic for an HIV test to ensure that they, their husbands and any infected children get timely access to HIV care and treatment services.

Although most of these classic studies focus on secret knowledge passed on during initiation rituals or in secret societies, they provide an important analytical tool for understanding HIV disclosure within intergenerational households in Malawi. George Simmel, in the first major study of secrecy, argued that owning a secret gave a person both social leverage and a feeling of “moral solidarity” with fellow secret keepers (1967: 348). Drawing on Simmel, De Jong argues that the selective revealing of secret information to some people helps build “communal affect” (2007: 10-14; see also Gluckman 1963), or the idea that a secret shared strengthens bonds and intimacy, since individuals who share a secret often work actively together to protect it. This characterisation of secrecy alludes to the fact that being related by “blood” is not enough to create bonds between two related individuals; rather, kinship needs to be made, often by sharing and exchanging material goods, services, emotions and knowledge (i.e. secrets) over time (Carsten 2000; Notermans 2004; Nyambedha 2008). Studies of secrecy also highlight how secret-sharing can be a strategic act to garner social, economic or political support (Murphy 1980). For example, Hejoaka (2009) argues that when women in Burkina Faso disclose their HIV status to family members they do so to gain social support and to ensure the continuity of care for their children if they die.

Another important facet of secrecy explored by anthropologists is that the content of a secret is less important than who has the right to tell it (Gable 1997). As Bellman argued: “the contents of the secrets are not as significant as the doing of secrecy” (1975:221). This observation is significant for HIV disclosure processes in Malawi since women are embedded within households with hierarchical gender and generational dynamics, which regulate how secrets, or “chisisi”, should circulate among and between socially embedded persons. For example, Lwanda (2003) argues that overt references to HIV are hidden in Malawi out of a sense
of propriety that respects male/female and intra-female power relations. Others also highlight how concealment from others is a form of etiquette that is used to maintain gender and intergenerational hierarchies (see also Bochow 2012; De Jong 2007). These insights help us explore the various ways that men and women withhold or reveal their HIV status to some and not others. However, I depart from earlier studies which emphasised the role of secrecy as a form of communication, to stress how practices of HIV disclosure and concealment establish, challenge or reproduce social hierarchies.

In Malawi HIV disclosure is an intergenerational process. The unique characteristics of the grandparent/grandchild relationship has long been noted by anthropologists working in Africa. Radcliffe-Brown (1950) noted that the relationship between alternate generations was characterised by warmth, openness and sympathy, whereas the relations between parents and their children are much more formal and hierarchical. Grandparents in his analysis also had the power to interfere in the relationships between parents and their children. For example, children who felt they were being mistreated by their parents could appeal to their grandparents for intervention (see also Fortes 1949: 236-240). More recent research on the fostering of AIDS orphans by grandparents throughout Africa support these earlier observations. Numerous studies highlight how children raised by their grandparents are often considered spoiled and undisciplined, since grandparents are more like friends to their grandchildren than disciplinarians (Abebe 2012; Roalkvam 2009; Young and Ansell 2003). Therefore, despite efforts made by health care workers to create a space of openness and HIV unexceptionalism by modelling an ethic of forthright candor at Temwa Rural Hospital, my research highlights how gendered and intergenerational dynamics within TMGs are the driving force behind HIV disclosure practices and that these dynamics have a direct effect on the timing of a child’s HIV diagnosis.

A secret shared is a life saved: The biopolitics of HIV disclosure

At their core HIV testing strategies past and present are a form of biopower. According to Foucault, power in modern societies is exercised at the level of life itself, or through the careful management and surveillance of the vital characteristics of human existence. He developed this idea to explain broader shifts in the way populations were managed since the seventeenth century. For the first time, the health, illness, death and birth of populations emerged as economic and political issues that could be managed by governments and other social institutions
Accordingly, biopower operates on a continuum between, at one end, a range of biopolitical measures aimed at improving population health through economic policies and public health efforts and, at the other end, interventions aimed at individuals to discipline, regulate and monitor bodily conduct (Nguyen 2009: 112-113). However, according to Foucault, biopower is not an oppressive, dominating force but it is productive. There is no guarantee that the targets of any given intervention will “do as they ought” (Bentham cited in Li 2007:5; Nguyen 2005). In the context of HIV/AIDS interventions, patients are encouraged to become active and responsible consumers of medical services and products (Rose 2007). “Responsibilisation” refers to a neoliberal “logic of choice” (Mol 2008) where complex issues are framed as matters of choice and where health information and medical technologies are treated as neutral aids to help individuals make the right decision (Beckmann 2013: 162-3). For example, health care workers in Malawi routinely offer “opt-out” HIV testing during pregnancy (even though most women feel that testing is mandatory) and encourage women to give birth at the hospital (even though they might live too far away to get there), to wean their babies at six months (even though there is no food at home), and to disclose their HIV status to their intimate partners (even though that could result in divorce). The possibility that a patient might not follow these recommendations is interpreted by health care workers and policymakers alike as a failure by the patient, rather than the outcome of a series of socio-economic and gendered factors that limit decision-making.

Although national HIV testing strategies have shifted from patient-led to provider-initiated approaches, they are still heavily informed by a series of assumptions about personhood and well-being that animate “behaviour change” efforts (Hardon and Posel 2012). As Nguyen (2010, 2013) argues, most of the early efforts to prevent new HIV infections were based on observations that mass education campaigns alone were not preventing the epidemic from spreading; rather, health interventions needed new technologies to help “empower” patients to be “responsible” citizens – or to “know” their status. A large part of these efforts was the introduction of what Nguyen (2010, 2013) calls “confessional technologies”, or an assemblage of counselling technologies designed to motivate patients to get tested for HIV and reveal their

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87 Foucault termed the first the “biopolitics of populations” and the second an “anatomo-politics” of individual bodies (1978: 135-37). I will not make a distinction between the two here; partially for clarity, but also because I do not think the boundaries between these two forms of biopower are clearly differentiated in practice.
status to others. As Nguyen argues: “empowerment required disclosure: being able to be “out” and talk about being HIV-positive” (2013:S442). To encourage disclosure, GHIs throughout Africa offered empowerment-training workshops and encouraged people living with HIV/AIDS (PLWA) to form self-help support groups.\textsuperscript{88} According to Nguyen, at the core of these initiatives was a powerful notion that secrets can make you sick, and the key to recovery was to “confess.”\textsuperscript{89} Thus, while routine HIV testing during pregnancy de-emphasizes individual “choice,” the “confessional imperative” still infuses HIV-prevention strategies deployed by GHIs and governments alike (Hardon and Posel 2013: S1; Hardon et al. 2011).

From the perspective of HIV prevention policy and programming, secrecy remains a pejorative notion; it is considered undesirable, psychologically harmful and something to be overcome (Hardon and Posel 2012: S1).\textsuperscript{90} In particular, secrecy is understood as something that undermines well-being by perpetuating and reproducing stigma (Reid and Walker 2003; Wood and Lambert 2008). Yet, confidentiality, or the practice of keeping secret all facets of the relationship between client and health care worker, played a pivotal role in early voluntary HIV testing and counselling (VTC) programmes throughout the region (Butt 2011; Obermeyer and Osborn 2007; UNAIDS/WHO 2004; WHO 2007; Yeatman 2007). The assumption was that assurances of confidentiality would combat fears of HIV-related stigma and thus increase the likelihood of timely HIV testing and treatment uptake, as well as motivate those who were positive not to transmit their infection to others (Agnotti et al. 2009; Kaler and Watkins 2010; UNAIDS 2006). Over time the effectiveness of these assumptions was ambiguous at best, and confidentiality began to emerge as the source of, not solution to, HIV-related stigma (Hardon et al. 2011). As a result, most HIV treatment guidelines now advise people who test positive to disclose their status in order to prevent new HIV infections, improve treatment adherence and

\textsuperscript{88} As Nguyen (2010) argues these testimonials were used to gain access to valuable resources including food and medicines. Although I did not study this directly, I think it’s worth noting that support groups seem to be on the decline in Malawi as access to ART improves. The only support group in Temwa was essentially defunct by 2008, largely because they were no longer effective at helping individuals gain access to scarce resources (see also Kalafonos 2011 on how support groups help individuals get access to resources).

\textsuperscript{89} According to Nguyen (2013) the idea of confessional technologies first appeared in Hunt (1997). Nguyen argues that he uses the idea to draw attention to the ongoing links between faith based organisations (FBOS) and NGOS and to invert the assumption that counselling reveals a heretofore undiscovered self and argue instead that counselling creates new forms of personhood (Nguyen 2013: S441).

\textsuperscript{90} Nguyen (2013) argues that Freudian ideas about secrecy as pathogenic infuse confessional technologies.
garner psychosocial care and support (Moyer 2012). The assumption is that routine screening and disclosure will over time reduce stigma and discrimination.

The idea that HIV-related stigma limits truth-telling has had a lot of influence on HIV-related policy and programming. The standard argument is that HIV-positive women are afraid of being ostracized, divorced or beaten, and so they hide their status from their husbands. The root of this problem is often identified as gender inequality in marriage. To alleviate this problem Malawi rolled out a social marketing campaign referred to as “One Love” in 2009, which urged individuals to take charge of their own well-being, to be “empowered” to think and act in more “healthy” ways (Lupton 1997; Obermeyer et al. 2011). This campaign was promoted through various avenues, including evangelical churches, billboards and health promotion posters (see also Classen 2013; Spronk 2009). This campaign promotes companionate ideals of marital fidelity and emotional intimacy on the premise that this will “break the silence” around HIV/AIDS, and ultimately reduce stigma, decrease HIV transmission rates and increase HIV treatment uptake for both adults and children (Anglewicz and Chintsanya 2011; Escove 2010; Hirsch and Wardlow 2006; Hunter 2005; Parikh 2007; Wood and Lambert 2008). Although One Love is representative of a global shift towards companionate marriage, the interpretation of these ideals varied greatly (see also Hirsch et al. 2010: 10-11). While many of the women and men I spoke to expressed a desire for the ideals promoted by One Love, many grandparents often expressed the opposite – asserting that an emphasis on emotional intimacy between spouses undermined their authority and caused couples to neglect their natal family obligations (see also Classen 2013). Moreover, while a few women used companionate ideals to make claims on their husbands, such as the importance of going for an HIV test together, men often used the same ideals to claim authority over their wives.

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91 One Love was launched in October 2009 by the Pakachere Institute as part of a regional Southern African initiative to address Multiple Concurrent Partnerships, which is considered one of the drivers of the epidemic in the region. The mission statement of the Pakachere institute is to: “empower all Malawians, particularly the vulnerable living in rural areas to practice and sustain health seeking behaviours to so as to lead healthier lives”. [http://www.pakachere.org/group-item/program/one-love/](http://www.pakachere.org/group-item/program/one-love/), accessed February 23, 2015.

92 According to the Pakachere Institute’s website the key messages of the campaign are: i. Having multiple and concurrent sexual partnerships puts you and your loved one at risk for HIV infection. The more sexual partners you have, the more the risk of HIV infection. ii). Reduce the number of sexual partners that you have to reduce your chances of getting HIV; iii). Stick to and be faithful to your one and only sexual partner and you can be sure of less or no risk to HIV infection; iv). If you are in a polygamous relationship, respect the founding principles of polygamy. Stick to the wives that you have. You should understand that if one person is infected, it means all of you will be infected; v). To be sure that you are not at risk of HIV infection, go for HIV testing and counselling so that you know your status and the status of your sexual partner before having unprotected sex. [http://www.pakachere.org/the-one-love-project/](http://www.pakachere.org/the-one-love-project/), accessed February 23, 2015.
ideals to question the motive behind their wives’ requests for an HIV test. For example, in one young unmarried man’s words: “in marriage there should be trust. If my wife asked me to go for a test, it must mean either she misbehaved or she thinks I did.” Thus, as the ideals promoted by One Love disseminated throughout Malawi, it spurred new social practices and encouraged both men and women to re-evaluate their current relationships according to the recommended ideal.

Earlier HIV/AIDS prevention efforts focused on the promotion of the “ABC” approach, or Abstinence, Being faithful and Condom use (Kaler 2004; World Bank 1997). As Figure 14 below shows, ABC programs emphasized abstinence before marriage, especially for young women. The most insightful critiques of both of these approaches argue that an emphasis on reducing extramarital partnerships fails to recognize the many reasons (outside of sexual fulfillment) that men and women may cheat on their partners (Hirsch et al. 2010), including solidifying same-sex friendships (Smith 2009), obtaining financial support (Bryceson and Foncesca 2006; Hunter 2009), building status among peer groups (Simpson 2009) or securing domestic help, such as cooking and cleaning, while away from home for work (Wardlow 2009). To engage with these criticisms and with epidemiological data which suggested that most new HIV infections occurred within long term stable relationships (married or not), where abstinence is not an option and condoms are problematic for families who want children (Campbell 2003; Schatz 2005; Smith 2007), more recent HIV prevention and treatment campaigns emphasise fidelity within a single sexual partnership (see figure 15). Thus, One Love differs from early prevention efforts which focused on abstinence before marriage and now focuses on openness and transparency within a single monogamous intimate partnership.

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93 The National AIDS Commission launched the ‘One Love Campaign’ in Malawi on November 28, 2009 http://www.onelovesouthernafrica.org/index.php/countries/malawi/, accessed March 12, 2012. Although the actual effect of MCP’s on HIV transmission is still up for debate, especially in places like Malawi which has a generalized epidemic, it currently dominates current HIV prevention rhetoric throughout the region (refs; more info on this required?)
Figure 14 The ABC Approach (Circa 2007), the emphasis placed on abstinence, especially of girls.

Figure 15 “One Love” Campaign (circa 2009): It acknowledges premarital sex but asks people to minimize their partners.

The launch of Malawi’s “One Love” campaign in Malawi was ubiquitous, with radio broadcasts, roadside signs, bumper stickers, t-shirts and posters across the country. Suddenly, in public venues and during interviews, “one love” was being quoted back to me when I asked
about HIV/AIDS, disclosure and marriage. The One Love campaign (still ongoing) relies heavily on emphasising the affective ties between sexual partners and depicts couples holding hands, or cuddling in front of a TV – activities that I have only ever seen in cities among middle class and wealthy families. This campaign paid little attention to the social and economic forces that might drive multiple partnerships, including how poverty, inequality and mobility might drive concurrent sexual partnerships (Helleringer et al. 2009; Thomas et al. 2010). For example, police officers and teachers are transferred regularly and commonly posted in districts far from their own home villages; they also have the highest HIV rates in the country at nearly double the national average (NSO 2010; Sikstrom 2010). Nor did the campaign examine issues around internal migration and mobility that might create instability in long term relationships. For example, the two tenants I knew with HIV positive children were in temporary marriages to satisfy de facto employment criteria for tobacco labourers, where farm work is divided strictly by gender. This is particularly important since couples will spend months or even years living separately from each other in a context where communication is difficult without affordable mobile options, the internet or cheap transport. The campaign also provoked serious debates across the country about making polygamy illegal, an issue that directly affects Northern Malawi, where nearly 23% of all marriages are polygamous (NSO 2010).

This campaign also depended on the promulgation of gender and sexual stereotypes, which are then confounded by local practices and discourses. One Love campaign posters emphasize how young “beautiful” women use sex to acquire wealth, while irresponsible men are driven by their “natural” sexual urges (see also Montgomery 2012; Stadler 2003). As a result, the very meaning of HIV infection is bound up with ideas about “the sort of people who get this illness” (Epstein 1995: 414) that have been shaped by over two decades of HIV prevention campaigns relying on these overused tropes. It is no surprise, therefore, that Malawians, such as the couple who came to use a negative HIV test as proof of fidelity, tend to connect HIV infection to sinful behaviour or sexual immorality (see also Peters et al. 2010; Smith 2009; Wardlow 2008;). As one 18 year old mother said when I asked her how she thought she got HIV: “I was just behaving badly... moving around, crossing over... (a euphemism for having sex with multiple partners).” However, while GHIs focused on HIV prevention tend to imagine men as the enemy, and women as powerless and vulnerable victims, these tropes did not necessarily resonate with all Malawians. The Youth Alert poster (Figure 14) from 2007 reads ominously:
“She is beautiful. You think she is well behaved. Don’t cheat yourself. She can have HIV.” Malawian men for example often insisted that it was Malawian women who could not be trusted, because of their love for money. As one 25 year old man said:

“Malawian women are only yours when they’re looking at you. She can tell you she’s going to take a bath, but really she’s meeting another man somewhere else.”

Another explained: “Malawian women are always hunting for money, so you can never trust just one. It is better to have many until you find one that you can really trust.” Or as many others told me more succinctly: “Have many, choose two, trust one.” These ideas were also widely expressed in popular songs and music videos. The women I spoke to, on the other hand, felt it was very rare for a woman to cheat on her husband for money and cited instead “revenge” as their primary motivator for infidelity within long term relationships; either revenge for an infidelity or the failure to “take good care” or “be a good husband.” These competing discourses about the origins and drivers of the HIV epidemic in Malawi form what Sherry Ortner (1996) has called “serious games.” Like any game, these issues are hotly contested and are constantly rubbing up against competing gendered discourses about the assumed motivations for multiple partnerships in Malawi’s One Love campaign. More importantly, health policies promoting HIV disclosure neglect to take into account Malawian perspectives that women, just as much as men, are responsible for bringing HIV infections into a marriage. Therefore, although there are many benefits to HIV disclosure (Skogmar et al. 2006), there is also much at stake for women and their children in particular, including domestic violence, divorce, lost child custody battles and even death (Parsons et al. 2004; Paxton 2002).

Routine HIV testing of women during ANC reveals more than just the presence of a virus in the bloodstream: it also hints at marital infidelities and secrets kept from partners (such as previous marriages), and it forces couples to confront any lies or information withheld from one

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94 For example, a very popular song from 2010 was “Chop my money” by Nigerian band P-Square. The video depicts a women using her “sexual seductions” and “sexual corruption” to buy luxury items (i.e. Kate Spade shoes) on her boyfriend’s debit card. [https://www.youtube.com/watch?v=17vC8qZILJE](https://www.youtube.com/watch?v=17vC8qZILJE). Another by very popular Zambian artist “Dalisoul” shows a man haggling with his wife over $10 for food to feed his own children and then giving his “ATM” (slang word for girlfriend) much more: [https://www.youtube.com/watch?v=UAXf6gbU9JA](https://www.youtube.com/watch?v=UAXf6gbU9JA).

95 Men also told me that they cheated on their wives out of “revenge.” For example, one married man told me he cheated on his wife because she did not visit enough and he suspected she was cheating on him. She was away working in another district (health care worker) and could only visit twice a year.
another. The questions that a positive diagnosis raises about a partner’s honesty and faithfulness have very real social consequences for some people, and disclosure is rarely undertaken casually. For instance, one wife found cheating on her husband in the bushes was forced by her in-laws to walk naked through the town with her lover as everyone watched. It is also fairly common for women to track down their husbands in local bottle stores to confront them or their girlfriends, which often results in tears and fistfights between the two women. While these marital outbursts were the source of amusement for some (and a constant source of town gossip), they were a real source of pain for those involved. The husband of the cheating wife poisoned himself soon after his wife left him. Another woman attempted to abort her pregnancy after she found her boyfriend with another woman and was found dead the next day from blood loss. Another young mother was beaten unconscious and left in the road one evening after she confronted her husband about his infidelity at a bottle store. Many women also broke down in private with me and asked for advice about how to stop their husbands from cheating, often by asking for new food recipes or trying out new skills in bed. Accusations of infidelity also often lead to the breakdown of the marriage, with either the husband or wife leaving. In these cases, many grandparents take over the care of young children after a divorce, and one parent almost always loses custody of their children, with many long term consequences for that child’s access to valuable social and economic resources in the future, such as land and money for school fees. Therefore, beyond the obvious benefits attributed to HIV disclosure, we must consider how secrecy and truth-telling are embedded within a wider matrix of relationships, hierarchies, cultural norms and sanctions while also considering the ways that health policies reshape these relationships.

My findings do suggest that the health policy promoting “One Love” has been somewhat successful at reorganising social relationships in Malawi, although perhaps not always in ways that are considered desirable. As Shore and Wright argue, a key feature of policies is that they often “migrate into new contexts and settings, and acquire a life of their own that has consequences beyond the original intention” (2011:3). As instruments of governments, NGOs and public agencies, policies are used to classify and regulate the subjects they wish to govern. In that way, policy is an “organising principle” like “family”, “nation” and “class” (2011:2), which is used by people to live their lives and conceptualize their social relationships (Berger and Luckman 1966 in Shore and Wright 2011:2). Thus, the “work of policy” is never predictable; grandparents in Malawi use HIV testing and disclosure policies to reaffirm their legitimacy as
advisors and decision-makers within intergenerational households, while a few women were able to contest gender inequalities in marriage. For example, some women disclosed their HIV status strategically to challenge male authority in marriage (i.e. by proving infidelity with a positive HIV test), garner social or economic support (from natal kin and in-laws) and reinforce valued social relationships (such as between their child and his or her grandparent). Although some researchers argue that divorce is in some cases a positive side effect of routine testing, since these women were likely in a “bad” relationship and are more likely to obtain better care from their natal families anyways (see for example Parrot et al. 2011), divorce is rarely a positive outcome for HIV positive children. Since *lobola*, or the bridewealth that transfers ownership of children to their paternal kin, is paid in phases I found that it was rarely paid for children with HIV, since it is assumed that they will die young. As a result, most remain with their maternal kin where their access to land and money for school fees is extremely limited (see Chapter Six for more details). Thus, while One Love provides Malawians with a new organising principle on which to redefine a “good marriage,” the idealized companionate marriage is rarely achieved. Rather, divorce was the most likely outcome for the men and women who tried to actualize these ideals in everyday life and the authority of grandparents was reaffirmed.

**Secrecy in Everyday Life: Tensions on the border of the (in)visible**

“I haven’t told anyone [that my son and I have HIV] because we are afraid of being laughed at... You see, to tell people we go to the hospital to get the medicines, then they will preach to the people that ‘you see that one...she is getting the medicines for this and this at the hospital; they are going to die this year.’ They will just be telling their friends like it’s a song.”

- Judith (38 years), tenant from southern Malawi

As Judith indicates, stigma and discrimination remains a notable feature of the HIV epidemic in Malawi. Based on the idea of what Goffman (1963) called a “significantly
discrediting attribute,” stigma is intimately linked to multiple forms of social exclusion and harassment. In particular, HIV testing makes visible what many are attempting to keep invisible – namely “wajumphikha” or the idea of “crossing over” cultural taboos and expectations. In this context, “crossing over” includes sexual practices outside accepted norms, including postpartum sexual intercourse in marriage, extramarital affairs or prostitution. While I recognize that stigma remains a feature of the epidemic, I am sceptical about its pervasiveness in Malawi and the overall usefulness of the term for understanding HIV disclosure more generally (see also Johnson 2012; Peters et al. 2010). As Parker and Aggleton (2003:17-18) note, most studies of HIV-related stigma have focused on it as a thing that one individual does to another, rather than as a social process that feeds upon, strengthens and reproduces existing inequalities of class, race and gender. To conceptualize stigma as a process linked to the reproduction of social difference helps us highlight the limitations of HIV policies that aim to reduce HIV related stigma by promoting HIV disclosure. While I do not want to discount the importance of feeling laughed at, or the fear of physical violence, for being HIV positive, I want to broaden our discussion of HIV disclosure beyond the “confessional imperative” to consider both the affective and strategic dimensions of truth-telling (Hardon and Posel 2013: S1).

The concept of stigma often glosses over a wide range of emotional responses to HIV/AIDS, such as shame, fear, confusion, guilt, anger and grief (Kaler 2011; Peters et al. 2010; Smith and Watkins 2005). Finding out that you have a life-threatening illness and that someone you love and trusted likely gave it to you, or that you may have infected someone you care about, including your own children, evokes complicated emotions. Also, fear of stigma does lead to non-disclosure in some cases, but interpreting non-disclosure as a proxy for or as synonymous with stigma is problematic since it obfuscates other important purposes of and motivations for secrecy, including compassion (de Klerk 2012), respect (Bochow 2012; Moyer 2012), intimacy (De Jong 2007; Lugalla et al. 2008), a form of etiquette to preserve privacy (Gable 1997) and political strategy to shore up allegiances and boundaries (Bok 1982; Simmel 1906). For instance, while Judith chose not to disclose her HIV status to anyone out of fear of “being laughed at,” she also went on to elaborate that she chose not to tell her parents specifically because they were “drunkards” and could not be trusted to keep secrets. Judith’s non-disclosure was also strategic; as a migrant tenant farmer from southern Malawi, Judith was alone in Temwa and had no close relatives nearby to confide in, and she worried that if her employer found out he would think she
would be too much of a burden to employ. Therefore, health policies that naively promote truth-telling without considering what information is withheld, from whom, and the strategies used to keep information concealed, fail to recognize that there are situations where HIV disclosure is neither necessary, nor tactically advantageous.

Secrecy, or the intentional concealment of information, is very much a part of everyday life in Malawi. Information withheld from friends, neighbours and family members goes well beyond HIV/AIDS to a variety of intimate topics, including any signs of above-average prosperity, naming serious illnesses, marital problems, pregnancies and new relationships. For instance, while public spaces in most houses tend not to have any items that could indicate above average wealth, master bedrooms are often crammed to the rafters with books, chairs, desks, bicycles, sewing machines and other valuable goods, especially in very rural areas. In other words, relative wealth is something to be hidden, not “disclosed.” Similarly, like many other places in the world, naming any serious illness or asking why someone is admitted to the hospital is also considered extremely rude (Wood and Lambert 2008). At funerals, the cause of death is only referred to euphemistically in most cases, and is only discussed openly in more intimate settings in the days following a funeral during routine condolence visits. Young couples may also date for years without telling anyone in their family that they are in a serious relationship, right up until they are engaged. Pregnancy is also a widely kept secret, and the pregnant mother should never tell anyone about her pregnancy; it is up to others to figure out over time (see also Chapman 2003; Ringsted 2008). Therefore, the assumption by health policy makers that silence or deliberate concealment around HIV/AIDS automatically indicates stigma is misleading since there are many kinds of information that are characterized by complex secrecy and truth-revealing practices in Malawi.

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96 In the days following a funeral it is common practice to visit the family of the deceased to offer your condolences, which usually includes giving a small amount of money for funeral expenses. During these visits a close relative almost always recounts the last days of the individual who died and here is when someone will be explicit about HIV/AIDS related deaths. In my experience, while the cause of death at the funeral may be “malaria” during these more intimate visits the cause of death is usually identified as HIV/AIDS straight-out or euphemistically. For example: “You know Malawi these days. He was just falling sick every time.” The visitor is expected to “read between the lines” but respect the privacy of the individual who just died. Some of the verbal strategies around secrecy described in the literature include: “deep talk”, “slow” or “curvy talk”, indirect speech, rhetorical play (Bellman 1984; Rosaldo 1984; Weiner 1984) and “scripted omissions” (Wood and Lambert 2008).

97 In my own experience, having access to information that I was not socially positioned to “know” was extremely hazardous both to my credibility as a researcher and my husband’s safety. For example, as a white woman married to a Malawian I often had access to male-only social spaces and therefore I often had access to information about their extracurricular activities not normally the purview of woman. In one instance I disclosed to a friend that her
Wakabisa, or “hiding,” refers to the strategies that people employ to conceal certain kinds of information from others, including misdirection and verbal elision. In particular, HIV/AIDS, like pregnancy, is hard to conceal because the symptoms are so well known and HIV treatment is collected from a health centre frequented by friends and family. Also, as I noted in the beginning of this chapter, the HCT room is set aside from the rest of the hospital, with both the entrance and exit visible to passersby at the busy market place. To avoid questions, some families reported that they would take little known or circuitous paths to the hospital on ART clinic days to confuse neighbours about their destination. Others also developed “cover stories” for their frequent hospital visits or my home visits, such as telling neighbours they had TB but not HIV. A few women started small businesses, like selling homemade beer at the busy chirabu (men’s drinking area), to raise money for transport costs to and from the hospital and also to avoid questions about their frequent visits to town. To my absolute horror, one mother told her neighbours that I was visiting them so often because I was trying to adopt their daughter. Secrecy, as Hardon and Posel (2012) note, is also an embodied social practice, and people often developed strategies to silence bodily signs of HIV infection, such as orangey-brown hair, wounds on the skin, weight loss and the blistering rashes that are a side effect of ART medicines for children. For instance, Ruby, a six year old girl who started developing wounds on her head and had the tell-tale orangey brown hair, told me she was wearing a headscarf to hide them, a practice which is extremely rare in children. Orange hair was also hidden in toddlers, who would be covered in the knit caps normally only worn by newborns. More dramatically, mothers would occasionally dye their children’s hair to cover up the undesirable colour.

Despite efforts to hide the visible bodily signs of HIV infection or allay suspicion by developing a cover story, nearly everyone disclosed their HIV status to someone. Caregivers

98 In pregnancy similar strategies are employed. For instance, women wear very baggy clothes up until the moment that they want their pregnancy known, at which point they transition from wearing their chitenje (fabric cloth word around the lower body) under their clothes to over them making the pregnancy very visible to everyone. Hair colour in adults and children is an endless source of discussion, and orange hair is generally disdained for everyone. Common causes include malnutrition and HIV/AIDS, but it can also be related to employment (fisherman often wore tuques to prevent their hair from turning orange) and in children to playing or working outside extensively.

99 husband was cheating on her. When her husband found out he threatened my husband’s life and I was widely sanctioned by nearly everyone for not “respecting” my husband. I was only eventually forgiven because the married woman concerned was related to me by marriage and it is acceptable for one “sister” to tell her own “sister” this kind of information if discovered. Of course the same “rules” did not apply to men; it is permissible for men to inform each other of a wife’s infidelity.
often carefully chose individuals they felt would be instrumental in providing care and support for the sick child (see also Hejaoka 2009). For instance, most primary caregivers disclosed the child’s HIV status to a grandparent or the child’s older sibling since they were sometimes responsible for administering treatment. Primary caregivers who were also HIV positive cited fears about their own (sometimes perceived) imminent deaths as a reason to disclose a child’s HIV status to another family member. By disclosing they hoped to ensure quality care for the child on ART even after their deaths. Being HIV positive in Malawi also enables access to valuable resources provided by governments, Faith Based Organisations (FBOs) and NGOs. For example, each village in this area has a village development committee (VDC) made up of volunteers who gather relevant information about their neighbours to make decisions about the distribution of valuable goods to the most vulnerable. As one mother and father explained to me:

It’s a secret thing. We have only told the grandparents, but everyone knows since we got fertilizer coupons from the VDC last year [which were only distributed to HIV positive households].

Others chose not to tell their parents out of compassion. As one mother explained to me:

I haven’t told my mother because all of my brothers and sisters are dead except for me. If I told her we had HIV she would be thinking that soon we would die.

Therefore, HIV disclosure is not just a proxy indicator for stigma levels in a community, but a social process reflecting careful thought and attention to both the economic resources it might garner as well as the social impact it might have on overburdened or unreliable family members.

Another important aspect of secrecy highlighted by Bellman (1984) is that often it is not the content of a secret that is important but who has the right to tell it (also Mendelson 1967; Murphy 1980). Advanced HIV infection is nearly impossible to hide in regions hardest hit by the epidemic since the signs and symptoms of infection are so well known (Butt 2011; Moyer 2012). This is particularly true of children who develop HIV related symptoms much quicker than adults (de Baets et al. 2008). For instance, Rhoda, a young mother with a five year old HIV positive daughter explained:

It is a secret thing. I only told the grandparents. But everyone knows because they could see how she was falling sick over and over again, and then how quickly she got better [after starting treatment].
This sentiment was confirmed when a drunken neighbour stumbled by the house one afternoon and shouted out in my direction in English: “This one has HIV!” While Rhoda recognized that most of their friends and neighbours had “figured out” their HIV status, she insisted it was still a secret thing. Therefore, an important aspect of secrecy is that a secret is something that nearly everyone knows but tacitly agrees not to talk about it (at least when sober) (Gable 1997).

In the final section of this chapter I will draw on this insight to examine the intergenerational aspects of HIV disclosure in households with HIV positive children. First, however, I explore how men and women negotiate HIV disclosure within their intimate relationships by highlighting how companionate marital ideals promoted through HIV prevention and treatment efforts (like One Love) shape marital expectations. In particular, I want to examine how men and women redefine and contest what a “good marriage” is in relation to evolving health policies and how marital expectations are shaped by the social and economic situations that limit renegotiation efforts. Second, I want to explore how grandparents, who are not targets for these HIV prevention and treatment efforts, reassert their authority to intervene in marital relationships and child care decision making by drawing on their authority to tell secrets. Lastly, I want to conclude by considering what this means for paediatric HIV treatment programmes aiming to increase treatment enrolment by “breaking the silence” around infection.

To explore how “the confessional imperative” is transforming social relationships in Malawi I draw on Charles Piot’s (1993) study of secrecy in everyday life. Unlike most studies of secrecy, which focus on ritual contexts or secret societies, Piot’s (1993) study among the Kabre in Togo shows how all daily interactions are filled with hidden messages - greetings, gossip and responses to the demands of elders. He argues that the borders of the in(visible) are tied to notions of shame, equality and hierarchy. By that he means that social hierarchies are established during the inevitable “moment of truth” – since all secrets are eventually meant to be told. For example, a person’s wealth is deliberately hidden during their lifetime, but it is revealed at their funeral, fixing his position within a hierarchy of persons. Or after years of secret exchanges between two families arranging a marriage between their children, a public exchange solidifies the authority of the wife-givers over the wife-receivers. To understand secrecy this way allows us to see how silence sets in motion a set of processes that leads to the perpetuation and renegotiation of social hierarchies. Thus, “the confessional imperative” in HIV/AIDS policy
forces the moment of truth, making certain what was left (in)visible through strategic silences. I conclude with a discussion about how this may or may not reorder social hierarchies.

“There was no love there”: Divorce and HIV disclosure in marriage

As I have noted, sharing a secret can also bring people closer together, or what De Jong (2007) calls communal affect. In that sense, Malawi’s One Love campaign, which promoted companionate ideals of marriage such as open communication and trust, presumes that marriage is a safe space for women to share secrets. For a few of the women I spoke to, this was the case. As one woman in Malawi put it succinctly: “I told my husband [I had HIV] right after I was diagnosed, because it is a secret thing (chisisi).” Christina, another young mother of a two year old boy explained that she told her husband “straight out the very same day” after she tested positive during her second pregnancy. She explained:

I told my husband because with him I saw that he can be the one who can give us a future, because this is his child so he cares. Also because my mother and father and all my grandparents are dead, so he is the one that I can feel free with.

Although Christina, like a few others, felt little reservation about sharing their status with their husbands, because after all “they are the ones who can care for us,” “feeling free” depended on a number of factors, including the presence of children, the stability of the marriage and the quality of the relationship with grandparents – Christina for instance highlights that she told her husband because the grandparents are all dead.

Although some women in my study disclosed their HIV status without repercussions, this was not always the case. For instance, Molly (a 25 year old mother with an 18 month old son with HIV) and her grandmother related the events following her diagnosis:

Molly: I was found positive on this pregnancy. Nowadays they just tell us to tell our husbands, so I just told my husband straight out because in marriage there should be openness. But after Kelvin was born he chased me [sent her back to her home village] and said: “You have this disease, you should go home.” I stayed [in the marriage] for a while to finish farming [tobacco]… but things just continued like that [arguments] so I came home [to live with her parents].
Grandmother (interjected): We said to her that he was behaving badly, that he was not caring for her or our grandson, so we encouraged her to say: “You should be coming home to stay with us.”

“Good care” for Molly’s grandmother was agreeing to go for an HIV test with his wife. However, since he refused to do so, he gave Molly grounds for a divorce. Although Molly’s husband’s behaviour was widely disparaged, this was partially because she was from a relatively wealthy family, with a large social support network (parents and grandparents), and she was related to the royal Tumbuka family (a fact they made note of right away during my first home visit). Through these connections Molly was also able to leverage child support in the local traditional courts for her son. While it seems that her divorce had not affected her unduly, this is not always the case since most women’s situations are more precarious.

Nondisclosure was often characteristic of unstable, new or temporary relationships. If there were no children in the marriage women were very unlikely to disclose their HIV status. For instance, Maria, an 18 year old mother, explained that she did not tell her new husband that she had HIV because he was not her son’s father. While most women are tested routinely during pregnancy, a growing body of research on men indicates that they are much less likely than women to benefit from treatment (Callaghan 2015; Dovel et al. 2015; Oberymeyer et al. 2009; Skovdal 2011). Thus, women are often in the difficult position of trying to encourage their husbands to go for an HIV test after they test positive themselves, a fact that almost always raised uncomfortable questions between intimate partners. Most women worried that a request for an HIV test would be interpreted as either an accusation of infidelity – which it sometimes was – or an admission of guilt. Of the few men I spoke to, most withheld their status or refused to go with their wives to be tested because they were afraid that their wives would “shout at them” or that the marriage would end, sometimes with their wives taking the children with them if the lobola, or bride wealth that transfers ownership of children in this context, had never been paid. Thus, disclosure within marriage was rarely taken casually, but was often strategically

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100 Their house had two large maize granaries, and Molly was going to grow tobacco the following season, a major sign of wealth in the area.
101 Molly petitioned for half of the maize that she farmed with her husband, but was granted money to buy lactogen, or formula, for Kelvin since she stopped breastfeeding him when he was six months old according to hospital recommendations at that time.
102 Since few men can pay the full lobola at marriage it is usually paid in installments over time. The result is that early in a marriage, the ownership of young infants and children is often uncertain. This is complicated even
negotiated by women to ensure marital stability and economic support for themselves and their children in the long term.

Many women were using Malawi’s “One Love” campaign to evaluate their own marriages. The decision to disclose, a partner’s reaction to disclosure and the response to the request for joint testing were all interpreted as signs of love or its absence in marriage. As a result, non-disclosure in marriage, or a partner’s refusal to go for an HIV test with them was interpreted as a sign that there was “no love” in the relationship. Or, in other words, keeping secrets within marriage undermined the sense of communal affect. As one mother of a five year old on treatment told me when I asked about how she felt about her husband never telling her his status: “We don’t love men, we only pray for them.” Alice a 36 year old mother of three also explained:

I was tested when I was pregnant, but when I found out I was positive I just decided to stay quiet [not tell her husband the results]. Instead I asked my husband, “Let’s go for an HIV test together.” He refused. Ahhhh!! So I said to him: “You are refusing, so will the marriage be there? Because in the house we need to be understanding each other but you are showing that there is no love.”

He said no again, so I told him that the hospital was advising us to go together but since he was refusing to go along I thought it was better for me to leave him, so that is why I am back here in my step-father’s home with my mother.

Like Alice, most women did not disclose their HIV status “straight out” like Christina but preferred to disclose their HIV status to their husbands indirectly. Many would approach their husbands “after some time,” as they put it, and suggest that they go for a test together. Others would disclose their HIV status to a grandparent, who would then consult and advise their husbands on the wife’s behalf. Therefore, in some cases, men and women knew each other’s status only through a third party, not because they had ever discussed the issue directly between them. Whatever strategy for disclosure was chosen, most women and men saw HIV disclosure as

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103 Some men did make the same semiotic links between disclosure interactions and love, but were more likely to interpret disclosure as a sign that there was “no respect” in marriage. However, I did not talk to enough men to feel confident in either likelihood.

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an opportunity to build unity and openness in their marriage and any rejection of their efforts as a “sign” that there was no love. This often resulted in divorce, and is one of the main reasons that most children on treatment at Temwa lived with their matrilineal kin (see for example Anglewiez and Reniers 2014).

This indirect preference for disclosing HIV is “respectful” or it shows “nchindi”. This highlights another important aspect of secrecy, noted by anthropologists Eric Gable and William Murphy, which is that sometimes it is not the content of the secret that matters but who has the right to tell it. While some women are slowly asserting their authority to disclose their HIV status, and many do so, successfully garnering support from their husbands, family and village Chiefs, the outcome is often very uncertain in the long term. Alice, for instance, returned home, but was living in her step-father’s home village without access to land and had left two of her older children with her husband in his village. Many who divorced because of HIV disclosure often remarried later but withheld their status in the new marriage, like Maria. More harshly, but less common, were the broken hearts, domestic violence, property destruction and court cases sorting out child custody that centered around accusations of infidelity. Therefore, while Malawi’s routine testing strategy is designed to help prevent new infections in children and ensure timely treatment for pregnant women and their husbands, it sometimes pushed them into even more precarious circumstances. HIV testing and disclosure promotion has introduced new ideas and norms about what a “good marriage” looks like, similar to those promulgated by romance movies and Christian-based counselling strategies discussed by other researchers (Pype 2012; Spronk 2009, 2011). One Love also assumes that love marriages are desirable and encourages women in particular to think about marital disclosure interactions as moments for both trying to put companionate marriage into practice and assessing just how companionate one’s own marriage is. However, most households in Malawi are multigenerational, and grandparents are also taking up the confessional imperative in their own ways. For example, Molly’s grandmother above felt that her son-in-law’s refusal to go for a test was legitimate grounds for her granddaughter’s divorce. As I show below, many grandparents inserted themselves into this process and were the ultimate authorities behind a decision to divorce or not, or who would look after an HIV positive child.
“You can tell the grandparents anything”: Respect in Intergenerational households

“You know, we Malawians have a special relationship with our grandparents.”

“I’ve been told it is more like you’re brothers and sisters.”

“Yes, exactly! You know my granddaughter is in Form 2 (grade 11), and she left school complaining of malaria. And I said to her, ‘granddaughter, what is really wrong?’ She started to cry and told me that she was pregnant, and could I tell her parents because to tell them such a thing herself… Well. Of course I would tell her parents, but I also asked her why she would risk her future that way, and she said “he bought me soap.”

Laughing loudly and shaking his head in disbelief he said to me: “He bought her soap! Twenty kwacha! [5 cents]. You see, she could tell me, her grandfather, such a thing. That is how it is with grandparents. You can tell them anything.”

“What about tenants? They don’t come here with grandparents, so who do they tell their secrets to?”

“They should treat their bosses like grandparents.”

- Conversation with a senior chief – fieldnotes April 2009.

In Malawi, everyday interactions are filtered through concepts of hierarchy, which shape how men and women, young and old should interact with each other (see also Gable 1993: 356). Without “respect” or hierarchy, social and economic relationships are not orderly; people say others “will hate you” for behaving “every which way.” For example, during my fieldwork two men were imprisoned for being gay, leading to widespread donor disapproval and consequent financial freezing. Many Malawians, however, were genuinely confused about how social relationships between two men in marriage could function. As many said to me, “Who respects who in such a marriage?” Everyday interactions are shaped by “respect”, or nchindi, and there are a variety of bodily and social practices used to express “respect.” For instance, women eat separately from their husbands at all times, do not call them by name in public and are rarely

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104 I discuss the relationship of tenant farmers with their employers in Chapter Five in more detail.
seen with them outside of the home. Similarly, patients kneel in front of doctors when making requests. Men wearing hats must at all times take them off when greeting men older than she was. Men must also dismount their bikes when greeting village chiefs (knowable by the black hats they must all wear) and must employ the greeting “tilipaskumba”, or “on my knees for you.” Married women are also never allowed to talk to their father’s-in-law; they can only pass messages to them through their children. For example, if dinner is ready a daughter-in-law might say loudly to her newborn baby so her fathers-in-law nearby can hear: “tell your grandfather food is ready.”

Grandparents, or agogos, on the other hand, have a very familiar relationship with their grandchildren and are widely regarded as important sources of advice and conflict management. As confidantes and counsellors, nearly everyone “feels free” to share their secrets with grandparents, and they are often the first person told about a positive HIV diagnosis, a pregnancy out of marriage or marital disputes and are often called to counsel married couples through difficult times. Grandparents are also not allowed to discipline their grandchildren – a widely cited reason for the “bad behaviour” of orphans raised by their grandparents. Significantly, most married couples are assigned a “muthenga” or “go between”, at the time of their marriage, and this person, is called on to help negotiate marital disputes, including HIV disclosure, throughout their lifetime.105 Therefore, the presence of grandparents is crucial to both successful HIV disclosure within marriage and early diagnosis of children with HIV since they often play critical roles encouraging HIV testing and HIV treatment initiation. The following abbreviated diagnosis trajectory of a three year old boy illustrates my point:

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Three year old Robert and his grandmother Ruth lived a short walk from my house in the nearby neighbourhood called “Mtangwanika,” or “busy busy.” Aptly named, Mtangwanika housed over a thousand migrants from Zambia and Malawi’s northernmost districts of Chitipa and Karonga. The labyrinth of mud and brick houses crowded around a single borehole was home to beer brewers, minibus drivers, small business owners, aspiring entrepreneurs and

105 The “go-between” is usually a grandparent but not always – it may also be a friend who has what is considered a successful marriage. However, the go between is always older than the married couple. In other parts of Northern Malawi the “go-between” is also called the ankhoswe (Classen 2013).
many others who got by doing piece work labour (*ganyu*) for food. One day I stopped along the way to greet some of the kids I recognized from my English class; Lucy’s three year old sister was in a tin tub\textsuperscript{106} getting her hair dyed a dark black: “The sun turned it orange,” her mother told me.

Ruth and her husband Mr. Dewe stood out from their neighbours for a number of reasons: the tall mango trees out front offered rare proof of their twenty-five year residency; their living room was crowded with books, furniture, a sewing machine, a fat cat and four well-clothed grandchildren. Mr. Dewe was also a very memorable man: friendly and thoughtful, his successful business occupied a central building in town.

On that particular sunny day in Ruth’s back yard, she exuded youthful beauty, and answered my questions without evasion or subtext (which was rare, but more common with elders). Robert wore a hot pink muscle shirt, jean shorts and shiny white shoes. He moved back and forth between us, seated in the shade shelling maize, while a group of children playing next door were cooking wild vegetables in an old soup can over a small fire. One boy lit up a blade of dry grass with a flourish and told me: “When I grow up, I’m going to be a smoker.” Despite the fact that Malawi was one of the largest tobacco producers in the world, cigarette smoking is rare and often considered slightly sinful. His audacity sent his friends into gales of laughter, and Ruth shook her head and said to me ruefully “*kamwana (small children)*,” as if to say, these older children are behaving like babies.

Ruth passed Robert a packet of the fortified peanut butter supplied by UNICEF and distributed by the hospital to malnourished children. Eight months into his HIV treatment, Robert was a very happy, fat toddler, but this was not always the case. The first day we met, Robert was weak and undernourished, unable to walk. When Ruth explained to me the series of events that led up to Robert’s eventual HIV diagnosis, she emphasized the fact that she always suspected that something was wrong and that it was her eventual interference that saved his life. As Ruth said:

> When Robert clocked one year old he was just falling sick every time. We would take him to the hospital and they would give him painkillers or antibiotics or something like that, and for three or four days he would be okay and then he would

\textsuperscript{106} Infants and young children are bathed outside in the yard.
fall sick again.... You see, I have stayed with many children and most can go for three years or more without falling sick like that, so this one, he made me wonder.

After nearly two years of this [31 hospital visits over two years according to his health passport], and after his father took another wife, I told my daughter, that she should take Robert to get tested for HIV, but she was just running away from the test.... Maybe it was because she was in a new marriage, but I could see how Robert’s body was just finished, so when his mother was away ordering tomatoes for business I took him to the hospital to get him tested myself and he started the medicines the next day.

Ruth’s narrative illustrates how the complexities of disclosure between intimate partners affects the timing of HIV diagnosis for children with HIV. As she notes, women may choose not to have their child tested or continually put it off. Married women told me that they worried that a child’s HIV positive status would put their vulnerable relationship in further jeopardy. If the child is positive, this means that they too are positive, which means that her husband is also likely positive, or she had a previous partner who was positive, and both of these possibilities are threatening to a marriage already characterized by other vulnerabilities. In this context, new marriages, polygamous marriages, unhappy marriages or marriages without children or with young children only are unlikely to survive such a revelation. Grandparents, however, are immune to these problems – their primary responsibility is to their grandchildren, and therefore it is not only morally appropriate for them to intervene, but in many ways a moral imperative. Or as Ruth explained further when I asked why she felt she had to be the one to take Robert for an HIV test: “I am his grandmother. I am the one who should be taking care of his life.”

Ruth’s story also brings us to an important aspect of secrecy: it is that a secret is something that almost everyone knows, but only certain people, in this case grandparents, can talk about it (Bochow 2012; Murphy 1980). Grandparents played very important roles in getting HIV treatment for young children largely because they are often free to discuss taboo subjects, such as HIV infection, directly and without social censure. For example, eight of the children on ART in my sample had a grandparent as a primary caregiver and unlike most children with HIV
their HIV status was not kept a secret from neighbours or friends, but discussed openly. In some cases I almost felt that the lack of privacy around that child’s HIV status was a bit reckless, given that he or she would grow up and forever have their HIV status known to neighbours and friends. Grandparents also frequently went out of their way to counsel others, such as neighbour or friends, to get outwardly symptomatic children diagnosed. For example, a year after Robert was diagnosed, Ruth also took her younger sister’s son for an HIV test, and he was also diagnosed with HIV. As she explained: “I saw how he was falling sick like Robert, so I told my young sister to go for a test.” Ruth’s sister did go for a test “straight away,” or as she told me when I asked her why she got her son tested for HIV: “My elder sister told me to.” Thus, truth-telling is shaped by the age-cohort (among siblings) and generations of the two individuals meant to share a secret. Elders are able to “speak the truth,” whereas younger siblings or children are meant to be more circumspect. Thus, my findings indicate that TMGs with grandparents are more likely to initiate treatment than those without.

While grandparents played crucial roles in most children’s treatment trajectories, increased mobility for work and high mortality from HIV over the past two decades means that not everyone has grandparents around to help them negotiate these difficult situations. The following diagnosis trajectory of a one year old girl illustrates my point.

One year old Grace and her mother Marianna lived a short walk from my house in Mtangwanika, not far from Robert and his grandmother Ruth. Like everyone in the neighbourhood, Marianna and her husband were migrants. Marianna had come to Temwa nearly a decade ago to “do business” (sell beer) and “chat” with her sister, who at that time lived nearby. Although she only intended to stay for “a year or so,” she met her husband and they married a few months after she arrived. It was her second marriage, and although she did not know for sure, she thought she was her husband’s fourth wife.

Marianna came to Temwa from a rural area near the Zambian border close by, but both of her parents were dead. Her husband was a Chewa from Southern Malawi, who originally came to work as a tenant farmer on an estate but now “did business” and rented land from local landowners to grow tobacco. Together they built a house; it was small, but it was one of the few that had an iron sheet roof. They had four children, ages ten, seven, six and two the day we first
met. At some point her husband’s nephew (sister’s son) came to stay with them after the death of both of his parents. There were no grandparents or relatives living nearby.

Marianna and I met when she was a few months pregnant with her fifth child on a routine prenatal home visit with one of the local HSAs. I interviewed her in the first phase of my research about the political economy of the region, but her unusual outspokenness and proximity to my house meant that it was easy to stay in touch. By the time her baby, named Grace, was born we were friendly acquaintances. Grace was a beautiful baby; chubby cheeked, healthy and a normal weight. Whenever I passed by Marianna’s house to say hello I often found Grace strapped to her older sister’s back while Marianna did business in and around town. However, a few months after she was born I was sent a message that Grace was admitted at the district hospital for malaria – the case was so serious that she almost died. A month or two after that Marianna’s husband was admitted to the district hospital, also for “malaria,” but discharged two weeks later. Around the same time, when Grace was about eight months old, her health also started to visibly deteriorate rapidly; she lost a considerable amount of weight, her hair turned white and she always looked miserable – by that I mean she was puffy cheeked, listless and never smiled. One day I ran into Marianna coming back from the hospital and I felt relieved when I saw Grace sucking on a peanut butter packet for malnutrition from the hospital.

Nearly two years into my research, I had spent enough time around children with HIV to suspect that she was likely positive, and that Marianna possibly knew this already, but was delaying treatment for her own reasons. I discussed these issues with my research assistants and a health care worker: what should we do? Was there anyone who could advise her? Who should we talk to? My research assistants both felt that I should go and advise Marianna to take Grace for an HIV test. As Maggie said to me: “they are not from here, so there are no grandparents. You can be the one to talk to her.” After we collectively decided to intervene, we went by Marianna’s house twice, but both times we found her husband outside with a group of male friends. It was not the time to broach a sensitive topic, but we did encourage her. As my assistant said to her: “Grace does not seem to be improving. The hospital can know what is wrong – it is better that you go there and talk to the doctor…. We have seen many children ‘like Grace’ get
better after visiting the hospital.” Although we were discreet, I hoped that Marianna understood what we were suggesting.  

Soon after this, I started to see Marianna at the hospital on ART clinic days – but she would stand outside the HTC room near the borehole chatting in the shade. I approached her each time and asked if there was anything I could do, and each time she told me she was just “visiting with friends.” Mr. G, the HSA in charge of the clinic only laughed ruefully when he saw her outside: “Yes, the baby is positive, but she doesn’t want to come in.” When I asked why, he only shrugged and said: “some people are just like that.”

A few weeks later we heard that she had divorced her husband; he had left her in the house and returned to his home village. The week afterwards I was at Temwa hospital for the very last time; I was saying goodbye to staff and patients before I returned to Canada when Marianna walked in with Grace. She was there to “start the medicines” and smiled at me with some relief. Mr. G, ushered her in like an old friend. I wished her and Grace well and said my final goodbye.

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Marianna’s story was typical of the women who delayed HIV treatment for themselves and their children while married. Unlike Molly she did not have a grandparent nearby who could support her if she divorced. Until her husband left her with the house, her only option was to move back to her home village where she did have land, but it was being farmed by a relative. Divorce would also mean leaving her children, the tobacco yet-to-be-harvested in the fields and her only source of income – her beer-brewing business. Nor did Grace have a grandparent who could interfere on her behalf; while my research assistants urged me to act as a proxy grandparent, both propriety and my desire to prevent a conflict between her and her husband prevented this conversation from happening fully. Although I would describe Marianna as a forthright and almost brazen woman, she never discussed her HIV status with me directly,

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107 The district hospital did routine testing of all children over six months using PCR or virological testing technologies. Although I do not know for certain, it is very likely that Marianna found out Grace had HIV when she was admitted at the district hospital. For this reason, she was eligible to start ART before the standard 18 month cut off at Temwa, where only rapid testing was available.

108 It is important to note here that according to my ethics guidelines I could not reveal that my research was centrally about children with HIV, to protect the confidentiality of those children on treatment that I was seen with in and around town.

109 I do not know this for sure, but I suspect he did this because he felt close to death.
although “reading between the lines” I was certain she was telling me she was positive after her husband was admitted for “malaria.” However, as Piot (1993) argues in regards to a different African context, ambiguity is actively maintained in social encounters to show respect, to be polite and to prevent conflict. Grandparents, however, can transcend these restrictions because of their age and authority. Thus, they are able to interfere directly in HIV treatment trajectories in ways that married women are not.

This is because while alternate generations have familiar relationships, siblings (stratified by age), married couples and parents and their children are far more hierarchical. For example, Mercy, a 16 year secondary student caring for her 12 year old HIV infected brother, Lameck, knew for years that her brother had HIV. Prior to his eventual diagnosis at 12 years old, Lameck was sick for nearly 10 years with chronic ear infections, malnutrition and frequent bouts of serious diarrhea. Mercy’s explanation for why she was unable to interfere illustrates my point about the importance of age and generational hierarchies in truth-telling:

So I knew that these illnesses might be coming from my mother because of the way she died last year [extended illness, loss of weight]. I had that feeling, but because we are staying together with my young mother [amama wadoko – the mother’s younger sister]... and the grandparents are all dead.... well for me to actually say “this might be HIV” well, it was a problem...To say before the parents [generation]... they will challenge you and say: “how do you know this?”

As Mercy’s statement illustrates, without grandparents to consult, she was unable to approach her “young mother” (an aunt) with her suspicions. Rather, her brother went undiagnosed for years, and is mostly deaf because of these delays (Chapter Six). Thus, “the secret” is less important than the ways it could not be shared between a child and her parent’s generation in the absence of grandparents.

Asking others for advice is a common practice in Malawi, and over time I was occasionally consulted about marriage, child care and HIV. To be asked for advice is a sign of respect, and establishes a hierarchy between two people – the advice giver and the receiver. One afternoon a young man approached me at home a year after his mother’s death from what he suspected was AIDS (but never confirmed) to confide that his older brother’s son was just
looking “finished.” He suspected that nephew\textsuperscript{110} also had HIV, but he did not know how to advise his older brother without the grandparents. If the grandparents were alive, he explained, he would go consult with them, and they would advise his brother for him. I suggested that perhaps he should just talk to his brother directly, since it was a life or death situation. He was horrified and replied quickly: “No. I could never. No. That would not show respect.” Silence and secrecy therefore demarcate age cohort and intergenerational respect. Speaking too freely with parents, or older siblings, is considered disrespectful and is widely sanctioned.\textsuperscript{111} Grandparents on the other hand, due to the familiar relationship are more likely to be disclosed to and because of their age-seniority able to intervene at the same time.

**Conclusion**

Understanding how women negotiate their authority to share or not share secrets within intimate partnerships is essential for policy makers to understand why increasing male partner involvement alone during antenatal care is unlikely to produce the outcomes they desire. While campaigns like One Love are encouraging men and women to rethink how men and women share secrets within marriage, in practice HIV disclosure rarely leads to the idealized outcome of a companionate marriage. Rather, men and women often delay HIV disclosure to maintain the marriage. An HIV diagnosis often raises difficult questions about a partner’s fidelity, honesty and love, and may result in divorce, especially in new marriages or marriages without children. Although routine testing is meant to ensure that HIV positive children are identified and treated early, HIV disclosure delays between intimate partners often undermine these efforts. My findings indicate that disclosure delays between intimate partners have serious health consequences for children, including death. To date, programmes in Malawi have focused their efforts at changing marital expectations and communication strategies through social marketing campaigns like One Love. A number of programs throughout Southern Africa are also now trying to increase male partner involvement in PMTCT and ANC programs (Dunlap et al. 2014).

\textsuperscript{110} In this context your brother’s sons are also yours - there is no word for niece or nephew from the paternal side.

\textsuperscript{111} I cannot go into details here about this, but to “know” information that you should not based on your age, generation or gender opens you up to witchcraft accusations. When Mercy says that the parents will ask “how do you know this?” they are alluding to the fact that only a witch would have access to secret information. I discuss witchcraft in Malawi in a bit more detail in Chapter Three, but see Friedsen (1996) for more a more thorough discussion on knowledge and witchcraft accusations.
While these efforts reflect a rising awareness about the difficulties women face disclosing their HIV status to their husbands after a diagnosis, they fail to recognize how intergenerational dynamics influence HIV disclosure within families and how this might influence the timing of HIV treatment initiation.

These findings suggest that HIV prevention and treatment policies that promote disclosure within intimate relationships, without considering the wider network of kinship ties that make up most households, are liable to have unpredictable outcomes. While the aim of programs like One Love is to promote companionate ideals of marital relations, these ideals are difficult to attain in practice. While a few women used these ideals to challenge the legitimacy of their marriages, most of these challenges resulted in divorce, which ultimately undermines the long term social and economic well-being of children from that marriage. Grandparents are also inserting themselves within the HIV disclosure process. In many cases they played key roles at helping infected children get diagnosed and start treatment. While HIV policy and programming to date has not considered the role that grandparents play in intergenerational households, my findings indicate that they are well placed to help ensure timely access to treatment initiation for children. An effective strategy may simply be to train elders in rural communities to act as volunteer HIV/AIDS counsellors and mediators, ensuring that the full benefits of disclosure are attained by everyone.
Chapter 3: “Will Kiniwe Become a Child?”: Delayed Treatment Initiation and Social Suffering at Temwa

November 20, 2009. By the end of the dry season in late November, preparations for the first rains were in full swing. On our way to visit Eleanor and her five year old HIV positive granddaughter Kiniwe, bicycles rattled by piled high with fertilizer bags, and farmers dotted the landscape preparing the fields for planting. Tenants were distinguishable from their landowning neighbours because they did not greet us as they wandered past carrying watering cans on their way to the tobacco nurseries near the river.\(^\text{112}\)

Although we had arranged the home visit during our first interview at Temwa Rural Hospital, Eleanor was still surprised, but pleased, to see us when she saw us walking towards her house. We were ushered inside and told to wait a few seconds so one of her sons could find us something to sit on in the otherwise unfurnished living room. “I enjoy sitting on the mat with you,” I said, and tried to join her on the ground, but Eleanor laughed my reassurance away, insisting that she would be too embarrassed to have a guest sit on the floor. Instead we sat on a narrow bench her son borrowed from a neighbour. After we were settled, her two eldest sons and her husband came inside to greet us, but left quickly to repair the nkokwe (maize storage container) in the yard out front. From inside we could hear the faint echo of their radio as they worked.

After the formal greetings, Eleanor asked without preamble: “Will Kiniwe live long enough to become a child?” Startled by her question, I struggled with an answer. I was tempted to cite statistics from epidemiological forecasts, but I could not easily reconcile their calculations with Kiniwe’s life circumstances, which was marked by the death of both of her parents, ongoing HIV-related infections and food insecurity.\(^\text{113}\) While I hesitated, my research assistant used her own experiences meeting children with HIV on treatment to reassure Eleanor:

Before I did this work, I was like you, I didn’t know children could take the medicines and be ok, but I don’t think you should worry. From what I see, I think it’s possible for

\(^{112}\text{This was the main method I learned to use to distinguish tenants from landowners. As “visitors” tenants are not able to greet, or welcome, visitors to the village area (see Chapter Five for more details).}\)

\(^{113}\text{As Lock and Nguyen (2010:25-27) argue epidemiological forecasting may be able to predict how many people will die within a given population but they cannot predict who will die with any certainty.}\)
children like Kiniwe to go to school and maybe even grow up and get married. Now with
the medicines, you can’t even know a kid can have this disease by looking at them.

Eleanor was visibly stunned by Maggie’s reassurance; she had no idea that a child might live
beyond “a few years” on treatment. Conversely, I was shocked by Eleanor’s doubts. A month
erlier during our interview at the hospital, she outlined her key role in obtaining treatment for
Kiniwe; as she explained, the social conditions of her daughter’s life made her granddaughter’s
HIV diagnosis almost certain:

I started wondering about Kiniwe when my daughter was pregnant with her. Kiniwe’s
father took a second wife, and that woman was just looking very sick… Two years after
Kiniwe was born my daughter had a baby boy, but he died before he started walking [less
than a year old]. When Kiniwe was three years old her father died and my daughter
remarried another man, but not long after they married the [second] husband also died
and so she came home to live with us. My daughter was just very sick at that time [she
was diagnosed with HIV after her second husband’s death] and it was then that I knew
that Kiniwe had HIV. [Kiniwe was four years old at the time.]

Although Eleanor emphasised that she knew Kiniwe had HIV based on events within the family,
I still wanted to understand why years passed between her initial suspicions (from even before
Kiniwe’s birth) to when she was finally taken for a test when she was nearly five years old –
years spent, moreover, taking Kiniwe to the hospital repeatedly to be treated for a variety of
recurring illnesses and more than two years after the death of her own infant brother, likely from
HIV himself. Eleanor explained by referring to a specific set of visible symptoms that made ART
desirable:

It was clear. She had little life left and she was refusing to eat. She was having a fever all
of the time, and she was coughing too much. You could see for yourself that her body
was weak, especially when you compared her to her [older] sister who was just looking
fine.... But my daughter was just delaying Kiniwe’s HIV test, so it was me that forced her
to go with Kiniwe [for a test]. She didn’t want the test... maybe she was afraid. I don’t
know why she was running away.... But finally it was me that forced her to take Kiniwe
for a test. You see this scar by her [Kiniwe’s] nose? Her sister scratched her sometime
back but I saw that the wound was just going on and on without healing. We would put
oil on it, and we took her to the hospital to get bactrim [antibiotics], but five months later
she still had the wound. So I forced my daughter to go with her for a test. I said: “This
child’s wound will not heal, go with her to the hospital. The doctor should test her, and
they should give her medicine according to how she is in her body so that her wound
should heal.”
Eleanor asserted her confidence in ART further when she attributed her daughter’s recent death to her daughter’s refusal to take ART after she remarried. Eleanor began to cry when she recalled the circumstances that led to her daughter’s recent death:

It is just very hard... Maybe if my daughter hadn’t stopped taking the [ART] medicines when she remarried she would still be alive. But when she came to stay with us she was just very sick... She had pneumonia and she was vomiting in the night time. But after she returned to us she started taking the medicines again, but it was just too late. One night she started coughing so badly that we took her to the hospital and they sent us to Rumphi [district hospital], and she died just three days later. Now we are caring for her daughters, and it is tough for us to find food and clothing for so many [five children of her own and three orphans].

Eleanor’s insistence that her daughter would still be alive if she had stayed on treatment confused me further. Why would Eleanor attribute her daughter’s death to her failure to take her ART medicines consistently, but simultaneously insist that Kiniwe would never become a child? In this chapter I explore this apparent paradox by drawing on the concept of “social suffering” (Kleinman et al. 1996) to illustrate the social dimensions of ART initiation and long term adherence for infected children.

A key aim of Global Health Interventions (GHIs) aiming to diagnose and treat children with HIV is to identify them early, ideally before they develop any HIV-related symptoms. From a public health perspective, HIV treatment delays are very dangerous. If ART is started too late, or after any HIV-related symptoms appear, treatment initiation in children can accelerate rather than prevent death. For instance, research shows that deferring ART initiation until HIV-related symptoms appear increases mortality by more than 400% (Violari 2008). Changes in the WHOs pediatric treatment guidelines since 2008 reassert the importance of early treatment initiation for children (WHO 2010, 2013). However, my findings indicate that children at Temwa initiate ART much later than recommended; all but one of the children on treatment had already developed serious HIV-related symptoms before the day they started treatment. While national

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114 At Temwa, at least two children that I know of died within a month of starting treatment and two others were described by health care workers as “too sick” to start treatment and died soon after, despite failed attempts to improve their health with food supplements.
treatment guidelines recommended that infants should be tested at 18 months, the median age of
diagnosis at Temwa was three years. Surprisingly, like Kiniwe, treatment was often delayed for
months and even years in some cases despite a strong suspicion of, or even knowledge of the
child’s HIV status. Several studies from sub-Saharan Africa have documented similar delays
across various settings despite optimal drug supplies, yet, surprisingly very little is known about
the factors underlying late ART initiation (Lahuerta et al. 2013; Nash et al. 2011). My findings
add to our understanding of the factors leading to treatment delays by considering how the
“social life” of ARTs intersects with alternative sickness etiologies, local ethnophysiologicals,
极端 scarcity and a lack of social support that undermines people’s confidence in life-long
treatment regimens for children.

Most GHIs trying to improve treatment uptake emphasize a two-pronged approach. The
first emphasizes the importance of “treatment literacy” to improve “therapeutic efficiency”
(Schenker 2006:3). The idea behind this approach is that knowledge of healthy behaviours
translates into behaviour change (Yoder 1997). These efforts aim to reduce treatment delays by
improving HIV counselling procedures and by focusing on translating the concepts of viruses,
immune systems and ART to people with limited education and exposure to biomedical theories
of disease (Ashforth and Natrass 2005: 285; Graham et al. 2007). The assumption here is that
effective use of ART is dependent on a commitment to biomedical models of health and healing
(Niehaus 2014: 352). At Temwa ART counsellors used a cardboard flip chart to educate
individuals about the benefits of ART by comparing HIV to arrows that penetrate the body’s
immune system; the immune system in turn was depicted as “soldiers” with shields trying to
protect the body. In these illustrated depictions, ART protects the body like a “warrior’s shield”
(see also Ashforth and Natrass 2005 for similar depictions in South Africa). Second, as discussed
in the previous chapter, to improve the timing of treatment initiation for children in particular,
policy makers emphasize the importance of routine HIV testing and counselling for pregnant
mothers during antenatal care (ANC). In this case, the assumption is that if pregnant mothers are
educated about the importance of early diagnosis and the benefits of ART, they will follow

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115 Since my research started about a year after Malawi changed their PMTCT guidelines not everyone had been
tested during pregnancy; however that would not be the case now.
116 As noted in Chapter two, these efforts are also meant to reduce HIV/AIDS stigma and instill “optimism” in
patients about their futures and reduce onerous enrollment procedures that result in unnecessary delays (Ingle et
al. 2009; Wouters et al. 2008). I take this issue up in more detail in Chapter Four.
public health recommendations to prevent vertical transmission, such as giving birth at a hospital where their babies can take an HIV prophylaxis, and bringing their child back to the hospital for treatment if they test positive.\textsuperscript{117} However, while policy makers imagine routine HIV testing and counselling as the first pivotal step on the road to timely HIV treatment for infected children, I argue that a number of social and material factors that have little to do with “knowledge” impact the timing of testing and treatment efficiency. Rather than ascribe treatment delays to local, culturalist explanations of disease or a lack of understanding about the disease or the treatment itself, I argue that treatment delays reflect the uncertainty surrounding long term treatment adherence for children with HIV. While nearly everyone I talked to had a good understanding of the biological mechanisms behind HIV/AIDS and ART, they also felt that medicines alone could not extend life in any meaningful way. Rather, therapy management groups (TMGs) caring for HIV positive children emphasized the social conditions of their lives that undermined treatment efficacy in the long term. For example, Eleanor went on to emphasize how difficult it was to “take good care” of Kiniwe, when she had seven other children to look after. 

To explore these issues I draw on anthropological engagements with embodiment and social suffering to examine delayed HIV diagnosis for children in Malawi. According to Arthur Kleinman and colleagues, social suffering results from what political, economic, and institutional power does to people, and how these forms of power influence peoples’ responses to social problems (1996: ix-xi). It is an important concept because it shows how social and biological problems are interrelated, such as the relationship between poverty, malnutrition and HIV transmission (Kleinman 2010; Stillwagon 2006). I extend the argument of these and other scholars by showing that HIV is not just an objective abnormality found in an individual’s body, but a lived experience continuously constituted by his or her experiences with macro forces and their social relations (Rock 2003; Smith-Oka 2014; Tapias 2006). In other words, health and ill health are social processes not just physiological ones.

\textsuperscript{117} The earliest this could be done at Temwa was at 18 months or when rapid antibody tests are effective in infants (see Chapter One for details). Another approach is to improve diagnostic testing technologies so that infants can be tested younger and initiate treatment as young as possible. I do not think this alone will be effective at reducing treatment delays for the same reasons I do not think counselling alone will work. However, I do think developing more appropriate pediatric formulations may help reduce treatment delays for some children. For example, I suggest below that medicines administered via a “patch” like nicotine or birth control, would be appropriate in this setting for infants younger than one.
I use these insights to challenge the public health perspective that improved HIV counselling or increased knowledge about ART alone will improve treatment uptake. Rather, it is my contention that delayed HIV treatment initiation in children signals “tensions in the social landscape” compounded by economic hardship and scarcity (Tapias 2006: 411). For the primary caregiver trying to raise a child with HIV, the disease was a symptom of broader social, economic and physical destabilizations in their lives. The concerns articulated by these caregivers (mostly mothers and grandmothers) point not only to scepticism about the therapeutic efficacy of ART for children, but also to the fragility of kinship and other ties of social obligation. When Eleanor worried about what would happen to Kiniwe in the future if she were to die, she is talking about the unreliability of others, not the medicines themselves. Divorce, death, food insecurity and migration all limit the ability of primary caregivers to effectively mobilize resources for infected children within the larger network of care that makes up a child’s TMG. Policymakers on the other hand have only really envisioned entry into treatment, but have not imagined the whole trajectory of a child’s life in the way their caregivers have. Mothers and grandmothers, in particular, either imagine premature death, or a prolonged life of ultimate suffering, especially if they die before the child can fend for him or herself. Thus, delayed HIV treatment uptake is a lived expression of their social suffering due to differing degrees of social support and economic duress. My research, therefore, provides an important contribution to our understanding of long-term treatment adherence for children living, and growing up, with HIV.

In this chapter I privilege the concerns and perspectives of caregivers raising children with HIV over epidemiological forecasting and clinical trials, which in some ways suggest that they should be more optimistic about treatment than they are (see Chapter Six for further discussion). While most primary caregivers emphasized the ability of ART medicines to relieve a child’s visible HIV-related symptoms in the short term, such as Kiniwe’s wound, few had any long term expectations that the medicines could extend life beyond a few years. While GHIs continue to focus their attention on developing better counselling guidelines, testing technologies and treatment regimens, primary caregivers have different concerns. They emphasized the poor social and economic conditions of their lives that made treatment ineffective, such as a lack of food or social support from other members of the child’s TMG. This chapter uses the concept of

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118 Another approach has emphasized improved pediatric regimens or diagnostic technologies. Also helpful but unlikely to solve these problems.
social suffering, first developed by Arthur Kleinman and colleagues (1996) to emphasize how ART interventions are understood and adhered to over time. My findings that delayed diagnosis is a product of social processes and not due to a lack of information or understanding about what pediatric HIV is or how it should be treated indicates that children with HIV are underserved by HIV care and treatment services. For GHIs targeting young children with HIV, the implication is that the wider network of relations beyond the primary caregiver-child nexus needs support as well since they are critical at helping primary caregivers secure the resources they need to ensure successful treatment adherence for a child into adulthood over many years.

“I started wondering [if she had HIV], when her mother was pregnant with her”: Social Suffering and HIV

This chapter builds on theoretical distinctions between disease, illness and sickness that ground contemporary medical anthropology. Since the 1970s, “disease” has been defined as the material reality of suffering, usually defined in biological or physiological terms (Young 1982). Illness, on the other hand, is the lived experience of a socially devalued state and may bear little relation to the underlying pathological process (Kleinman, et al. 1978: 251). For example, a person diagnosed with HIV can live many years without having any symptoms – yet he or she may change their behaviour to limit the possibility of passing on the disease to another. On the other hand, a person suffering from chronic pain or seizures may never know the physiological cause of their suffering (Gawande 2003). “Sickness” on the other hand is a blanket term covering both “disease” and “illness” that focuses the processes through which worrisome behavioural or biological signs become socially significant (Young 1982). Anthropologists have shown how the lived experience of specific diseases varies from context to context. For example, in India patients suffering from Hansen’s disease, more commonly known as leprosy, are shunned and withdraw from social life, whereas in Nigeria those affected mostly go on with life as normal (Barrett 2005; Waxler 1981). “Sickness” is also used to understand how health and ill health are reproduced at the societal level (Kleinman 1980). For example, the conditions under which a person grows, lives, works and ages influence the likelihood that he or she will suffer from one disease or another. It is a fact, for example, that diabetes incidence is rising worldwide in Aboriginal and other disadvantaged populations struggling with the after effects of colonialism.
and ongoing oppression and discrimination (Rock 2003). Thus, drawing attention to the lived experience of a disease and its social distribution expands our understanding beyond the material or physiological causes of a specific to disease to help us explore the political and social determinants of health.

The concept of social suffering emerged out of these earlier distinctions, and I use it here to explore the connections between late diagnosis for children with HIV and ambivalence about the long term therapeutic efficacy of ART for children. As many anthropologists have argued, the body is not independent of social relations and forces, but rather is continuously constituted by them (Kleinman et al. 1997; Scheper-Hughes and Lock 1988; Turner 1997). Ultimately, I argue that delayed treatment initiation in Malawi is linked to ideas about children’s bodies and how they function, economic scarcity and what Tapias (2003) refers to as “failed sociality.” Failed sociality is when the relationships one normally relies on fail, when a person can no long meet their own social expectations, or even when someone exceeds the expectations of others and thereby induces the envy of others (Tapias 2003: 402). At Temwa, an array of illnesses were often attributed to failed sociality, including, as I discuss in more detail below, HIV infection in children.

The concept of social suffering has particular salience for children living with HIV for two reasons. First, as Kleinman (2010) argues, the concept highlights how the institutions that are put in place to relieve suffering (such as hospitals distributing free medicines) can actually make suffering worse. For example, in chapter four I discuss how the structure of Malawi’s pediatric HIV intervention as a vertical program poorly integrated into other health systems limits treatment uptake; and in chapter five I examine how this excludes marginalized populations, such as tenant farmers. Secondly, the pain and suffering of a disorder extends beyond the individual affected to the family and social network supporting that individual (Kleinman 2010). This is particularly true of infants and young children with HIV since they are mostly unaware of their infection and rely completely on the adults around them for their survival. In this chapter I focus on the “social life” of ART in and around Temwa Rural Hospital to consider how primary caregivers contend with the reality of raising a child with HIV, given the complicated caregiving arrangements that often surround sick children.

To examine these issues this chapter is divided into two parts. In the first half I discuss fairly widespread ideas that ART has limited long term efficacy and that it can even be
dangerous under specific social and economic conditions. I do this by examining these reservations in relation to medicinal practices and local ethnophysologies in Malawi, or the culturally variable ways that the body is conceptualized and experienced (de Bessa 2006; Geissler 1998; Palmer et al. 2014). I consider the ways that “medicines,” which I define very broadly to include any substance that can effect desirable social or physiological changes, are imagined to work in this context. I consider how these ideas interpellate with the form (adult dose tablets taken daily for life) and function (to manage, but not cure the infection) of ART for children and how that influences the timing of treatment initiation. In the second half of the chapter I consider more carefully the timing of ART initiation, given conflicting ideas within a child’s TMG about their safety and long term efficacy.

My findings indicate that the timing of ART initiation is directly linked to the development of visible signs of HIV infection. The body and its ailments communicate polysemous messages of neglect, economic scarcity, social change, or marital or household conflict. Many of these messages are imbued with moral value and often suggest who or what may be at “fault” for the infection in the first place. Initiating treatment is often an effective means of avoiding social censure or community interference: perhaps the mother can remarry without speculation about a possible HIV infection. Or both mother and child can resume their normal activities, like work and play. However, while many primary caregivers felt that ART was efficacious at solving the immediate signs of infection, from their perspective treatment can never replace the benefits of good food, money for school fees or already-dead loving grandparents, mothers and fathers. In the long term, the social conditions that led to infection in the first place are not ameliorated with treatment, and the demands of treatment, including monthly hospital visits and “good food” that improve their efficacy, place additional burdens on the sometimes tenuous social relationships within TMGs. Thus, I argue throughout that the timing of an HIV diagnosis and subsequent ART initiation for children is shaped by specific expectations of the medicines’ therapeutic efficacy, the demands placed on different members of the TMG, fears around drug safety and the long term feasibility of ensuring treatment adherence for a sick child.
“They should give her medicine, so that her wound should heal”: Medicinal Practice and the Body

The term for medicines in Malawi is “mankhwala.” It is a broad term used to refer to a variety of substances, such as roots, leaves, bark, grasses, seeds, fungi, animal parts, agricultural fertilizers, pesticides and western pharmaceuticals, including antiretroviral medicines.119 Contrary to western biomedical conceptions of “medicines,” however, Malawians use the term mankhwala to refer to any type of compound that is considered both physiologically and socially efficacious, which in this context may refer to both negative and positive effects (see also Friedson 1996:192, n.15). A variety of mankhwala, both herbal and biomedical, are used after breaking a social taboo, to repair social relationships and to heal bodies (Morris 2011). Mankhwala, therefore, also take the form of good luck charms, love potions and protective amulets, which are very commonly worn by infants to protect them from the evil intentions of others. Therefore, a distinctive feature of mankhwala in Malawi is that their potential benefits extend far beyond what most policy makers or clinicians would consider the therapeutic context.

Dangerous or harmful mankhwala, are sometimes referred to as “nyanga” and are used in the practice of witchcraft by individuals called “witches” (ufwiti). Unlike the Azande in Sudan described by Evans-Pritchard (1937), witches in this context effect their evil deeds through the conscious manipulation of specially prepared mankhwala/nyanga. These are sold in public spaces and marketplaces throughout Malawi or purchased from sing’anga’s (traditional healers) secretly. Friedson (1996) notes that these dangerous mankhwala are made with a witchcraft base called chizimba, which is usually from animal parts, including lion claws, porcupine quills, hyena brains, hair, nails or bones, which are considered the most powerful chizimba. Throughout my fieldwork there was also an increasing concern over the use of human flesh and children’s body parts, such as the straight hair characteristic of new born babies, to make powerful chizimba.120 For example, one mother with a two year old on treatment told me that her four year

119 As discussed in the Introduction, there is a tremendous amount of linguistic and ethnic diversity in this area, but “mankhwala” is a term used in all the languages of Malawi. However, the majority of this discussion covers medicinal practices in northern Malawi. See Morris (2011) for a more detailed discussion of herbalism in Southern Malawi. There is also a tremendous amount of variety of herbal remedies derived from locally available sources used to treat a range of ailments from village to village depending on specialized knowledge and micro-ecology of where people lived.

120 Friedsen does not mention this, and I was told that this was a new development since the year 2000 and was a sign that the apocalypse was coming (see also De Boeck 2005, 2009).
old died from pneumonia because the grandfather made chizimba out of her hair. As a result, most parents did not allow their children to walk to school alone. In one dramatic incident my neighbour’s son did not return home at sunset, leading to a panicked search involving the police. His parents were terrified that he was taken by an ufwiti for his body parts since, as a twin, his body parts were thought to make potent chizimba. Luckily he was found 5 km away at an aunt’s house. While some might think this was mere superstition, individuals do make and buy nyanga. For example, the graves of newborn babies were dug up so that various bones could be used to make nyanga. Others worried that their children would be kidnapped for their body parts. For instance, one tenant farmer spent 10,000MK (around 80CAD), or nearly a half year of his wages, on mankhwala to protect his children from kidnapping by witches for their body parts.

A very important aspect of mankhwala is their ability to heal, repair, and either create or improve social relations with others. Like in many other contexts, in most cases no one I talked to made any great distinction between bodily illness and social misfortune, and both can be treated with mankhwala (Friedson 1996). For instance, one afternoon I witnessed a scuffle between two brothers over the correct handling of their youngest brother’s asthma attack; the eldest brother was very angry that no one consulted him before they called a taxi to take the boy to the hospital. The fact that he had no phone and that the asthma attack was acute did not dissuade him from insisting that it was his “right” as the eldest to determine the course of action for his sick brother. The two brothers exchanged “bitter” words in front of neighbours and the extended family, which prompted a grandmother to organize a sit down meeting to discuss the situation the following day. After some debate it was decided (by “the grandparents”) that the two brothers should take mankhwala to neutralize the bad words said between them. This medicine was procured from a local sing’anga and it was made of a bitter tasting mud from the base of a river, which they then had to eat together in front of relatives.

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121 Babies who are stillborn or who die within the first week are not given a full funeral. Older women take the body and bury it in the woods without the parent’s involvement. During my fieldwork my neighbour was found in one of these graveyards with a newborn’s finger bone, and he said he dug up the body to make a medicine for getting rich. The church intervened and conducted an all night prayer healing session for him, which seemed to satisfy everyone.

122 This medicine was applied to various parts of the house, ‘protecting’ those inside from witches.
Love potions are also widely used by women both to keep current partners and to attract new ones.\textsuperscript{123} Indeed, Malawian men often worry that their partners are using these \textit{mankhwala} in secret, and in at least one case a marriage was ended after a husband discovered a love potion in his wife’s possession. Another important aspect of witchcraft in Malawi is that only a blood relative can bewitch you, since it is sharing blood that makes someone vulnerable to an attack. For example, rumours surrounded a wealthy villager in Temwa with two visibly disabled children; the suspicion was he somehow used the “medicine” in his children’s body parts (hair, nail clippings) to get rich, which highlights the sense of dangerous uncertainty in people’s closest relationships.\textsuperscript{124} Also, using \textit{mankhwala} for social gain also often carried with it inherent risks, or potentially dangerous side effects (Etkin 1992).

Everyone in Malawi has at least some knowledge of how to make \textit{mankhwala} to treat common ailments, including headaches, wounds, and other common childhood illnesses, especially various types of diarrhea, fevers and coughs. Protective amulets in particular were very common in young children and were often worn around a child’s neck or waist to protect them from illness or from dangerous conditions associated with growth and development, such as \textit{luwombo} (the closing of the fontanel), teething or learning how to sit. However, older men and women are the most likely to have specialized knowledge of herbal remedies for children, while young parents often said they did not know what went into the \textit{mankhwala} the agogos (elders) had given their child. As Prince et al. (2001) also noted in Kenya, children as young as 8 years old also had a wide knowledge of the medicinal use of common trees and shrubs. In Temwa, children regularly gathered their own fruit and hunted birds to play “\textit{kudimbika}” (house), and I heard children as young as two years old ask for their “\textit{mankhwala}” when they were feeling sick.

\textsuperscript{123}For example, I interviewed a local love potion maker and she made two special compounds for me. The first is called ‘hurry-to-me’ potion and it is made up of the bark of four trees pounded into a powder in a ‘katuli’ (small mortar and pestle) \textit{(mbonekera, chimweemwe, muchemeni, povyatulo} and the wood of the muluwuka tree kept separately). I was instructed to place it in my face cream so that it could be absorbed into my blood through the skin. I should apply it while thinking of the person I want to fall in love with. He will then rush to me. The second is a much more powerful potion that many of my Malawian female friends recommended, but hide from their partners. Also a powder, I was instructed to insert it into my vagina before sex and my partner would never leave me afterwards.

\textsuperscript{124} These children were never diagnosed with a biomedical disease, but based on their facial features alone I suspected they both had Down Syndrome.
Everyone in Malawi also recognizes the efficacy of western pharmaceuticals, including the few that are widely available for free at government hospitals, such as artemesian treatment for malaria (commonly referred to as “La”\textsuperscript{125}), antibiotics (referred to by their common brand names of either bactrim,\textsuperscript{126} flagyl and amoxicillin\textsuperscript{127}) and “panado”, the brand name for paracetemol, a mild analgesic.\textsuperscript{128} Amoxicillin and flagyl were often out of stock at health centres, but were also considered “more powerful” than the commonly prescribed bactrim and highly sought after. Twice during my fieldwork neighbours “borrowed” a few of the amoxicillin tablets I was prescribed when they came to visit after they heard I was sick; significantly, I never had any problems procuring these sought after antibiotics. Many people also reported disappointment if they went to the rural hospital and were only given “panado” since “getting medicines” was cited as the primary motivation for going to the hospital. In this sense, patient expectations shaped the clinical encounter, and is why Mr. N., often felt compelled to prescribe panado to nearly every patient who visited the hospital.\textsuperscript{129} A survey in town of the commercial medicines available for purchase also indicated that Malawians use a variety of over-the-counter medicines for mild coughs, stomach pains, indigestion and body aches, and most of these sold for 10-20MK (5-10cents) for two pills.\textsuperscript{130} Therefore, in practice, there is a wide variety of mankhwala available in this region, and mankhwala are used to heal a variety of problems, both physiological and social.

\textsuperscript{125} In 2007 the government discontinued fansidar SP, a malaria treatment because of widespread resistance (Lansgrud et al. 2013). However, Malawians regularly complained that La was too powerful and that they preferred fansidar, which they sometimes took instead if they had old tablets at home. My experience with La echoed these observations; while very effective, I was completely unable to work while taking the medicines — a side effect that people felt was very troublesome.

\textsuperscript{126} Bactrim is the trade name used to refer to the generic antibiotic known as co-trimoxizole and used to treat a variety of bacterial infections including respiratory tract infections, skin and wound infections, urinary infections etc.

\textsuperscript{127} Amoxicillin was widely considered a stronger medicine than Bactrim but was also much more likely to be out of stock at the hospital. It is also used to treat bacterial infections and is the world’s most commonly prescribed antibiotic for children.

\textsuperscript{128} Of note here is the increasing numbers of spurious and counterfeit drugs infiltrating the markets in developing countries (Gautam et al. 2009; Hoppu et al. 2011). The WHO (1999) estimates that 25% of all the drugs available in developing countries are counterfeit, which could have serious effects on both health outcomes, as well as people’s perceptions of drug efficacy, which could have long term effects on the use of western pharmaceuticals in these contexts.

\textsuperscript{129} It was suggested to me that one of the reasons some people went to other health centres first was because Temwa rural hospital was known for following antibiotic treatment protocols designed to prevent treatment resistance.

\textsuperscript{130} I was also told that you could buy antibiotics from Tanzania illegally in this market; however, no one would directly admit to doing this whenever I asked.
The important point here is that in Malawi *mankhwala* works not just on the physical body, but also works to sustain particular views of society and social relations (Schepers-Hughes and Lock 1987). That is, medicines also have what anthropologists call “social efficacy,” or the ability to affect the relations between those experiencing illness and those trying to treat suffering by suggesting something about all of the people involved (Whyte et al. 2002: 23). For instance, a very popular song from Zambia titled “Panado” after the widely prescribed brand name tablets for paracetemol goes: “[Young man singing to his girlfriend:] Ah! My dear! You are sick, not feeling well…But I am here, I love you…. I can prove it, because I am here giving you a panado.” In this case, panado is a metaphor for love. As one grandmother stated when I asked why she went to the hospital with a sick grandchild: “Getting medicines, it is the best way to be taking care.”

Similarly, in Malawi, children are almost always given some type of medicine when they fall sick; but whether or not these medicines work on the body is sometimes less important than who gave them. For example, the two brothers who argued about their youngest brother’s asthma attack were arguing about who had the right to get him medicines, not about whether the medicines were a good idea. Also, often when I asked tenant farmers if they had a “good employer,” they would feel that they did if their employer gave them medicines when they were sick. In this way, prescribing or administering medicines for a child has effects on social relations. To some extent, going to the hospital and getting medicines for a sick child is a performance for others that shows proper care-taking; those who do not “get medicines” for example are often criticized by friends, neighbors and community members. Fathers who have long been absent from a child’s life, for example, may suddenly decide to procure medicines for their child, which indicates to the child that they “belong” to their father’s kin. Therefore, giving a sick child specific medicines is not always about their therapeutic efficacy, but about reaffirming social relationships between individuals and avoiding social censure by neighbours who might criticise specific health strategies for sick children. I discuss this in relation to ART in more detail below.

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131 [http://www.youtube.com/watch?v=c_JAzhpahwU](http://www.youtube.com/watch?v=c_JAzhpahwU)

132 In some cases children can be overmedicated. Hardon (1987) found that women in the Philippines overmedicated their children to prove that they were a “good mother”. Doctors also are guilty of overprescribing antibiotics to reaffirm their authority during clinical encounters (Stivers 2002; Stivers et al. 2003).
“The doctor should give her medicine according to how she is in her body”: Disease Etiologies and Health Strategies for Sick Children

All members of a child’s TMG take even mild childhood symptoms seriously, which often precipitate immediate intervention, either through the use of home remedies, taking a child to a hospital or consulting a sing’anga, a traditional healer. Determining the cause of the illness, or its etiology, is often an important first step in determining a course of action. Disease etiologies are also used by TMGs to evaluate the effectiveness and appropriateness of treatment options available for children. While minor childhood ailments were often seen as “natural,” such as coughs due to cold weather or dusty roads, prolonged or serious illnesses, or illnesses that developed suddenly without warning, provoked more in-depth speculation (see also Green 1999). In these cases, most of my respondents considered poor or damaged social relationships as the mostly likely cause of a child’s ongoing health problems, either because a person who should help could not or would not help. Immoral or irresponsible behaviour by husbands and wives, as well as the evil intentions of others or of Satan, also seemed like more probable causes of serious illnesses to most of the people I spoke with. Pediatric HIV/AIDS, which is characterized by the rapid progression from common childhood illnesses to severe, debilitating disease, often prompted more complex, and often overlapping etiologies. I discuss the implications of this for treatment initiation below.

The most common symptoms of childhood illness reported to me were a “warm body during the night,” not eating, weakness, crying, coughing (chikoso), watery stool and vomiting (see also Einarsdottir 2004; Gottlieb 2005). These symptoms are almost always noticed by the mother first, but occasionally fathers or grandparents play key roles in identifying a sick child. Typically, however, if a child is sick the first action likely to be taken is to increase the frequency of breastfeeding or try to find “good food” for the child, which included soya porridge, fruits, ngaiwa (whole grain maize flour porridge) or sobo, a sugary drink sold in shops. A few reported avoiding some foods for their children, including eggs, guavas and groundnuts, which are sometimes thought to cause diarrhea. In addition, child illness is also associated with poor child spacing practices, and may indicate that the mother is pregnant before she has finished weaning the “back child” (or the child usually on the mother’s back). In these cases, the mother terminates breastfeeding immediately.
I had difficulty ascertaining how widespread the use of herbal remedies and *sing’anga’s* was in the early treatment of childhood illnesses. More than two decades of public health intervention aimed at discouraging traditional healing practices meant that many people were reluctant to talk about these practices with me, since I worked at the hospital. However, over time, my observations suggested that infants are almost always given “herbal baths,” or bath water with herbs mixed in, during the early stages of an illness, and as they grow older these herbs are mixed in with their porridge to make different kinds of medicines, both preventative and therapeutic (see also Bezner Kerr et al. 2007, 2008; Langwick 2005). These herbs are usually free and gathered by relatives or a neighbour from the “bush” nearby. According to the surveys I conducted at Temwa rural hospital, many senior male members of TMGs (such as fathers, uncles, grandfathers), also purchased panado (for pain, fevers), and a wide variety of over-the-counter medications, including cafemol (for fever), conjex (cough), cofrid (cough), tumbocid (for stomach pains) and ORT packets (for diarrhea) from shops close to home if they had the money. Some landowners or estate managers also gave over-the-counter medicines, or special foods such as soya porridge, to their tenants during the course of a child’s illness.

If the symptoms continued, or worsened, after these initial interventions, the next step in the child’s treatment trajectory is usually a visit to a hospital. Although a mother can make routine decisions about her child’s health (such as vaccinations, or under-five clinics) without anyone else’s consent, in almost all cases women consult with their husbands, in-laws, mother, friends or landowners (in the case of tenants) before going to the hospital and are usually escorted to the hospital by an older female relative. Tenants, who are in the area without older relatives, are often accompanied by their employer or other tenants living nearby or working on the same farm. Men rarely brought their children to the hospital on their own, although in a few cases men combined business in town with a hospital visit or carried a sick child on a bicycle. Of the 185 people surveyed in April 2010, 68% reported that their child had been sick in the last 30 days.

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133 There does not seem to be any difference in the use of herbal remedies by ethnicity (Tumbuka, Chewa, Nyika, Yao, Lomwe) or livelihood (tenants, landowners and farmers renting land in the area) since of the 12 who reported that they used herbs in the survey six were Tumbuka landowners, four were tenants and two were renting land. However, there is a relationship between the use of traditional healing remedies and religion. Eight of the 12 mothers who reported giving herbal remedies belonged to the “Nationale”, or African church, which embraces “traditional” practices (personal communication, local Reverand of the Nationale Church in Temwa).

134 Although the issue of over the counter medications is beyond the scope of this chapter it is important to note that there are growing concerns about the safety and effectiveness of these medicines (Sherefstein et al. 2007).
days, and nearly 75% of those had brought their child to a hospital or health centre “to get medicines.” Of the people who reported bringing their child to a hospital, nearly all (86% or 81/94) were prescribed medicines, although a few were given ORT packages and panado only. Going to the hospital and only being prescribed panado was the number one complaint that people had about Temwa, and if this occurred families would often just go to another health centre down the road hoping for a different outcome. Of those who did not bring their sick child to a hospital (27/126), most used home remedies, including over-the-counter medicines from local shops or herbal remedies, while very few (only tenant farmers) reported doing nothing at all (2% or 3/126). Of the medicines that were prescribed, panado, in tandem with another medicine, usually bactrim, was by far the most common medicine given to treat a range of reported symptoms including cough, diarrhea and fevers (see Table 4; also Sosolo 2007).

Table 4: % of children given any Mankhwala at the time of sickness by type in the last 30 days

April 2010 (n=126)

<table>
<thead>
<tr>
<th>Medicine</th>
<th>Number</th>
<th>%</th>
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<tbody>
<tr>
<td>Panado</td>
<td>70</td>
<td>56</td>
</tr>
<tr>
<td>Bactrim</td>
<td>47</td>
<td>37</td>
</tr>
<tr>
<td>ORT</td>
<td>12</td>
<td>10</td>
</tr>
<tr>
<td>Herbal medicines</td>
<td>12</td>
<td>10</td>
</tr>
<tr>
<td>Aspirin</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td>LA (antimalarial)</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td>Cafemol</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Flagyl</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Unknown</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Tumbocid</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Quinine</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Calamine Lotion</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Conjex</td>
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135 Three people reported buying bactrim from a local shop; at the time of my research I did a survey of all of the shops in town to see if they were selling and all said that they did not because it was illegal. However, I was told by others in town that Bactrim was almost always available for sale in most markets. Some argued that these antibiotics were brought from Tanzania, while others argued that they were sold by health care workers to the shops, however I was unable to confirm either scenario (see also McPake 1999).

136 Thirteen caregivers also reported that their child had been given Vitamin A and Mbenzazole (an anti-helminth medication) at a mobile clinic in the last thirty days as part of Malawi’s primary health care programme.
Most people stated that they went to the hospital before going to see a sing’anga’s because hospital services are free, but also because they felt that the medicines available at the hospital worked. However, it was also common for TMGs to take children to see a sing’anga if the prescribed pharmaceuticals failed, or if the symptoms reoccurred. In that sense at least half of the children with HIV on treatment that I worked with were taken to see a sing’anga at least once before starting ART. As nine year old Robert’s grandmother explained:

I had a very big problem with him. He was very swollen here [pointing to her abdomen]. I was going with him to the hospital often and often but they were just telling me lies [he was taking medicines but not getting better]. So you know how villagers are, they were just saying he’d been bewitched so we took him to see a sing’anga. But those medicines failed too… So we brought him back to the hospital for a test [2 years later]. If I hadn’t done that I am sure we just would have buried him.

Another mother [amama walala, or mother’s eldest sister] reported a similar experience:

Our son isn’t really going to school here in Temwa because he has difficulty hearing. When he was younger he was having wounds inside the ear and masses of blood were coming out. So we took him to the hospital but the medicines didn’t work, so we tried traditional medicines because, you know, we have witches here. So after the medicines at the hospital failed we took him to see a sing’anga, and at least that made the wounds stop so now at least he can still hear a little bit.

In both of these cases a sing’anga was sought out when biomedical treatment failed, or when symptoms persisted or got worse. Other signs of bewitchment in both of these cases were the death of one of their parents, and two siblings each. These are all signs of misfortune indicating that the root cause of the illnesses were closer to home, nearly always related to the jealousy of

<table>
<thead>
<tr>
<th>Medicine</th>
<th>1</th>
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</thead>
<tbody>
<tr>
<td>Nalidixic Acid</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Fansidar</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Cofrid</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Cough syrup</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Stearns</td>
<td>1</td>
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</table>

137 This is an antibiotic I have never heard of being prescribed in Malawi – I have no idea where this medicine was obtained.

138 Fansidar is the type of malaria treatment used pre-2008 until resistance to the medicine was considered too high for it to be effective (Lansgrud et al. 2013). However, this family still had some left at home and used it to treat their child for malaria-type symptoms.
resentment of close relatives. Determining who is causing the illness and what type of witchcraft was used is crucial for most successful treatments. Thus, a key role of a sing’anga is to identify the witch and then neutralize him or her, often through protective medicines applied to the victim’s body or around his or her house. While some Malawians who used sing’angas reported that they were not even sure if witchcraft was “real,” I never met anyone who categorically stated that they do not believe in witchcraft-based illnesses, even health care workers. Therefore, sing’anga continue to play an important role in the treatment of serious childhood illnesses, yet they are often overlooked by policy makers when designing health interventions (Green 1999).139 More importantly, these treatment trajectories also indicate that biomedical treatments are used regularly, even when other disease etiologies are suspected. This indicates that a firm understanding and acceptance of biomedical etiologies does not always preclude other overlapping etiologies that underlie health strategies for sick children (Legare et al. 2010).

In recent years, with the resurgence of Pentecostal and Evangelical churches, prayer has also become an important tool in the treatment of childhood illnesses. Illnesses in these cases are caused by Satan. For example, many people told me that pediatric HIV was a sign that the Apocalypse was coming. As Lois, the member of an evangelical church said to me, “to my side in the Bible it is written that in the last days there will be different diseases, so I feel that what was written in the Bible is now being fulfilled.” Also from this perspective, witches still exist but are considered Satan’s helpers (but with less consciousness or intent than in the more “traditional” understanding of witchcraft). Therefore, an alternative to visiting a sing’anga to combat witchcraft is regular Church attendance and prayer. Many Malawians told me that the increased popularity of Evangelical Churches was that they protected people better from witchcraft attacks than other Churches, which often denied the existence of witchcraft altogether. In terms of childhood illnesses, I was told that some evangelical churches in Temwa advocated against the use of western pharmaceuticals; sick individuals who pray instead and recover are considered faithful. Although local pastors and reverends insisted to me that they encouraged

139 This is likely because most policymakers feel that with more “education” these “beliefs” will disappear. However, Adam Ashforth (2002, 2005) and many others highlight how witchcraft accusations are actually increasing in many places and are directly related to rising inequalities in many African settings. All of the Malawians I spoke to agreed with this assessment; many cited increasing “greediness” as the root cause. Examples given to me of this are relatives that eat together in their house as a nuclear not extended family; individuals who hide food from their extended family; individuals who gain wealth but refuse to share it with their extended family, etc.
their worshippers to visit the hospital when they were sick, I met adults who stopped their ART to pray instead. None of the children on treatment I met had their treatment interrupted for this reason; however, only two of the children on treatment belonged to a Church that supported prayer as a healing technique. Although I cannot say for certain that children belonging to these Churches are vulnerable to treatment delays (since as discussed in the Introduction, there is no way to know if undiagnosed children with HIV belonged to these churches), I suspect that religious affiliation does play a role and is likely to become even more important as these Churches are attracting new members everyday (see also Dilger et al. 2010; Mattes 2011). Nevertheless, the treatment trajectories I gathered illustrate the complexity of the dynamics within TMGs as they respond to the progression of HIV-related symptoms in infected children (see also Kaufert and Lock 1998: 1-3). They indicate that Malawians are engaging with a number of therapeutic techniques and disease etiologies simultaneously. Rather than viewing biomedical models in opposition to religious or witchcraft based disease etiologies, most Malawians have integrated them into their understanding of their child’s illness. Next I discuss how disease etiologies shape medical practices and treatment uptake in Malawi.

“Her body was really finished”: Forms of medicinal practice, the body and therapeutic efficacy

Particular understandings of disease etiology and the human body also shape medicinal practices throughout Malawi (Kaspín 1996). In particular, the perceived severity of the illness dictates the preferred method for administering mankhwala. For instance, for “small diseases” (matenda wadoko), mankhwala are administered orally by drinking herbs gathered by a relative or a traditional healer mixed in water or in porridge. For children who have not started taking food yet (under six months old), the medicines are rubbed onto the skin by putting the herbs into lotions or put into a child’s bathwater. The idea is that the medicines are absorbed into the blood through the skin. As one informant explained to me: “sweat comes out of the body, so why can’t things go in the same way?” For “bigger diseases” (matenda), oral medications are preferred; and for very serious or life-threatening conditions, the preferred method to take medicines is by inserting them directly into the bloodstream, usually by making small cuts with a razor blade and then rubbing the medicines or herbal remedies into the wound. These small cuts are usually made
at the lower back, knee, thumb and hip joints and, frequently, on the chest slightly above the collar bone. As one healer explained to me: “The chest is the best place to cut and apply the medicines because the blood comes fast, but there isn’t too much.” Almost every Malawian I have ever met has small scars on various parts of their body, which were inflicted to treat or prevent severe illnesses.\textsuperscript{140}

The same logic used in herbal remedies is applied to western pharmaceuticals, with oral medications considered appropriate for milder illnesses but injections (either by IV or needles) widely preferred for serious illness, especially malaria.\textsuperscript{141} This preference for injections for serious illnesses may account for the reported over prescription of injection anti-malarials in Malawi (Chandler et al. 2008). In addition, some medicines are administered the same way herbal remedies are applied, by inserting the medicines into the blood stream through wounds on the skin. For instance, people sometimes open antibiotic capsules meant to be taken orally, and apply the powder inside the capsules into wounds on the body. As someone explained to me: “If the wound is very serious, or you have those lumps in your groin [referring to lymph node swellings] from the infection this way is much better since it goes straight into the blood.” This was also one reason people preferred the antibiotics amoxicillin and flagyl to the more available bactrim, since they are prescribed in capsule, versus tablet format, allowing people to administer them directly into the bloodstream.\textsuperscript{142}

Young children in particular are perceived to have “soft” bodies, which refers to the permeability of their skin relative to adults (Einarsdottir 2005). As a sing’anga from Temwa explained: “Babies’ bodies are soft because they don’t have any medicines in the body, but an older person has many medicines in their body, and they have usually been sick before, whereas a baby usually hasn’t.”\textsuperscript{143} Children with soft bodies also had “raw blood” (ndopa iteta). If a

\textsuperscript{140} One pastor explained that the reason children were more likely to get HIV now is because parents are less likely to protect their children from witchcraft attacks with these methods.

\textsuperscript{141} For another example of how the application of western pharmaceuticals are reinvented in different contexts, Parish (2011) notes that Ghanaian migrants in Paris suffering from common colds are given paracetemol, not to be swallowed but to be hidden in socks, or pockets, or worn in necklaces to react with their experiences and entrap witches trying to cause them harm.

\textsuperscript{142} I will not go into detail here, but a person’s emotional state also influenced the therapeutic efficacy of medicines (see also Rehun 1994).

\textsuperscript{143} I would suggest that these ideas reflect an emic understanding of the concept of immunity (see Martin 1994 for a discussion on the origins and interpretations of “the immune system” in North America). While HIV treatment adherence counselling uses the metaphor of the “shield” that protects the body, I think drawing on these ideas of permeability might be more effective, especially for children.
child’s body was soft and/or his her blood was “raw,” gentler forms of administering medicines were preferred such as the use of amulets and herbal baths. While people agreed that children’s bodies are softer than adults bodies, there was no consensus about how and when a child’s body stops being soft. There was also no consensus about when and how a child’s blood stops being “raw” (iteta), nor was there any clear picture of how raw blood affects the use of medicines. Some say that a child’s blood ripens very quickly, often within the first month of life, while others told me that the blood is not fully ripe until puberty. One sing’anga from southern Malawi working in Temwa told me that there was no such thing as “raw blood” (ndopa iteta), although he acknowledged that most people thought so. However, he agreed that children’s bodies were “softer” (meaning that the skin is permeable). Still others said they did not know anything about children’s blood or their bodies and suggested that I ask a sing’anga or an elder person since they were the ones who had specialized knowledge about these issues.

The ripening of a child’s blood and the permeability of their bodies were often mentioned whenever I asked primary caregivers if they had any concerns about giving ART to their child. Despite the lack of consensus, understandings of children’s bodies and the relative ripeness of their blood and the softness of their bodies informed most people’s health strategies for sick children. Everyone also agreed that the medicines you take as a child slowly accumulate in your blood, offering lifetime protection from disease, misfortune and witches. However, the protective nature of medicines could be negated if the person taking the medicines broke the taboo that went along with the prescription. For example, I was told that there was a medicine that could stay in the bloodstream forever, as long as the person taking it did not eat okra. Many people also told me that the reason children were now more vulnerable to witchcraft, unlike in the past, is because some families were not giving children these medicines early in life that would protect them later on.

Kaspin (1996) argues in “a Chewa cosmology of the body” that newborn babies are “cold”, children “cool” and adults of childbearing age “warm”, however I never could confirm if this was an idea commonly held in the North with any consistency, although these ideas were articulated by some people. However, “heat” and “cold” was often cited as the cause of many childhood illnesses and the cure. For example, the body can be “cooled” through the use of medicines, dancing to drums to cool down the vimbuza spirits heating the patient’s blood, or by drinking the fresh blood of animals (Friedsen 1996), which probably explains why Malawians refuse to eat meat that isn’t very well done. Infants are also heavily clothed and a hat is worn at all times to protect the child from any drafts. More common were metaphors associating the body as either “raw” or “ripe” – words also used to refer to farm crops (see Einarsdottir 2004). Interestingly, Mary Douglas did her formative research in Malawi as Mary Tew (1950) and later developed the theory of purity and danger (2005), which incorporates ideas of “the raw and the cooked”.

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Perceptions of therapeutic efficacy were also influenced by fears that the medicines were “too strong” for children, especially infants less than one year old. As one health care worker from the district hospital, where they started testing infants for HIV at six months, explained, “some mothers of smaller children are reluctant. They feel babies are too small and ARVs are too strong. We have counselled these mothers, and some have said ‘no’ and some leave and don’t come back.” At the time of this interview, which was in the first few months of my fieldwork, I assumed that caregivers were worried about giving small children split-tablet adult doses of ART, which, as I explained in Chapter One, was standard practice in resource-poor settings at the time of my research. However, I soon realized that the drug formulations themselves were not what worried caregivers, since there are no paediatric formulations for any pharmaceuticals or herbal medications in Malawi. Rather, caregivers with young children expressed concerns that their child’s body was too “soft” and their blood “too raw” (ndopa iteta) to be given medicines orally, since the preferred method for giving medicine to young children is through the skin, by putting medicines in the child’s bathwater. This issue was not a major concern for my informants where HIV testing was not available to infants younger than 18 months, but, for at least two mothers who sought out HIV testing for younger infants at the district hospital, it led to treatment delays. Although this issue was a minor concern during my fieldwork, I suspect that it will become a bigger issue as more countries adopt the WHO’s recommendations to treat infected infants as early as possible.

As a pharmaceutical intervention that requires life-long treatment adherence, ART is also distinct from any other medicinal intervention in Malawi. Everyone was very conscious of this difference and they used metaphors to make sense of them (see also Setel 1999; Schumaker and Bond 2008). For example, many people compared HIV infection to a puncture in a bike tire. As a friend said to me: “HIV is like a puncture, and the medicines are like the patch. You can’t cure the disease but they stop your tire from going flat.” Patients at the ART clinic also joked they were there to get their “maunits,” which is phone credit bought in small increments to use pay-as-you-go cell phones. “Maunits” in this context is a practical metaphor; just as phones need units of time to “add minutes,” so too does the body infected with HIV need medicines to “add

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145 The closest comparison are the medicines required to treat TB infections; however, none of my informants made any comparison to them on their own. Although two primary caregivers had TB, Temwa did not offer sputum tests and it was likely underdiagnosed as a result (Straetemans et al. 2010).
life.” As one woman explained to me: “these medicines dilute the disease in the blood, but they don’t kill it.” This metaphor was also telling since in this context “maunits” are also something most people were constantly asking others (such as an older sibling, or wealthier relative) to send to them, highlighting how successful treatment was dependent on successful social relationships with others or the ability to depend on others to “top you up.”

While these metaphors circulated widely, they occasionally clashed with commonly held ideas about children’s bodies. In at least two cases that I know of, children were taken off ART because a caregiver (a grandparent in both cases) felt that the medicines were no longer required. Just as the efficacy of herbal remedies is maintained throughout someone’s lifetime once they have been ingested, some felt that once a child was healthy, or their blood had “ripened,” they would no longer need ART since children can “grow out” of the disease. A few also maintained that since a child was not sexually active the disease would eventually leave their body, making ART unnecessary into adulthood. In this instance, local understandings of medicinal practice did directly contradict the biomedical importance of adhering to ART to prevent unnecessary morbidity and early death in a few cases. While few children had their treatment interrupted because of these ideas, the importance of life-long treatment adherence was used to evaluate the efficacy of ART, the benefits of daily pharmaceutical intervention for the rest of the child’s life and were used to make decisions about treatment adherence. Significantly, most of the children with HIV around Temwa never even initiate treatment, and fears about treatment safety, especially for very young children, played a significant role in caregiver’s decisions to delay treatment initiation. Thus, expanding access to ART for infants especially will require engaging with people’s explanations for ART withdrawal along with ideas about children’s bodies and preferred methods to administer medicines to infants.

“The way I am in my house”: Failed Sociality and HIV Infection

To understand if treatment delays were related to a lack of understanding about how children get HIV I asked every primary caregiver how and why he or she thought their child got HIV. When I asked them how their child got HIV, all but one of the parents I spoke to had a
logical, scientifically sound explanation for why their child had HIV.\textsuperscript{146} For example, Dorothy, a mother of six year old twins, explained: “Grace has a twin brother, but he does not have HIV like us. At the time they were being born he came out first and everything was just ok. But with Grace… Eish! There was lots of blood and it was very difficult. I think that is why he doesn’t have this disease and she does.”\textsuperscript{147} Brenda, a mother of a two year old boy on treatment, also explained: “We live very far from the hospital. The nurses there told us we should give birth at the hospital to get the “drops” [nevirapine prophylaxis], but the pains came on early and during the nighttime. We could not make it in time.”

Although a few suspected that transmission occurred at birth, most thought that transmission occurred through breastfeeding, a perception that is supported by research on the most likely causes of vertical transmission in Malawi (Moses et al. 2008). For example:

The nurses were just telling me stop breastfeeding when she was six months old. \textit{But the way we stay at home}, the grandparents were just saying that there wasn’t enough food [so she could not stop breastfeeding].

- Lucy, mother of two year old Uchi on treatment

At a certain point, I had wounds on my nipples, but there was no food at home, so my husband said I should just be breastfeeding her. To my thinking, she got HIV at that time.

- Dorothy, mother of three year old Joyce on treatment

I was found positive, but I over-breastfed her [past 6 months] because of the \textit{way we stay at home}, so I knew in my heart, I was convinced that she too must be positive.

- Rita, mother of six year old Lisa

Lionel got HIV from breastfeeding because I over breastfed up to 2 years, and at that time his father was still going out with other women.

- Thelma, mother of nine year old Lionel

When I was found with this disease they [the health care workers] told me that the child could also get HIV from breastfeeding so they told me the child stop breastfeeding at six months…. \textit{But the way I am in my house,} there is nothing [no food] that I can give him. So I just ignored the doctor. That is why I knew he had HIV.

\textsuperscript{146} The only exception was a father of an eight year old infected girl who insisted that her mother never had HIV, but that his daughter got HIV from him in the womb. This led me to suspect that his wife was either never tested for HIV or never disclosed her HIV status to him, even after their daughter started treatment.

\textsuperscript{147} Grace was born before nevirapine prophylaxis was available in Malawi.
Rita, mother of two year old Owen

Only one of the mothers I interviewed was able to stop breastfeeding at six months according to the national guidelines at that time, and her son died before he was two years old. Although there is obviously no way to verify their deductions, what is most important about them is that nearly everyone understood the biological mechanisms behind vertical transmission of HIV. It was clear from their accounts that they understood that HIV was a disease that infants could get from their mothers in utero, at birth and through breastfeeding. Most actually had an exaggerated sense of risk, and were usually surprised to find out that a child did not have HIV if they were infected themselves and failed to follow recommended practices. This suggests that public health efforts to educate mothers about PMTCT have mostly been successful and a lack of knowledge about pediatric HIV/AIDS is unlikely the reason behind treatment delays.

Although I was initially confused by statements like Thelma’s, which linked the fact that they “over breastfed” with their husband’s sexual behaviour outside marriage, I soon realized that while nearly everyone understood how vertical transmission worked, their behaviour, or the behaviour of others explained why their son or daughter was infected. All of the TMGs I talked to asked themselves a version of the question that the Azande of Sudan have asked anthropologists for generations (Evans Pritchard 1937). Why did their child get this disease at this time? Alongside their descriptions of the moment they suspected the virus passed from their body to their child’s were also descriptions of the economic and social conditions that made vertical transmission almost impossible to prevent. Rita and Lucy could not stop breastfeeding because there was no food at home; Brenda went on to explain that they did not own a bicycle and could not afford to have a car take them to the hospital in the middle of the night, which is 15km away from their village. For Thelma, she breastfed longer than recommended because her husband was spending time, and therefore money, that could have been used for food on another woman. Rita and Lucy also felt that their relationships with others, such as the authority of husbands and grandparents, superseded their concerns. While I have already discussed in the relationship between health care decision making and gendered and intergenerational household

148 The causes of his death was unknown, although from her explanation it sounded like he died of dehydration; since the formula was so expensive she had been diluting it to 1/3 of the recommended dose. This is one of the reasons that rapid weaning at six months is no longer promoted as part of PMTCT programmes. The national guidelines now encourage women to breastfeed exclusively for the first six months, then breastfeed until one year and then wean.
dynamics in Chapter Two, what I want to highlight here is that relationships people felt they should be able to rely on, such as with husbands or in-laws, were too faulty or poor to be reliable. Many expressed these concerns by prefacing their explanations by reference to “the way we stay at home,” which, upon further explanation, meant social discord or economic instability. In that sense, despite a good understanding of the biological mechanisms behind HIV/AIDS infection, for them “failed sociality” was the root cause of each infection and these concerns are central to understanding treatment delays in children.

The reasons behind these unreliable relationships varied greatly in each case. Most of the primary caregivers raising children on ART were either single mothers living with their maternal kin, either due to divorce or the death of their husbands, or elderly grandparents, which limited their access to resources for their children substantially. For example, one mother explained that she continued to breastfeed because her in-laws lived in Mozambique; therefore, geographical distance made it impossible for them to “help find good food as they did when [she] lived with them before [her] husband died.” For others, in-laws or grandparents, often a major source of social support, were already dead or too old to offer any substantive support. In many cases, the “lobola”, had never been paid or not paid in full, making it unclear who was ultimately responsible for the care of the child (see for example Roalkvam 2005). In a few cases caregivers did mention that “poverty” (mpawi) was the cause of their suffering – this was especially true of tenant farmers. However, when I asked them to explain what “poverty” meant, most mentioned their inability to find cash, either from work or from members of their extended family, either because they were too poor themselves or unwilling, and therefore “too greedy.” Thus, from the perspective of the caretakers I spoke to, HIV infections were emblematic of a broader social and economic instability in their lives.

Pediatric HIV communicates polysemous messages about neglect and scarcity as well as about marital and household conflict. Thus, these messages invariably evoke moral values and sometimes unleash an intricate politics of blame. Many primary caregivers located “fault” for these infections in the failure of parents to meet their social obligations or social roles. For example:

\[149\] As Stadler (2003) and Dahl (2009) argue, more than two decades of HIV/AIDS prevention campaigns focused on individual behaviour change likely inform moral understandings of HIV transmission.
What happened is that he my son married Mathew and Paul’s mother. After they had the two boys, my son was coming home on his bicycle and he found their mother in the bush [having sex] with another man.

-Grandmother Esther, caring for two HIV positive grandsons

[Kiniwe’s] father snatched someone’s wife who was already looking very sick when my daughter was pregnant with this one [Kiniwe], so that is why I believed that this child also has to be sick.

- Grandmother Eleanor caring for six year old Kiniwe

Blame was not always directed at others. A few felt responsible for their child’s infections and identified their own moral failings as the ultimate cause of an infection. For example, one 18 year old mother with a two year old on treatment explained: “At that time [before I was pregnant] I was just moving around [sexually active with more than one partner]… Crossing over [behaving beyond the bounds of socially acceptable behaviour].” Thus, to say that a child has HIV signals to others that a mother may be suffering from a bad marriage, or mistreatment from her in-laws. It may also signal that she “crossed over” (wajumpikha) the bounds of socially acceptable behaviour. These signals, in turn, often lead to interference by family and the wider community. In one case, a husband was ordered by the courts to pay for his son’s formula after he took a second wife. In many cases, the early signs of pediatric HIV infection are indistinguishable from malnutrition; many reported that neighbours, landlords or extended family members brought them food or advised them on how to feed a baby properly. However, this inference is not always desirable. Grandmother Esther for example used her daughter-in-law’s alleged infidelity to take over custody of her grandsons.

The resentment or jealousy of others was also considered a factor in the transmission of HIV to others. In this context, it is very dangerous to accumulate more wealth than your extended family or to not “share” with them. As I discussed briefly above, witches are always blood relatives of the victim, since, as it was explained to me on numerous occasions, only two individuals who share the same blood can transmit diseases or misfortune to each other.150 For example, one young mother of a visibly malnourished one year old (later diagnosed with HIV)

150 There were many reasons foreigners were not vulnerable to witchcraft attacks. First, most Malawians thought everyone was rich in our countries, therefore there was no jealousy (the root of most witchcraft attacks). Also, since we did not have blood relatives in Malawi, we were by definition exempt.
noted sardonically to a group of older women instructing her how to feed her sick daughter: “Look at me! Maybe I am a witch…. I almost killed my own child.” The social pressure to share with family is so intense that nearly every tenant I spoke to cited fears about returning to their home villages with any wealth they accumulated while in Temwa. Landowners also took pains to either share any gains with relatives (often through informal labour practices for food or by paying school fees for example) or they took pains to hide obvious signs of prosperity from others. I noted that most witchcraft accusations about a child with HIV were in polygamous households; this was often because the husband often favoured one wife over the other, which often led to accusations of neglect and mistreatment. Thus, from the perspective of the TMGs I spoke to, children get HIV because the social relationships that shape their access to food and health care are faulty and unreliable, not because a virus is able to pass from one body to another. I explore the implications of this for treatment delays in children below.

“**You could tell just by looking at her**”: Social censure and the timing of ART initiation

Most caregivers started noticing signs of HIV infection when a child was less than 12 months old. Early symptoms were often common childhood illnesses, such as ear infections, fevers, coughs and diarrhea. In every case, caregivers sought out biomedical care early at Temwa Rural Hospital, most went repeatedly over a number of months and sometimes years. Typically, the primary caregiver was prescribed medicines to treat various co-infections, such as LA for malaria or antibiotics to treat a variety of skin, lung and diarrheal infections. As the child’s symptoms progressed, almost every primary caregiver I talked to noted that “medicines” were no longer working and that the child was “sick every time.” In many cases, hospital visits increased as the symptoms progressed; in some cases, children visited the hospital two or three times a month for frequent cases of malaria, diarrhea and coughs. Although it seems hard to believe, in only a handful of cases did a health care worker recommend an HIV test based on the child’s health records, a fact I take up in more detail in Chapter Four. After “some time” (between three months and 12 months on average) of frequent hospital visits, a consensus usually began to develop among the TMG (to varying degrees of certainty) that something more serious was going on. Often the constellation of symptoms were recognized as HIV, sometimes because the HIV status of the mother was known, but also because HIV is so widespread that
everyone was familiar with the typical trajectory for both adults and children: common illnesses that increase in frequency and severity, followed by sustained weight loss and, finally, death.

Treatment delays are particularly dangerous in children, since disease progression is much faster than in adults (Little et al. 2007). My findings, however, indicate that although caregivers often suspected that a child had HIV, it took months, and sometimes years, before they were brought to the hospital to start ART. Since I met nearly every child with HIV the day they were officially diagnosed, I asked each primary caregiver what worried them the most about their child’s health and why they chose that specific day to come to the clinic. In almost all of the cases, a desire to relieve the visible bodily or behavioural changes attributed to HIV was behind the decision to initiate treatment. As one mother said while pinching her own arm to show that there was no flesh left on her daughter’s body: “Her body was really finished, she was just so thin.” Another sister said of her brother: “His body was not ok, it was not good looking.” Just as Eleanor used the wound by the side of Ruth’s nose to convince her daughter to start Ruth on ART medications, almost very caregiver grew increasingly concerned about a child as their symptoms became more visible.

Visible signs of disease, such as swollen bellies, thin arms and legs, fuzzy hair, and wounds on the skin, all prompted some kind of interference from various members of the child’s TMG. Older female relatives in particular intervened in nearly every case. Rita, whose six year old daughter initiated treatment when she was four years old explained:

My ankhazi [father’s sister] saw how much she (Lisa) was sleeping... She knew something was wrong because her hair was turning brown on her head. She could also see that the child was losing weight so she brought me some likuni phala [fortified maize porridge], but they knew how I am in my body [HIV positive] so they were just advising me to go with her to the hospital for an HIV test.

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151 In nearly every case I knew the child started treatment the day they were tested for HIV. Tests rarely preceded treatment initiation by any length of time. This was due to a number of factors including the fact that disease progression was so fast in children that they were not eligible for testing until they were already sick; and few people took children for HIV tests unless they wanted them to start treatment. Thus, testing was considered by most caregivers a bureaucratic hurdle they had to cross to obtain treatment and not a diagnostic technology that revealed a disease that was only knowable this way.

152 Women have a special relationship with their ankhazi throughout life; usually she is the person that a woman goes to for advice about sex, childcare and marriage.
Another tenant whose two year old daughter developed a swollen belly, puffy face and orange hair was given soya beans and dried fish by her employer when he saw the child’s condition because he assumed that the child was malnourished.

Many others reported similar interference by friends and neighbours, but most did not like being the source of speculation and gossip in their communities. As Rita elaborated:

She was crying all of the time but her voice was not coming out.... We went to the hospital and a traditional healer, but none of the medicines were working. My mother was encouraging me to go for an HIV test but I guess I was just discouraged [felt like she was going to die].... You know when you have this disease people, they laugh at you.... They say “you are going to die soon,” so it’s better if you just stay quiet.

Although Rita’s mother encouraged her to go for an HIV test, Rita continued to delay, worried that people would find out that she herself had HIV. However, as time passed, and her daughter got visibly worse, she went for an HIV test: “My daughter was so thin, you could easily see that this one is very sick... Then “people” [just strangers passing by] could see her and were shouting at me so I came [to get a test]”. Therefore, while some delayed treatment initiation because they were afraid that other’s might “laugh at them,” the child’s visible symptoms often incurred so much social censure that it outweighed any social risk of unintentionally disclosing their HIV status to others.

Although one might be tempted to conclude that Rita’s reluctance stemmed from what many others have called HIV/AIDS stigma, I would argue that it was more complicated than that. Significantly, the health and well-being of children in Malawi is used to extrapolate information about the people caring for them. For instance, parents with a malnourished child are also often admonished by neighbours, relatives and health care workers if he or she has a sibling close in age; most Malawians feel that by getting pregnant early they risk the health of the older child who is usually still breastfeeding. In this case, it is not the malnutrition that is shameful but their irresponsible behaviour (see also Mabilia 2005). Since HIV/AIDS is a virus that children get from their parents, sometimes because they were unfaithful to their spouses, it evokes similar feelings of shame and guilt. As 18 year old Gift with an infant son on treatment reflected while in tears: “At first I was just feeling like there was no hope, that I had ruined his peace (mutendele)…. That he will blame me for giving him this disease [because she was sexually promiscuous]. But now, I see that he is happier. I am thinking that maybe there is a future for us.” “Peace” is a concept used by Malawians to refer to a state of harmonious social relations. A
person who has peace is not angry or resentful of others and is therefore unlikely to be a witch or to incur the resentment of others. Thus, while illness-related stigma exists, it does not stem from the disease itself but from the social conditions that led to infection in the first place (see Chapter Two for a more in-depth discussion about stigma).

The implications of this for the timing of treatment initiation are complicated. Most members of a child’s TMG felt very confident that ART could alleviate HIV/AIDS-related symptoms. This feeling was supported by anecdotal evidence and their initial experiences with the medicines. After a few weeks on treatment most children with HIV were significantly better, which relieved everyone involved in his or her care. During home visits I routinely asked: “what changes have you noticed since he/she started the medicines?” In almost every case, primary caregivers, usually the person responsible for administering the medicines twice-daily, noted visible changes in physical appearance and behaviour. Common reflections including comments on changes in body weight and appearance, such as “she is just getting fat” and “her skin is looking much better.” Most primary caregivers framed these improvements in terms of their ability to affect positive change in their social relationships with others and avoid social censure. ART allowed them to avoid a kind of social death by being able to re-enter their social worlds since treatment helped alleviate socially disruptive behaviour, such as excessive crying, or symptoms that led to social censure, like signs of malnutrition. As one mother noted: “Before I couldn’t go to church or to chat at friends’ houses because he was just crying all the time. But now I am free to go and chat.” Nearly every primary caregiver also felt intense relief that their children could also reenter social life. The most frequently cited benefit of treatment was that their children could now “play” and “chat” with their friends. Given that most members within TMGs recognized and valued the benefits that ART offers them and their children, why then is treatment so delayed?? And why do so few feel that treatment offers any viable long term solution for their children’s infections?

“What will happen to him when I die?” Failed Sociality and the Limits of Therapeutic Efficacy

Although almost everyone knew, from either ANC at the hospital or through radio broadcasts, that ART for children was now available, it was still relatively new during my research. Few people during my fieldwork had any direct experience with children on
Therefore, many primary caregivers like Eleanor had few concrete ideas about how well the medicines would work for children. As Rita explained one year after her six year old daughter started treatment: “At first I was very sad. I thought, ‘when will she leave me? [Die]’ But now I see that there is nothing she is complaining about. She is running a lot, she is playing... I think the medicines are good.” While many primary caregivers were very positive about the medicines’ ability to help children return to their social worlds, few had any long term expectations of the medicines even when they seemed to be working well.

The lack of direct experience with ART medicines for children was amplified by the secrecy surrounding ART for both adults and children. Unlike most medicinal treatments for common childhood illnesses, such as malaria, ART is taken in secret and rarely discussed with anyone outside of immediate family members. When asked: “who have you told that your child is taking the medicines,” everyone responded that only family members tasked with giving the medicines on a daily basis were told that the child was taking any medicines at all (see also Hejoaka 2009). Most of the children on treatment also had no idea what medicines they were taking or why. As Rita said laughingly of her daughter: “she thinks she's taking panado!” (I discuss HIV disclosure in more detail in Chapter Six). The following case study illustrates the lengths some primary caregivers will go to keep treatment secret from others:

Me: Who have you told that your son [three years old] is taking the medicines?

Miriam: Just my husband and the grandparents... His older brothers and sisters also know because sometimes they are giving him the medicines if I am away.

Me: How do you keep it from others? Maybe you have relatives visiting for a funeral, or your neighbours have come over to chat?

Miriam: We take the medicines in secret in the house, we don’t go outside. I hide the pills in my clothes so no one will find them.

Me: What about if someone sees you here at the hospital?

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153 Although most children did not have access to treatment a very small number did start treatment before the national roll-out in 2008, including one of the children from Temwa who had a relative that worked as a nurse at Mzuzu Central Hospital and obtained treatment for him in 2005 when she recognized the symptoms of pediatric HIV infection.
Miriam: When I’m coming to get the medicines, I just walk in the opposite direction until I find a road that doesn’t pass near my village so no one knows that I’m coming here (laughing).154

Another 12 year old girl on treatment noted that she thought for years that she was the only one in her family who was HIV positive until she found her mother’s ART pill bottles in the trash behind the house. Therefore, secrecy about HIV even exists between close family members, so treatment successes or failures are often unknown. The result of these concealment strategies is that few people have had any direct experience with ART for children, either within their own families or through observing others. Moreover, there were no support groups for caregivers with children living with HIV or any other forum for therapy management groups raising HIV positive children to discuss their experiences with others.

Despite the lack of direct experience with ART for children, many extrapolated from their own experiences on treatment or that of a close relative or friend to underscore their feelings about ART. While most felt positive about ARTs potential to help extend life, these feelings were tempered by the fact that everyone knew someone who had died while on treatment. For instance, Eleanor emphasized that her decision to start Kiniwe on treatment was based on her feeling that treatment delays and interruptions are dangerous. As she said: “she started the medicines again after some time… but it was just too late.” Miriam was also told by health care workers that her last born daughter, who was two years old when she started treatment, died after initiating treatment because she came late to get the medicines. As she said:

Our daughter was just vomiting all of the time with fever, chitkasa [swollen belly] and chingwenya [chronic diarrhea where the anus comes out] but we didn’t know it was HIV at that time… [Since she tested negative during ANC]. After some time [a year] the doctors saw in the health passport how many times we’d been to the hospital and so they sent us to get the medicines [ART], but they didn’t work because it [daughter’s condition] was already very serious.

154 Miriam went on to explain that although she went to these lengths to keep their HIV status secret, she also knew that nearly everyone in her village knew their status. She explained that this was because each village has a “village development committee” (VDC). VDCs are responsible for distributing government subsidies to vulnerable community members. Since a positive HIV status was often grounds to claim access to these resources, they had used it to obtain fertilizer coupons (others have called similar processes a form of “biological citizenship” see Petryna 2004, 2013). I discuss the idea of “secrecy” in more detail in Chapter Two.
Examples of delayed treatment initiation leading to death were occasionally cited as reasons to initiate treatment. For instance, Ruth, a grandmother caring for Robert, her three year old grandson with HIV, referred to her daughter’s successful ART as her motivation for seeking out treatment for her grandson: “You see, my eldest daughter also takes the same medicines, so I knew that taking him [her three year old grandson] for an HIV test was the best way for me to be taking care of him.”

Conversely, these deaths were also used to highlight the uncertainty surrounding successful ART in the long term. As Thelma stated emphatically, even after her son had been on treatment with few complications for more than three years: “I just think that maybe he will die, the way our friends die. Even the ones who are his age.” Doubts about the long term efficacy or ART medicines were reflected in questions about life expectancy and a general expectation that children would not survive to adulthood. Health care workers were also often asked about life expectancy, or as one put it:

Some parents think it’s a waste of time and resources. Why put [a child] on medicines if they won’t live until adulthood? Who is going to make sure they are taking the medicines every day? These are the kinds of doubts we face.

Therefore, despite enjoying the benefits of ART, most members of a child’s TMG did not expect treatment to extend their child’s life “beyond a few years.”

Primary caregivers framed these doubts in relation to their own poor health and their lack of resources, not just in material terms but also socially. Many felt that their own deaths, which they also felt were inevitable, would interfere with their child’s chances of surviving into adulthood. For example:

Lionel is just doing well, but the way I am in my body [HIV positive] I could die before he grows up. He can go and stay with my relatives [her mother’s brother’s family] but the way they stay [very poorly], I doubt they would be taking care of him the way he needs.

- Thelma, mother of nine year old Lionel on treatment

The time Joyce [six year old daughter on treatment] was born there was no problem, but I started having problems [her husband took another wife and divorced her], so as she has
been growing up I have been looking after her sickness alone. I have been admitted in the hospital twice, so it is something which is worrying me very much because her father is there and his relatives are there, but when Miriam is sick they are not helping me....

- Lydia, mother of six year Miriam on treatment

The problem [with treatment] is that I have been looking after her sickness alone. I have been admitted to the hospital twice, so it is something that is worrying me very much, because her father is there and his relatives are there but when Lisa is sick they are not helping me.

- Rita, mother of six year old Lisa

Many primary caregivers doubted that extended family networks would be able to look after their child in a way that ensured successful treatment adherence. Many like Thelma were realistic about the limited ability of their impoverished relatives to ensure that the children made it to the hospital each month to collect their medicines and that he or she was given “good food” which improved their effectiveness. Another concern for many was that if they died, “others” might marginalize their child after their death, preferring to divert scarce household resources to other children. By “others” they were referring to members of a child’s TMG, who emphasized their own household obligations to their own children or other sick relatives that they were also responsible for caring for. Thus, failed sociality was the main concern underpinning most primary caregivers’ concerns about their ability to ensure long term treatment adherence for HIV infected children.

**Conclusion**

In this chapter I have explored how the local ethnophysiologies and the signs and symptoms of HIV disease progression shape the timing of HIV treatment uptake, and ultimately treatment outcomes for infected children. I highlighted the ways that ART works on both “the body” and the social relationships that are often put at risk by the sight of a visibly ill child. Moreover, in real life, the efficacy of ART medicines is assessed not by scientists but by social actors who have their own criteria, expectations and personal experiences with ART medicines (Whyte et al. 2002). GHIs focused on reducing ART initiation delays and improving “therapeutic
efficiency” have largely focused on education campaigns, or improving ART adherence counselling techniques. These techniques emphasise the importance of life-long treatment adherence by reiterating that the pharmacological efficacy of ART improves under good living conditions. My findings indicate that a lack of understanding about the disease or the treatment itself is not a major factor limiting treatment uptake, although oral medications are not always considered appropriate for young infants in this context. Rather, primary caregivers in particular are worried about their ability to sustain the social and material conditions that improve pharmaceutical efficacy, which includes wider support of the child’s TMG.

Health policies and treatment protocols at Temwa Rural Hospital focus on entry into care by emphasizing the importance of routine antenatal testing and ART adherence counselling. This approach is at odds with the emphasis placed on long term treatment outcomes of ART by all members of a child’s TMG, who are more concerned with the quality of life possible for children living with HIV, given that most foresee problems maintaining the quality of care health care workers insist is necessary for the medicines to “work”. Many mothers and grandmothers in particular wondered if their children would ever be able to go to school, not just because they may not live that long, but it was hard for them to imagine others diverting valuable resources, like money for school fees, to a child who had a limited chance of survival. While GHIs focused on the ability of ART to relieve biomedical symptoms, primary caregivers emphasized the lack of social support and economic instability that characterized their lives. From their point of view the demands of ART, which requires a caregiver to visit a hospital every month, administer medicines every day and ensure good nutrition all at the same time, are not always achievable in this context. Caregivers intimately involved with the daily caretaking of an HIV-positive child were acutely aware of both the persistent and periodic crises that impact treatment efficacy, including the dangers of co-infections, toxic side effects from treatment, chronic food insecurity and death. Moreover, government run pediatric HIV care and treatment services in Malawi do not provide any additional social and economic support for TMGs supporting children with HIV, thus making it hard for TMGs to imagine overcoming their various challenges for years to come. However, ART programmes measure success by enrollment rates; very little attention is paid to the fact that few adults and children remain alive and on treatment after five years. This is very much at odds with how TMGs imagine or experience the challenges associated with ensuring a child survives into adulthood. While TMGs value the pharmacological efficacy of ART and are
thrilled when these children recover and return to their social lives, the broader social and economic conditions of their lives, their “social suffering”, will continue to undermine “therapeutic efficacy.”
Chapter 4: “It has to say Stage 3 in her passport”: The Bureaucratic Gaze at Temwa Rural Hospital

Temwa Rural Hospital’s HIV care and treatment services occupied one half of a large rectangular brick building. Health Surveillance Assistants (HSAs) offered free testing, counselling and distributed free ARVs every Tuesday and Thursday at the “ART clinic”. These services occupied three small rooms connected to each other in tandem. Since these rooms were only used by people with HIV, the comings and goings of each patient made their HIV status clear to anyone passing by. The first room on the South side of the building was used to test patients for HIV (HIV Testing and Counselling or HTC). The HTC room had two doors; one led outside to the busy hospital courtyard and the other opened into a second room. The second room was used by Nurse M to give patients their medicines each month. It was connected to the third room, the “ART clinic waiting room,” through a second narrow door. The ART clinic waiting room, or the third room in this line, was where patients gathered every Tuesday and Thursday morning to collect their “ART patient master cards.” Unlike health passports, which are health records kept by patients and brought to the hospital on each visit, ART master cards are kept at the hospital.

I sat in on the ART clinic every Tuesday and Thursday. Usually I sat on a long bench with the patients as they waited to collect their master cards. Most days at least a dozen men and even more women and children sat on the floor and spilled out the door into the yard outside. We all waited for Mr. G, the senior HSA in charge of the clinic, to arrive. As was often the case, the day got off to a slow start. Mr. G, a reliable and well liked man, arrived on time but he had to go and search for another senior HSA to find the key to the storeroom where the medicines were kept; rumours abounded that the medicines were being used to feed chickens or brew kachasu [cane liquor].155 After the key was found it was another hour before Nurse M, the only person with the authority to physically hand the medicines to patients, could get away from the

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155 Everyone I talked to insisted that some patients or health care workers sold ARVs for this purpose. I was told on numerous occasions that the medicines helped chickens grow fat and made alcohol very powerful. The idea was so pervasive that even President Bingu wa Mutharika made a public announcement urging everyone to avoid such practices.
maternity ward where another nurse was coping alone with four women in labour in the other half of the building. While we waited for Nurse M to arrive, patients grumbled about the delays. As one mother asked: “How can we be helped, when they come very late and we suffer from hunger?”

Meanwhile, Mr. G sorted through hundreds of ART patient cards laid out across a wide desk in piles at least a foot high. These cards kept a record of pertinent details regarding the patient’s health and treatment adherence: side effects, weight loss or gain, treatment regimen, health status at the time of initiation and the dates of each visit to the clinic. The primary aim of these cards is to monitor ART adherence: failing to adhere to the treatment regimen was not only dangerous to the patient, but to the entire national treatment programme since non-adherence increases the pace of treatment resistance, which could force the government to buy pricey second and third line treatment regimens (Barninghausen et al. 2011).

As was his habit, Mr. G distributed the patient cards (see Figure 15) starting to his right and slowly making his way around the room. Patients called out their names and village in front of the group - “Jane Gondwe, Madimba village,” and when found, the cards were passed around the circle until they reached the correct patient. Older men sometimes cut the line by approaching Mr. G’s desk to avoid the long wait. A few from far away collected the patient cards (and medicines) of friends and neighbours so not everyone had to make the long journey to the hospital. Throughout this process, Mr. G engaged the patients in friendly banter and answered their concerns with encouragement and humour. “How do we find good food?” someone asked, and he responded: “It is a struggle, but God knows (chiuta pera).” Unable to provide a medical solution to the lack of food, Mr. G offered a common reassurance about the nature of suffering and the means of salvation through God.

Mr. G, also recruited HIV positive children on my behalf and on this particular day he introduced me to a 29-year old mother named Jenny and her 11 month old “HIV exposed” daughter Mercy. “HIV exposed” is a term used to refer to infants and children who may have
contracted HIV during birth or who are at risk of getting HIV from their mother through breastfeeding, but their HIV status is still unknown.\textsuperscript{156} After Mr. G introduced us, he explained the purpose of my research and encouraged her to talk with me. She agreed and with her permission, I followed them into the adjoining room when it was her turn to collect her medicines.

I stood at the back while she sat on the Coca-Cola crate across from Nurse M who sat behind a simple wooden desk in the gloomy, unlit room. Her uniform was always crisp and bright white. Her nurses’ hat was perched jauntily on top of an eyebrow-raising weave, a short bob made out of black plastic threads that almost resembled real hair. Without a word exchanged between them, Jenny passed Nurse M her ART patient card and waited patiently while she looked over her records (see Figure 17). Nurse M wrote the date of the visit on the card, and quickly filled the rest out with answers to a few brief questions: How much do you weigh? Did you miss any pills? Jenny shook her head and added a curt “no” to all of her questions to indicate all was fine. Nurse M told her the date of her next appointment and then placed her card on the desk, which Jenny would pick up again the following month from Mr. G. Nurse M then leaned down and passed her a month’s worth of medicines from a cardboard box on the floor. The pills were in small plastic bags divided into monthly prescriptions. Jenny said “thank you” and put her pills into an old plastic sugar bag before wrapping them up into the fabric of her \textit{chitenje} [two metre piece of fabric worn as a skirt and tied at the waist]. After, we exited through the second door that led directly into the HTC room.

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{ART_patient_card_anonymized.png}
\caption{ART Patient Master Card (Anonymized)}
\end{figure}

\textsuperscript{156} As I have mentioned elsewhere, rapid antibody tests are not considered effective at detecting HIV in infants less than 18 months old.
The HTC room was where I spent most of my time, either recruiting new patients like Jenny or catching up with old ones after they collected their medicines. Like the patients themselves, it took me a few weeks to figure out where patients should go and at what stage they qualified for treatment. Jenny explained her journey through this process to me while Mercy sat on her lap quietly munching a *mandazi* (donut) that I gave her.\(^{157}\) Jenny’s description of how she came to know she had HIV, and how her daughter might get it, was typical of the stories I heard from mothers with HIV exposed infants and reflected national HIV treatment guidelines and standardized hospital procedures guiding the diagnosis and treatment of children throughout Malawi, at decentralized HIV treatment centres, at rural hospitals and health centres.

Like many of the women I talked to, Jenny tested positive for HIV when she was pregnant with Mercy, as part of routine, provider-initiated HIV testing available to all pregnant women in Malawi.\(^{158}\) Since Temwa did not have any laboratory technologies capable of determining viral loads or CD4 counts, which are used at district hospitals to determine the timing of treatment initiation, she was evaluated by a clinical officer (CO) in the outpatient department. At rural hospitals, COs used a clinical algorithm developed by the WHO to determine a patient’s “stage” on a scale of 1-4, with stage four indicating the most advanced signs of infection. During my research both adults and children in stage three or four could start treatment; those in stage 1 or 2 had to wait until they got “sick enough” to start.\(^{159}\)

To determine Jenny’s “stage,” Mr. N, the only permanent CO on staff at Temwa, examined her in the outpatient department (OPD) in a second rectangular building a few feet away. A CO is a mid-level health care professional trained in the biomedical model and licensed to practice the full scope of medicine and provide routine care outside of a nurses’ scope (Nyirenda and Flikke 2013). At Temwa Mr. N mainly performed general medical duties at the out-patient department (OPD) such as diagnosis and treatment of disease and injury, ordering and interpreting medical tests (such as malaria tests) and he performed routine medical procedures. He was also the only staff member at Temwa who could refer patients to the district

\(^{157}\) I gave snacks to every participant I interviewed at the hospital since most had travelled long distances and waited for hours at the hospital to get their medicines and few had the money to purchase food in town.

\(^{158}\) From 2006-2008 Malawi introduced routine HIV testing during antenatal care. HIV testing rates during pregnancy increased by 46%, from 52% to near universal testing at 98% (Kasenga et al. 2008).

\(^{159}\) Changes to Malawi’s national treatment guidelines in 2013 means that children under two now initiate treatment as soon as they are diagnosed.
hospital. During my research, Mr. N was the only health care worker at Temwa trained to identify children with HIV and to stage patients after a positive diagnosis.

Jenny’s description of her clinical encounter with Mr. N sounded very similar to my observations. She explained how he asked her a few simple questions about her symptoms, such as: “Do you have diarrhea?” “Have you lost weight?” “What about a cough?” She told him yes, yes and yes. A brief glance through her health passport also indicated that she’d been admitted for severe pneumonia the month before. Mr. N, interpreted her narrative and decided that she was “Stage 3,” which made her eligible for treatment. When I asked Jenny to explain in her own words how she felt the day she started treatment, she said she that it felt “like her stomach was collapsing in on itself” and that she was “sick to the point of death.”

As a Stage 3 patient, Jenny was told to see Mr. G at the ART clinic the following Tuesday for “adherence counselling.” Jenny did as requested. The following week she met Mr. G, who also did group ART adherence counselling for new patients, which was designed to remind patients of the importance of taking the medicines everyday for the rest of their lives (see also Mattes 2013). Afterwards, she was given her first monthly dose of ART. Within a few months, Jenny noticed a great change in her body, and the day we met she reported that she was able to “work very well.” As part of Malawi’s national prevention of mother to child treatment programme (PMTCT), Jenny was also told how to prevent her baby from getting HIV. She reiterated that during adherence counselling Mr. G told her to deliver her baby at the hospital so she could receive “drops” (mothers rarely knew the name of the medicine, but they meant nevirapine) during labour (which she did) and to stop breastfeeding when the baby was six months old (she was still breastfeeding the day we met) and that she was advised to bring Mercy for an HIV test when she was 18 months old (which she intended to do).

At 11 months old Mercy was already showing likely signs and symptoms of advanced pediatric HIV infection: chronic coughing, persistent fever and severe malnutrition. While it might seem obvious that she was HIV positive, these symptoms were common enough in uninfected children that without a more HIV-specific symptom, such as oral thrush, or an HIV test, it was impossible to know for sure whether she was positive or not. On the day we met for the first time, Jenny was visibly upset about Mercy’s health. She looked down sadly at the top of her daughter’s head and explained: “All [6] of my other children are already dead. This one is the only one left, and the way she looks… I don’t know if she can make it [survive].”
Jenny explained that her older children all died before 2008, or before children were eligible for ART in Malawi. These painful losses motivated Jenny to seek treatment for Mercy as soon as she started falling sick. However, at only 11 months old, Jenny was told that Mercy was “too young” for a test and that she should return when Mercy was 18 months old. In the interim, Jenny pursued every treatment avenue possible for her daughter. Jenny visited Mr. N in the out-patient-department (OPD) multiple times; each time Mercy was prescribed various antibiotics and mild painkillers for coughs, fevers, diarrhea and malnutrition.

Despite these regular visits, “Mercy would get a little bit better for a few days, then fall sick again.” More recently Jenny noted that Mercy was failing to eat and had lost a lot of weight. At this point Jenny removed Mercy’s hat to show me how her daughter’s hair had turned white. When I realized how malnourished Mercy was I immediately halted the interview and called in one of the HSAs to evaluate her. At my insistence Mr. J, one of the more experienced HSAs, weighed Mercy and reported that she only weighed 5kgs at 11 months – or almost half the weight of the average infant her age. Mr. J also took a “MUAC” measurement of Mercy’s arm circumference, which clearly showed that Mercy was “severely” malnourished. Based on these measurements, Mr. J advised Jenny to visit the hospital on the first Friday of the following month. There he told her Mercy could be enrolled into a food supplementation programme run by UNICEF. He added that Jenny must take Mercy at the beginning of the month since the hospital usually ran out of supplies by the second week. Jenny seemed hopeful at this new information and said she would do her best to make it. We asked her to come and find us the next time she was at the hospital, but we never saw her, or Mercy, again.

Jenny and Mercy’s treatment trajectory exemplified national pediatric HIV treatment policies in practice. For global health policy makers PMTCT programs are the ideal “entry point” into HIV care and treatment for infants and children. As I discussed in Chapter Three, the

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160 The national treatment guidelines say that a child cannot be tested for HIV until they are 18 months old; however the pediatric guidelines say that an infant can be tested as early as nine months and then classified “exposed” and put on antibiotics if they test positive. However, all of the health care workers I knew and observed only ever tested children for HIV at 18 months and classified all children younger than that with HIV positive mothers as “exposed”.

161 It was never my intention to interview mothers with HIV exposed infants but patients complained that I was talking to their ‘friends’ and not them so I decided to include them. However, I did not do home visits with them due to time constraints so therefore I did not have permission to follow up with Jenny at her home to know for sure what happened to them.
rationale behind this approach is that routine antenatal testing enables caregivers and health care workers alike to identify and treat children with HIV early, since HIV disease progression is much faster in children than in adults (Fassinou et al. 2004). In line with national guidelines, Jenny, like nearly all women in Malawi, was given an HIV test while pregnant with her daughter Mercy (Manzi et al. 2005). After she tested positive she was counselled on how to help prevent her child from getting HIV. Based on this information she gave birth at the hospital, but, like almost every woman I talked to, she did not stop breastfeeding at six months because of a lack of food at home. Jenny was also told that there were treatment options for children. As a result, she intended to have Mercy tested as soon as she was 18 months old. She felt strongly that the medicines would be the best way to help her daughter since they were also working well for her. While she waited for the test, Jenny always brought Mercy to the hospital when she fell sick and was prescribed various medicines. From Jenny’s account it seems clear that health care workers carefully followed Malawi’s national treatment guidelines. Yet, Mercy’s health concerns were left unresolved. In fact, it is likely that Mercy, like most children with HIV in Malawi up to this day, died before she was eligible for treatment.

My aim in this chapter is to explore this paradox: I focus on the contradictions between a declared global commitment to help children with HIV, on the one hand, and, on the other, the bureaucratic need to certify that each child is eligible for treatment. With HIV treatment “scale up” came major logistical and technical challenges for rural hospitals like Temwa. Roll out of free ART to decentralized treatment centres in Malawi necessitated a shift from physician-intensive care to care carried out by lower-level community health care workers, officially named “Health Surveillance Assistants” (HSAs) in Malawi. As non-medically trained personnel became responsible for “administering the epidemic,” national treatment guidelines and hospital procedures focused on standardized diagnostic and treatment protocols to facilitate the “technocratic shuttling of drugs into bodies” (Kenworthy and Parker 2014: 1). Standardized national treatment guidelines were ostensibly put in place to ensure good health outcomes for patients by reducing arbitrary or idiosyncratic practices, preventing mistakes and to enable comparisons across time and space (MOH 2007; Timmermans and Berg 1997). In that sense, task-shifting arrangements and standardized treatment guidelines operate jointly as a kind of prosthetic – a replacement for the missing physician’s care (Brodwin 2010; Hull 2012: 259).

162 The cost of formula was prohibitive for nearly every woman I spoke to; nearly 40$CAD/month during my fieldwork.
While these strategies have substantially increased the number of patients on treatment by moving large numbers of patients through the clinic-machine like an assembly line – quickly and efficiently – I argue that this does not always translate into good health outcomes for individuals.

Malawi’s national treatment guidelines were developed by a team of health experts at the World Health Organisation (WHO) in Geneva and adopted by Malawi’s Ministry of Health with few adaptations (Hunsmann 2013; Okuonzi and MacRae 1997). These guidelines are what Hull might call a form of bureaucratic rule, or “rule by writing desk,” since the clinical judgement of health care professionals has been displaced in favour of the strict application of scientific knowledge or “best practices” (2006: 252; Lambert 2006; Smith 2003; Swinglehurst et al. 2012; Williams and Garner 2002). To analyse how these guidelines operate at Temwa I draw on Foucault’s (1994) concept of the “the gaze.” Foucault (1994) developed the idea of “the gaze” in *The Birth of the Clinic* to argue that new developments in medical sciences since the 18th century, such as autopsies and imaging technologies, have altered how we understand and treat illnesses. He posits that these new biomedical innovations have resulted in the transformation of patients from social beings embedded within their communities, into an assemblage of diseased organs that need to be fixed. For example, Foucault argues that over time doctors began to ask their patients “where does it hurt?” rather than “what is wrong with you?” (1994 [1963]: xviii) since it was no longer necessary for physicians to listen to patients describe their illness experience to diagnose and treat. Thus the gaze often encourages health care workers to focus solely on the biological symptoms of disease, which deflects attention away “from the social arrangements and political forces that contribute to the incidence of distress and disease” (Lock 2001: 481). By using the concept of the gaze to understand clinical encounters at Temwa I aim to draw our attention to the ways that a focus on the “natural” or physiological symptoms of pediatric HIV infection undermines health outcomes for children infected with HIV by leading to missed opportunities for early diagnosis and timely treatment initiation.

In this chapter I draw on and build on the concept of the gaze by investigating Temwa hospital as a medical space where the gaze operates from afar, or as a kind of “bureaucratic gaze”. In other words, the gaze at Temwa is enacted through the bureaucrat’s eyes via the deployment of testing and treatment guidelines, clinical algorithms and patient charts developed

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in Geneva. Temwa Rural Hospital is also a medical space far different from the one imagined by Foucault when he developed the concept of the gaze. Most of the face-to-face medical care is done by the lowest cadre of health care worker; standardized guidelines developed in Geneva regulate hospital praxis, and the hospital lacks nearly all of the specialized technologies that allow physicians in other contexts to “see into” the body, including simple laboratory tests such as bloodwork. Thus, in this chapter I ask the following questions: How does the gaze in this context differ from that described by Foucault? How do lower cadre health care workers enact the gaze at Temwa? How do the characteristics of the gaze in pediatric HIV treatment programs result in barriers to care? I conclude that the “bureaucratic gaze” at Temwa has profound exclusionary consequences. I found that the symptom checklists and clinical algorithms meant to reduce errors and manage risk were often transformed into barriers limiting early uptake of ART for children. More specifically, they undermine the ability of health care workers to deliver more nuanced and patient-centered care at Temwa by limiting their ability to respond to their patient’s suffering, and to prevent deaths that they knew were highly likely.

This chapter is divided into three broad sections. First I focus on the deployment of Malawi’s national treatment guidelines within the clinical encounter. Most researchers have found that the gaze operates during clinical encounters through specialized ways of “seeing,” “writing” and “speaking” about their patients (Good 1995; Lock 1993; Reventlow et al. 2006; Rose 2007; Smith 2003). For example, Davenport demonstrates that the gaze dominated teaching messages in US medical schools; medical students were routinely taught to write down and elicit patient histories in a way that focused on the most concrete and immediate physical problems (i.e. blood work results) while excluding social histories (2000:321). While Temwa did not have access to any of the biomedical technologies found in other clinical contexts, COs do make notations in health passports about patients symptoms, conduct physical exams, and elicit patient histories. In these encounters the gaze operating at Temwa works much the same way as described by Foucault by focusing on physiological symptoms of diseased bodies. A major difference however is that an individual CO’s interpretation of a child’s symptoms is subordinate to the authority of checklists and algorithms developed elsewhere. Second, I follow the bureaucratic paper trails for certifying that patients are eligible for treatment. I illustrate how standardized protocols operate from afar by limiting treatment options for sick children and introducing unnecessary bureaucratic hurdles that undermine global health efforts to ensure
universal access to ART for children. Rather than relying on biotechnologies to “see into” the body to discover hidden pathology, this kind of “bureaucratic gaze” relies on standardized forms and procedures to help reveal the hidden diseases within. However, my findings indicate that standardized guidelines cannot “stand in” for the missing physician’s care or the biotechnologies that make medicine so effective in many other settings. In fact, my findings suggest that these technologies end up excluding many of the most vulnerable children from care.

Finally, in the last section of this chapter I emphasize the perspectives and motivations of health care workers at Temwa who must actualize Malawi’s pediatric HIV treatment programme without the basic necessities most health care workers take for granted (like running water) and in a context of acute health care worker shortages. I found that among HSAs, the lowest cadre of health care worker in Malawi with little to no formal training, there was a struggle to maintain a balance between following national guidelines, while simultaneously meeting the complicated health and emotional needs of their patients, who also happened to be their neighbours, friends and family members. As intermediaries between patients, their superiors, government oversight, and myself, on occasion, HSAs were often faced with social and moral quandaries not accounted for in standardized treatment guidelines (Agnotti 2010; Kyandoddo and White 2009; Standing and Chowdury 2008). To explore these quandaries I conclude with a discussion of Byron Good’s assertion that moral concerns suffuse medical care and occasionally irrupt and breakdown standardized practices (1998: 84-85). As he and others point out, hospitals are also sites of human suffering, fear, pain, loneliness, laughter and death (Garcia 2010; Livingston 2012). Hospitals are spaces where different kinds of “care” that go beyond the purely physiological needs of their patients are offered (Brown 2012).

Numerous ethnographic studies support the argument that the practice of “biomedicine” is much more socially produced than studies of the Gaze might reveal. For example, adherence to standardized protocols varies substantially between individual practitioners, different institutions, and countries, even when standardized guidelines are in place (De Jong et al. 2010; Payer 1989). Research also shows that physicians make decisions about which patients they will devote their time and energies to based on their personal evaluations of what makes a “worthy” patient (Higashi et al. 2013) to protect their own reputations or material concerns (Trostle 1996), or according to the physician’s own clinical judgements and experience (Livingston 2013; Smith 2003; Timmermans and Berg 1997). In South Africa, for example, researchers found that nurses
avoided checking children for HIV in routine settings since they felt it was unnecessary and that they did not have enough training to do so effectively (Horwood et al. 2010). However, HSAs, who are responsible for most of the face-to-face care with patients at rural hospitals, and health centres, are far different than the medical personnel imagined by Foucault. Rather than highly trained medical specialists, they are essentially cheap front-line clinicians or simple drug distributors (Campbell and Scott 2011; Druetz et al. 2015). Thus, my findings indicate that task-shifting in general prevents individualized responses to patient needs, and that techno-bureaucratic procedures in this setting undermine the ability of health care workers to apply practical or ethical judgement in cases not accounted for in standardized guidelines (Greenhalgh et al. 2014). For example, while Mr. J followed national treatment guidelines at Temwa by sending Mercy home because she was not yet eligible for treatment, he did so knowing that she would likely die as a result – or in his own words “not make it.” I conclude by reiterating a key finding that pediatric HIV treatment programs, which were formulated in distant settings with little knowledge about the realities of their target audiences, ultimately exclude large numbers of the very children they are trying to treat.

This chapter draws on participant observation at relevant “entry points” into HIV treatment and care for infected children identified in Malawi’s national treatment guidelines. These entry points include the out-patient department (OPD), the ART clinic, antenatal clinic, under-five children’s clinics, mobile clinics, village inspections and home visits conducted by HSAs. According to the national guidelines, all of these routine settings are realms where children infected with HIV should be checked for HIV-related symptoms and directed towards ART services using the clinical algorithms developed by the WHO. However, as I point out, in practice these options are foreclosed by the lack of training among health care workers and rigid guidelines that undermine alternative entry points into care. Semi-structured interviews and informal conversations with a dozen professional and non-professional health care workers at Temwa complement these observations. Unlike most of the chapters in my dissertation, this chapter relies less on the accounts of patients and more on twice-weekly observations of the clinical encounter.

**Best Practices/Worst Outcomes: The Bureaucratic Gaze at Temwa**
Many scholars have taken up the idea of the Gaze to fruitfully analyse “how social life and social problems have become more and more ‘medicalised’, or viewed through the prism of scientific medicine as ‘diseases’” (Lupton 1997: 95). Many scholars argue that the process of “medicalisation” is problematic for marginalized groups in particular since it often deflects questions of social inequality into the realm of illness and disease, where they are then treated with inappropriate medical therapies, especially pharmaceuticals. Some of the examples of how the Gaze results in unnecessary or problematic biomedical interventions are extreme. For example, Scheper-Hughes (1992) noticed that rather than addressing the root causes of poverty in Brazil, malnourished children were sedated with mild analgesics by prescribing physicians. More recently, Holmes also argues that the “acontextual clinical gaze” is the primary barrier to effective health care for undocumented Mexican migrants in the US because it excludes any consideration of the social, political or economic etiology of sicknesses (2012: 879-880). Holmes illustrates how the Gaze transforms higher rates of dental cavities among undocumented Mexican migrants into imagined genetic differences between them and Euro-Americans rather than the lack of dental care for marginalized populations. In other words, within the framework of the Gaze, illness derives from a patient’s biology or behaviour and not from the conditions that produce the illness in the first place – such as toxic exposure to pesticides, unsafe working conditions, and poor health care. In this way the Gaze focuses attention on the biology, culture or behaviour of the patient, rather than on any larger structural issues that surround that patient (Jenks 2011; Shaw and Armin 2011). It is a kind of detective work that is more interested in symptoms than causes. The end result is that that Gaze can exacerbate social inequalities by focusing our attention on biomedical interventions rather than larger social and political movements that might improve health overall (Briggs 2003; Fassin 2007; Hamdy 2008; Kleinman et al. 2007; Nguyen and Preschard 2003; Scheper-Hughes 2000).

I draw on and build on the concept of the Gaze as a medicalizing force with potentially detrimental side effects by investigating Temwa Rural Hospital as a place where the Gaze operates “from afar.” The migration of the Gaze out of the clinic to offices in Geneva occupied by “health experts” and “policy makers” reflects a broader transition in clinical medicine and health policy and practice that bases hospital praxis on population based statistical measures and scientific evidence (AbouZahr and Boerma 2005; Carr 2010; Erikson 2012; Glasziou et al. 2013; Storeng 2014). As Lambert and others argue, GHIs and governments worldwide are increasingly
relying on “evidence based approaches to medicine” (EBM) or “best practices” to formulate cross-national health policies and guidelines (2006: 2614; Dobrow et al. 2004; Greenhalgh et al. 2014; Niessen et al. 2000). The national treatment guidelines, clinical algorithms and checklists that were derived from the WHO’s meetings in Geneva set the parameters for what is considered “competent practice” at Temwa. Many of the experts who designed Malawi’s national treatment guidelines are trained physicians from elite institutions (WHO 2006). While nearly all of the everyday care at Temwa is administered by HSAs with little or no medical training, hospital procedures and policies regulating practice at Temwa reflect the basic assumption of the Gaze that the etiology of all diseases can be located inside the body (Lupton 1997: 98-100). Thus, although the Gaze is now one step removed, it has a profound influence on how patients with HIV are identified and monitored.

While there are benefits to an evidence based approach to health policy and practice (see Lambert 2006 for a review), a central argument of this chapter is that transnational treatment guidelines exclude the most vulnerable populations and exacerbate social inequalities. Ian Harper (2005) illustrated the negative consequences of relying on globalized statistical data on tuberculosis to formulate treatment procedures in Nepal. He found that statistical rendering “unintentionally, yet paradoxically den[ied] significant numbers of people who have TB access to treatment” (2005:144). He demonstrates this process through a single case study of a woman diagnosed with TB and her failed attempt to gain entry into a national treatment program. Devi was never able to get treatment because she did not fit into the strict globalised category of a “new smear positive patient,” since her smear test occurred before the official cut-off date and could not be verified. Although clinically it was clear that the medicines were helping her (she gained weight, had fewer coughing fits), the final authority rested with transnational treatment guidelines designed to prevent multi-drug resistance TB and she was denied treatment. Mercy above was also excluded from treatment because she was not eligible for treatment according to standardized disease categories, although it seemed clear to her mother, health care workers and myself that she would die without medical intervention.

Although it is beyond the scope of this chapter, it should be clear that even among health experts there is a good deal of controversy and debate about the WHO’s “evidence based guidelines”. As Van der Perre et al. (2013) recently stated: “Since the early 1990s guidelines on preventing mother to child transmission of HIV have dangerously shifted from recommendations supported by strong scientific evidence, to recommendations based on experts’ best guesses and extrapolations followed by field evaluation, and then to recommendations proposed on the ground of theoretical modelling and ideological principles with limited possibilities for validation or refutation” (2013: 3763). See also Nguyen (2013) for a discussion on “experimentality” in global ART roll out.
Transnational treatment guidelines, which are a product of the Gaze, also obfuscate the role that social institutions, which may be in place to alleviate suffering, such as hospitals or NGOs, can play at aggravating social inequalities. For example, Pfeiffer (2004) demonstrates how the NGO model of technical assistance provision intensified social inequalities in Mozambique by eroding the quality of the primary health care system serving the poor (see also Ferguson 1994; Kalafonos 2010). Hunsmann (2012) also illustrates how HIV/AIDS prevention policies in Tanzania rarely address the well-documented “structural factors” that facilitate new HIV infections, such as poor nutrition or parasitic infections, preferring to focus instead on changing the sexual behaviour of individuals. Others have also found that the formulation and application of formulaic procedures (clinical guidelines, algorithms, and protocols) erode the quality of patient care (Berg et al. 2003; Lambert 2006; Smith 2003; Swinglehurst et al. 2012). My findings contribute to a growing recognition that bureaucratic hurdles meant to monitor treatment adherence and improve health outcomes for patients with HIV often impede timely diagnoses and treatment.

The concept of the Gaze, as conceptualized by Foucault, depends on the presence of highly trained expert practitioners in clinical encounters. These trained medical personnel are taught how to “gaze” properly over time, either in training or through apprenticeship: it is as Good points out, a medium of perception, experience and mode of engaging with patients (1998: 86). Research on the Gaze over the last 60 years has mostly focused on the training and socialization of medical professionals at elite institutions in Europe or North America. Their findings support the general idea that as medical professionals become more competent (i.e. better gazers), they simultaneously become more emotionally detached, and that over time they increasingly value routinized procedures, biotechnological interventions and their authority to persuade patients that certain ways of behaving and thinking are appropriate for them (Conrad 1985; Becker 1961). Good and Good (1995), for example, argue that years of training teach medical students how to see and understand the body in a particular way – or as a set of interlocking functional organ systems. Medical training in particular encourages physicians-in-training to focus on the “hard sciences”, such as anatomy, histology and radiology, which they learn over time as the “most important stuff you have to learn” (1995: 93) The Goods argue that this process results in “competent” rather than “caring” physicians, which means that at the end of their training physicians are less interested in the person as a social being, and more interested
in the physiological aspects of disease. Prentice (2013) argues that in some ways this process is becoming even more extreme, with surgical students practicing their new skills on virtual, rather than human, patients. In the surgical context, technique and accuracy becomes more important than caring, empathy or even morality. Davenport (2000), however, argues that the situation is not so bleak. She illustrates how physicians often push back against the dehumanizing aspects of biomedicine and are concerned with finding ways of treating their patients holistically. Her research shows that medical students at a clinic for homeless people in California developed the concept of “witnessing” to try and maintain “a respectful focus on the entirety of a person’s life situation, not merely their ailment” (Davenport 2000: 316). Despite their efforts, however, the legal and technical exigencies of their jobs, such as filling out patient charts accurately and efficiently, often subsumed their efforts to maintain the humanism of their patients over time.

But how much can we generalize about the effects of the Gaze on the clinical encounter when most of these findings are derived from research with biomedically trained physicians in Europe and North America? How does Foucault’s notion of the Gaze operate when not only does the socio-economic context and clinical training differ from the Euro-American setting, but also the actual medical personnel differ dramatically from Foucault’s imagined doctor? How do HSAs “gaze” at their patients in Malawi and how does this delimit the imagined interventions for children presenting at the hospital with HIV related symptoms? There is very little research on the impact of the gaze on clinical encounters in non-Western settings. An exception is Wendland’s (2010) research with medical students at Malawi’s college of medicine. She found that medical students did not internalize the dehumanizing aspects of the clinical Gaze during their training in the same way as Good (1994) reports. She suggests that this may be because medical students in Malawi have very different life experiences: most Malawian students have greater exposure to death and corpses than their North American colleagues due to high death rates and to funeral practices that entail wide community participation, including the washing and dressing of bodies. The physicians she talked to also contend that the “wretchedness of clinical practice in Malawi” fashions them into better doctors; they argue that lack of technology at their disposal means that they have to be more compassionate, resourceful, and better able to see “the big picture of disease and health” than their colleagues (2012: 112-114). Despite these differences, medical students in Malawi did begin to see the body as a “worksite,” and learning how to see through and into it was paramount to becoming a real doctor (2010: 112-113). While
looking at blood slides and dead bodies was a part of medical training for Malawian physicians, the emotional detachment detected in other settings did not necessarily follow. Wendland’s research highlights how the consequences of medical education are not inevitable; rather her work shows the varied and dynamic nature of learning how to “gaze” (2010: 207-209). Nevertheless, the students she worked with were physicians-in-training, whereas most of the health care workers from my research were not trained in the medical sciences, but in how to administer and follow bureaucratic procedures and guidelines developed by health experts elsewhere. Thus, by analyzing the impact of the Gaze in a setting where there are no actual doctors, I contribute important insights into how biomedicine operates at a tertiary health care setting, such as that I studied, in rural Malawi.165

“Does she have a cough?”: The Gaze in Practice at Temwa

Jenny, along with most of the caregivers I met with sick children, visited Temwa Rural Hospital often, yet their children’s health problems remained unresolved. According to Malawi’s national treatment guidelines, children like Mercy, showing the possible signs and symptoms of HIV infection, should be directed towards HIV treatment services. A team of experts at the WHO developed a clinical algorithm to help health care workers in resource-poor contexts identify infected children using “clinical observations and simple investigations” (WHO 2006: 13). At Temwa, a graphic illustration of this checklist was pinned to the wall of the HTC clinic for the duration of my fieldwork (see Figure 17). This clinical algorithm provided a checklist of symptoms to help

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165 Marsland and Prince (2012) have recently argued that research into biomedical interventions have too often focused on hospital settings or medical technologies that are not readily available to most people across the globe. They argue that spaces like Temwa Rural Hospital lie at the “edges” and are important sites for understanding how “contemporary biopolitics” intersect with other medical interventions. Also, as Wendland (2010) illustrates in her ethnography, biomedicine may be a global system of knowledge and practice, but it is a highly contextualized pursuit.
health care workers recognize the early signs and symptoms of pediatric HIV infection, and funnel children into care from alternative entry points, such as under-five clinics and the outpatient ward. Mr. N, was the only health care worker on staff at Temwa trained to use the WHO’s algorithm and he did use it to direct children he thought might have HIV to the HTC clinic. However, more often than not, children with symptoms on the WHO’s checklist were sent home undiagnosed, with a prescription for a mild painkiller or a broad spectrum antibiotic. Like the standards and procedures developed for Nepal described by Harper (2005), for a variety of reasons the WHO’s algorithm was ineffective in a real life setting. I use ethnographic examples to demonstrate how the bureaucratic Gaze simultaneously revealed some children with HIV while concealing others.

These checklists are a product of the Gaze, since they reflect the basic assumption that disease is a physiological phenomenon waiting to be discovered by a discerning expert. A major problem with the clinical criteria Mr. N was supposed to use to identify children who may have HIV at Temwa was that these symptoms were common enough in uninfected children that they were rendered meaningless. At the time of my research, Malawi’s checklist included more than a dozen common childhood illnesses, such as chronic diarrhea, recurrent fever, malnutrition and various lung infections. Using these symptoms, nearly every single child who arrived at Temwa should have been tested for HIV since these illnesses accounted for nearly every hospital visit for children under five – and are the most common causes of mortality for uninfected children around the world (Black et al. 2003). For example, a survey I conducted at the OPD indicated that nearly all of the children brought to see Mr. N had one or more of the symptoms on the checklist.

To understand how this checklist worked in practice I sat in on patient consultations in the OPD. In the clinical assessments that I observed, Mr. N would ask as if going through the checklist: “Does she have diarrhea? Weight loss? Can I see inside the mouth (to check for oral candidiasis)? Can I listen to her breathing? (using a stethoscope to check for pneumonia).” These questions often prompted yes or no answers and were complemented by a brief perusal through the child’s health passport to determine the severity of any current illnesses and their duration. Most assessments lasted only a few minutes; Mr. N almost always had dozens of patients waiting to be seen outside his office. My observations indicate that most children had to have at least one other, more HIV-specific symptom, for Mr. N to suspect that the child had HIV. For example,
Mr. N told me that he often suspected HIV when a child had oral thrush or an enlarged spleen, since these were rare symptoms among uninfected children. However, HIV disease progression in children is neither linear nor predictable; a child with HIV may never develop any of these more obvious symptoms, making it hard for health care workers to distinguish them clinically (Spira et al. 1999). Rather, the variety of experiences and rates of progression among the children I met were often context specific. For example, malnutrition could exacerbate a child’s symptoms, speeding up disease progression. Researchers examining the effectiveness of clinical criteria for pediatric HIV in South Africa found similar results. Jones et al. (2005) observed that even when experienced pediatricians carefully evaluated children in the clinic they were only able to identify half of those infected at 12 months (see also Horwood et al. 2003). Based on these findings they concluded that “in an era of expanding antiretroviral scale-up programmes, clinical assessment remains an unacceptably insensitive diagnostic tool for ensuring that HIV-infected infants access care” (2005: 560). Thus, while the symptom checklist is technically accurate, it is an imprecise tool for COs in Malawi who are already dealing with high rates of morbidity and mortality in uninfected children.

Another reason that these checklists were ineffective in practice is that their deployment within the clinical encounter relied on both Mr. N’s ability to observe the physical signs and symptoms of HIV disease progression in children and the ability of caregivers to communicate these symptoms effectively. In the clinical encounter caregivers were also not always able to communicate their child’s health problems in a way that was either meaningful or recognizable to health care workers. Numerous anthropologists in many different settings have demonstrated that “idioms of distress,” or how patients describe their afflictions to health care workers, vary according to locally salient metaphors and common understandings of the body and how it works (Keys et al. 2014; Nichter 1981; Niner 2014; Smith-Oka 2013; Volk 2012). Unfortunately, patient descriptions do not always match biomedical classifications of disease. Kirmayer (2011), for example, describes how these disconnects impede access to treatment, accurate diagnosis and the effectiveness of prescribed treatments. At Temwa, caregivers with HIV positive children emphasized the illness experience over the biological symptoms of pediatric HIV. So, rather than say “my child is severely malnourished” they would complain about how their child no longer liked to play with friends, eat or chat with others. Or, a child may have both diarrhea and a fever, but the caregiver may only report the fever since they do not see the two as related. Similarly, in
my introduction, I describe five year old Katherine, who was brought to the hospital with leg pains and the failure to walk, but was sent home twice after being told that there was nothing wrong with her legs. The kind of knowledge that accrues to caregivers as engaged observers of their child’s everyday activities, such as subtle changes in their child’s behaviour, are instead dismissed as irrelevant or erroneous within the framework of the Gaze and in relation to the standards for diagnosis set elsewhere. In other words, the disconnect between the list of symptoms versus how caregivers understood and described childhood illnesses created missed opportunities for early diagnosis at alternative entry points into HIV care and treatment programs.

To some extent Malawi’s national treatment guidelines recognized that standardized diagnostic labels informed by the Gaze, or the narrow focus on biological signs and symptoms, was an imperfect tool. The poster depicted above by the Clinton Foundation translated the WHO’s clinical criteria into more accessible language; unfortunately this poster was produced only in English, or a language that few spoke in Northern Malawi. Malawi’s national treatment guidelines also recognized that there may be other “context specific” information about a child that made an HIV diagnosis likely. For example, they recommended HIV tests for children who had recently lost a sibling or parent to suspected HIV-related causes. However, the bureaucratic nature of the Gaze at Temwa often foreclosed this pathway to diagnosis. Patient histories were often done very quickly, if at all, to accommodate the long line of patients at Mr. N’s door. Moreover, he rarely elicited any information beyond the child’s presenting symptoms, since his questions were concerned with physiological symptoms and not the social circumstances of the child’s life. Jenny, for example, never told Mr. N when she took Mercy to see him that her six older children had already died, nor was there any place in Mercy’s health passport where this information could be recorded. This was partially because Mr. N did not always ask for detailed patients histories, but also because Jenny considered the information irrelevant – at that time she told me she assumed that they died from witchcraft attacks unrelated to Mercy’s symptoms.

These issues were confounded by the reality that the caregiver who accompanied the child to the hospital was not always aware of the child’s medical history; sometimes they did not know the full history, such as when a child changed custody after the death of a parent, or because they just forgot. Often when I interviewed caregivers and went through a child’s health passport with them they had to be prompted about previous visits to the hospital. In this way the Gaze revealed
some aspects of HIV infection (such as pneumonia or fever) while obfuscating others, such as the social impact on families (i.e. death of siblings), the variance in symptom presentation and the interpretation of the severity and duration of those symptoms.

ART patient master cards used to monitor patients on treatment were also a ubiquitous by-product of the Gaze at Temwa. Like the “diabetes flow charts” described by Ferzacca (2000) in his research with men diagnosed with adult-onset diabetes in America, these charts directed the narrative flow between patients and health care workers at Temwa. In most contexts there is some room for physicians to include social information about the patient considered relevant to their long-term adherence to the pharmaceutical intervention, such as their levels of food security, homelessness or drug addiction (Davenport 2000). In Mozambique, McKay found that the “processos clinicos,” or the patient records used to track patients on ART in Mozambique, were filled during psychology consultations with longer narratives describing psychological, social or financial problems considered relevant for treatment outcomes (2012: 548-549). However, patient ART master cards at Temwa were a barebones version of the intake forms used at better funded NGO projects in Malawi.

As the official written record of the patient’s treatment trajectory, Nurse M was in charge of recording the information onto these charts into pre-categorized compartments (see Figure 18). There was very little room or time to include any information considered extraneous by health experts from afar. In most cases interactions in the clinic were only about completing predetermined data fields (see also Greenhalgh et al. 2012). There was only a small one-inch space to include information outside of the Gaze’s purview. Nurse M could make “comments” in this space, but it was nearly always left blank. Using a pen to check off the appropriate boxes, Nurse M, only had room to record the date of each visit, the patient’s weight, possible side effects, pill count and the date of the following month’s appointment. Unfortunately, the process of filling out cards with information that was considered “medically important” excluded pertinent “non-medical” information. For example, missed doses were interpreted as a sign of non-compliance by patients and resulted in verbal chastisements by health care workers (see also Mattes 2011). Factors impeding a patient’s ability to make it to the hospital each month were irrelevant in this context, such as illnesses that prevented some patients from walking 20km to get to the hospital, a death in the family, or farming activities, such as planting and weeding, which are both time and weather sensitive. Household food security, and its known impact on treatment outcomes
and treatment adherence, was also not considered a “variable” worth noting; instead, caregivers were advised to feed children on treatment “good food” that in most cases was too expensive (meat) or unavailable in this region (fish, pineapples). Since children “do not complain properly,” as one HSA stated, any side effects related to their treatment were also rarely recorded. Like the clinical criteria used to identify children with HIV, ART cards privileged scientific evidence of infection over other forms of experience or expert knowledge that could promote earlier diagnoses and improve treatment adherence (Landsmans 2006).

“It needs to say ‘stage 3’ for her to start treatment”: Elusive moments of stability in the Clinic

Above I demonstrated how the Gaze operated at Temwa in ways described by Foucault – that a trained health care professional relied on biomedical categories to measure and manage difference, inadvertently excluding vulnerable children with HIV. I demonstrated how the Gaze often displaced a caregiver’s own “subjective” interpretation of and understanding of their child’s illness by the “objective” checklist developed in Geneva and used by health care workers to identify children with HIV. Here I want to analyse how a secondary displacement occurs when treatment guidelines developed far from Temwa regulate hospital praxis. While the deployment of standardized pediatric HIV treatment guidelines was considered vital for the expansion of ART programs into resource-poor contexts, I argue that by deferring clinical decisions to these algorithms and checklists health care workers fail to respond to their patient’s suffering. In particular, the technocratic requirement that anyone initiating ART needed a positive rapid antibody test was particularly detrimental for children with HIV, since most children die before they are eligible at 18 months.

Dodier (1998), in his work on occupational medicine in France, has argued that physicians work within different “frames” – what he calls the administrative and the clinical – to diagnose and treat patients. He suggests that within the administrative frame, or what I call here the bureaucratic Gaze, individuals are depersonalized and treated according to formalized categories derived from population statistics. According to Dodier, standardized protocols are developed to counteract the clinical judgements of individual practitioners within the “clinical frame,” which are variously considered as idiosyncratic, biased or out-of-date. Berg (1998) also argues that protocols are meant to anchor clinical decisions to moments or areas of stability. Or
in other words, most of these protocols are designed to help health care workers progress towards a definitive diagnosis through successive investigations and observations, or what Street (2006) calls “diagnostic closure.” As a techno-scientific script, treatment protocols often crystallize treatment pathways for patients, by redirecting them on pre-determined courses (Cooper 2012; Harper 2005: 133; Timmermans and Berg 1997: 276). Below I examine the case of a boy diagnosed with HIV and his caregiver’s failed attempts at entry into Temwa’s HIV treatment program. His case is a common example of how standardized guidelines meant to make up for critical human and health resources often fail to do so. Rather, the “moments of stability” considered bureaucratically necessary for the diagnosis and treatment of children with HIV remained elusive.

Twenty-one-month-old Emmanuel and his mother Gift were brought to me in the HTC room by Mr. G one sunny morning. As was his habit, he introduced them briefly: “This one [indicating the child] is HIV positive, but not yet on the medicines.” To Gift he explained in chiTumbuka: “She [meaning me] is talking to people who have children with HIV. Maybe she can help you if you talk with her.” Gift, an 18-year-old widow, sat on the chair across from me with Emmanuel on her lap. Although she was on treatment, she was very thin; later we found out that she’d been hospitalized recently for TB and, while doing a “bit better,” she still felt very weak.

Gift’s story was typical of most of the mothers I met: she tested positive while pregnant and started ART the same day; she was told how to prevent her child from getting HIV, and so she delivered her baby at Temwa so he could get “the drops.” She knew her son could get HIV at birth and through breastfeeding, and although she was told to stop breastfeeding at six months, she failed to do so because of a lack of food at home. When Emmanuel was around a year old he started “falling sick often.” She took him to her local health centre [near her village but with limited medical supplies], where he was prescribed panado [a mild analgesic] for mild coughs, fever and diarrhea. When she was hospitalized at the district hospital, Emmanuel was also given

166 Once I learned enough chiTumbuka to understand what Mr. G was telling possible informants I reminded him that I was not there to help patients directly (through food, money or medicines) and that perhaps his choice of words was misleading for patients. He objected and pointed out that I did give patients food when they visited and that I had helped patients by procuring them mosquito nets, food supplements or by providing information about hospital services.
food supplements, and antimalarial medicines. Although he would get better “for a few days,” his health slowly declined over the following months.

At 18 months she brought him to Temwa for an HIV test, as she had been counselled to do. Unfortunately, there were no reagents to do any HIV tests. The next month she tried again, but this time there was no HSA on duty who could do the test. When Emmanuel was 20 months, Gift was able to have him tested; the HSA wrote his status in his health passport and told Gift to find Mr. N in the outpatient department to have him “staged” to see if he was eligible for treatment. Gift recalled that it was getting late the day Emmanuel tested positive, and she needed to catch the matola back to her village; since it filled up quickly and she was not healthy enough to walk 23km with Emmanuel on her own, she decided to have him “staged” the following month.

We met Emmanuel and Gift a month later, the day she tried to have him “staged” by Mr. N. Strangely, after waiting in line for over an hour at the OPD, she was told by “the doctor” (without any explanation) to come back the next month. Sadly, by the time we met him, Emmanuel was severely malnourished: his hair was white and he weighed only 11 kgs according to his health passport. He was listless and unable to open his eyes, and he was no longer walking. Maggie and I were so concerned about him that we cut the interview short and called in Mr. G to see what could be done. I explained that Gift lived very far away and if she had to wait another month for Emmanuel to get help he might not make it, considering his rapidly declining health and severe malnutrition. Mr. G agreed, but said there was nothing he could do. He explained: “It needs to say ‘Stage 3’ in his passport before I can give him an ART card.”

Frustrated, I explained that she had tried to have Emmanuel staged, but that Mr. N had told her to come back the next month for some reason. While I was baffled, Mr. G understood the problem immediately:

Mr. N is at a [Ministry of Health training] workshop in Mzuzu. He will be back in two weeks. Mr. K is his replacement until then. Maybe you should take her to see him yourself.

With Gift’s agreement, I asked her to follow me as I marched us back to the OPD to find Mr. K. Mr. K was a retired clinical officer who worked at Temwa when Mr. N was away or sick. We found Mr. K seeing patients in the waiting room – a long line stretched out from the patient standing in front of him. The patient, a young woman with a baby on her back stood with her
hand outstretched while Mr. K wrote her prescription inside for the pharmacist: “bactrim [antibiotic] and panado” it read for pneumonia-like symptoms. I sat next to him and explained Gift’s situation to him. Then he explained:

I have never been trained in how to stage children, so she should come back when Mr. N is here.

Relatively new to Temwa, his answer astonished me. I tried to be respectful as I pushed him further:

I know I am not a doctor, but it seems to me that Emmanuel has all of the symptoms [I listed his problems from his health passport] that are on the poster in the HTC room. Mr. G tells me that all you have to do is write ‘Stage 3 or 4’ and then he can start treatment.

I will never know if he was persuaded by my argument, by pity for Gift and her son, or just by the urge to get me out of his way so he could move through the long line surrounding him, but he took Emmanuel’s passport and quickly wrote ‘Stage 3’ next to his HIV status. Victorious! I smiled at Gift with Emmanuel’s health passport clutched in my hand. We quickly made our way back to the ART room and found Mr. G. He smiled and then (without any irony at all) told me: “Now just tell her she needs to come back next Tuesday for the adherence counselling. I can’t start Emmanuel on treatment until she does this.”

Emmanuel died one week later.

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The bureaucratic necessity to stabilize, or standardise, who qualifies for HIV treatment and when are clearly at work in the example above. Many of the children who were able to get a definitive HIV diagnosis (that is one marked in the health passport after a rapid antibody test by a health care worker) even after all the barriers I outlined above, still faced a number of bureaucratic hurdles before treatment initiation. At Temwa, health passports and ART patient cards were considered the primary tools used to reach “diagnostic closure” and to then record these moments of stability (Street 2006). HSAs made notations in a child’s health passport when an official HIV diagnosis was obtained and COs wrote what “stage” they were in after a physical exam. While health passports could be obtained for a small fee from the hospital, patients like Emmanuel had to “pass” a number of institutional procedures before he could obtain an ART
patient card and therefore start treatment. First, he had to have an official HIV positive test result - a process that took over six months, despite repeated efforts by his mother and while his health slowly deteriorated. National treatment guidelines present this as a straightforward process, but resource shortages (and other social dynamics around diagnosis I discussed in detail in Chapter three) made this more of a challenge than might be expected. For example, the HTC room was only prepared to test patients for HIV twice a week, and only then if the supplies were in stock and as long as the only HSA trained to administer tests was on duty. Yet the OPD was open five days a week and the under-five clinics were held on Mondays and Wednesdays – or on alternating days with the HTC clinic which was open Tuesdays and Thursdays. For a month-long stretch in 2009 the hospital had no reagents to perform HIV tests and all patients who requested them were sent home (see also David 2014). It was routine for patients to be turned away. Also, transport costs and the distance to the clinic made it difficult for Gift to visit the hospital on the off-chance that she might find tests available or the HSA on duty.

After six months Emmanuel finally secured an official HIV diagnosis, meaning his HIV status was recorded in his health passport after a rapid antibody test. However, this was not enough to start treatment. He still had to be “staged” by a clinical officer – that is, his disease progression had to be determined using the checklist discussed above. Since there were no laboratory tests at Temwa to determine the severity, or “stage”, of the HIV related symptoms, Mr. N assessed each patient individually. On paper, this also seems like a straightforward process, yet it took Emmanuel repeated hospital visits to secure this assessment and only then after my (perhaps questionable) interference. As the only clinical officer trained in pediatric HIV staging at Temwa, any absences by M. N, either through illness (he also got malaria), competing duties that were more critical (i.e. two men cycled into a ditch while drunk required immediate attention), personal business, long patient lines or even his lunch break, disrupted this process for many. After Mr. N determined if a patient was “sick enough” to start treatment, the patient was referred to the ART clinic, where he or she had to attend adherence counselling on another predetermined day before they could obtain an ART patient card. Thus, ART initiation was often a process that took most patients weeks, and some months, before they were able to pass all of the procedural hurdles. For Emmanuel and many other children these delays were deadly.

For children with HIV-related symptoms, the duration and severity of their symptoms is often a key indicator that health care workers can use to identify them within the clinical setting.
For example repeated bouts of diarrhea that last longer than two weeks can be used to identify children with HIV. However, notations by health care workers in children’s health passports were typically very brief, often with only the date, the presenting symptoms and prescription written inside. This was done partially out of necessity – there were always long lines and many patients to be seen. However, the structure of the health passports was also not conducive for helping health care workers discern troubling patterns over a longer period of time. Aside from the child growth chart at the beginning of the passport, which is an excellent visual cue that can easily be used to see if a child is losing weight, there was no space for a health care worker to determine a child’s overall health status with a brief glance. Health passports are mostly made up of empty pages to be filled in by health care workers at each visit. Although it may seem surprising that health care workers may not always write down even a provisional diagnosis, this was often because a definitive diagnosis, or a “moment of stability,” was often hard to pin down without the certainty provided by laboratory tests or other biotechnologies found in most other clinical settings. The utility of diagnostic closure for most childhood illnesses was also unclear; aside from specific medicines for malaria and HIV, there was really only one kind of medical intervention possible at Temwa – a broad spectrum antibiotic. In fact, the health passport was primarily used as a prescription pad, which patients used to access free medicines from the pharmacy. As Foucault’s (2003) work on the Gaze suggests, biomedical work is portrayed like detective work; health care workers are supposed to put together pieces of the puzzle using their investigative skills to identify the hidden and dangerous disease deep within the body’s internal organs. From this perspective, the health passport is a tool that operates like a detective’s notebook – it should record relevant details about a patient’s symptoms, social relationships, medical history and test results – which he or she can then use to produce the “aha” moment – or in this case to reach diagnostic closure. However, in practice this detective work often requires a lot more time and technologies than most health care workers in Malawi have.

In a parallel example, Street (2006) describes health records at a Papua New Guinean (PNG) hospital as “artefacts of non-knowing” that either “open up” multiple pathways for pragmatic action within a hospital space or “close” pathways by moving people between specific

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167 Antibiotic resistance is a huge concern of the Malawian Ministry of Health and Mr. N did follow treatment protocols to prevent their overuse. In fact, this was the number one complaint that people had against the hospital; many felt that he withheld these medicines for personal, rather than clinical, reasons since few knew anything about antibiotic resistance.
spaces. She shows how health care workers in PNG avoided “diagnostic closure” to preserve treatment options for patients since there were few treatment options available. For example, an Australian doctor at the hospital was baffled by his colleagues’ seeming uninterest in the underlying cause of his patient’s suffering. His reply when questioned was simple – there was no treatment for his disease (cirrhosis), so a diagnosis had no utility since it only foreclosed the possibility of medical intervention. Instead he used medical records to correlate clinical symptoms with available treatment options. Health passports in Malawi operated in a similar way. They were not used as tools to identify the hidden, dangerous disease within the body only made visible by the health care workers’ expertise. Rather, in many cases, health care workers used them to maximize the possibilities for action and therefore increase the patients’ chances for improvement. Or as Street says in relation to PNG:

The medical record is not a device for moving biomedical work forward towards diagnostic closure; instead it is a device for holding biomedical knowledge still while allowing multiple pathways for action to proliferate (2006: 831).

Although health care workers often had no need of “diagnostic closure” to treat most common childhood illnesses, at times health passports were used as a “technologies of closure” out of bureaucratic necessity. Diagnostic closure was required for patients to access both anti-AIDS and anti-malarial drugs. To prescribe these medicines, health care workers are required to defer any clinical assessments to the authority of an actual diagnostic technology. In other words, even if the CO strongly suspected a child had HIV, in the absence of a positive test he was unable to prescribe treatment (see Figure 19). In this way, the Gaze defers both the clinical knowledge of the health care worker and the caregiver’s experience of the child’s illness to bureaucratic necessity. In the case of both Emmanuel and Mercy, it prevented both practical and ethical action on their behalf. This bureaucratic need stems from both concerns over prescription leading to treatment resistance that would threaten the health of all patients on treatment, as well as the migration of auditing and accountability strategies into the health sector (Mosse 2005;
Strathern 2000). As I noted in Chapter One, health care workers were under a lot of pressure to follow treatment guidelines to ensure the continuity of future donor funds.

The physical structure and organisation of Temwa hospital also disrupted the flow of patients through standardized procedures (see also Levy 2006; Street and Coleman 2012). For example, unlike district hospitals, which perform routine HIV tests on all children admitted to the hospital for one night or more, rural hospitals only administer HIV tests to children whose caregivers take their child to the HTC room and request one. While Mr N, the clinical officer at Temwa, could recommend that a child be tested for HIV, the division of labour at Temwa meant that he did not actually administer any antibody tests himself. If he felt a child needed a test, they were supposed to make their own way to the HTC room, which, as I’ve pointed out, was not open most days. The physical organisation of the hospital also reflected vertical donor support for narrowly defined health programs, such as pregnancy (the maternity ward), HIV/AIDS (the ART clinic), malaria and child health (the vaccination room) (Behague 2008; Janes 2004; Street 2012; Sullivan 2012). Each room of the hospital was dedicated to a sole purpose: HIV testing in one, maternity in another and so on, making the purpose of anyone’s visit to the hospital transparent to outsiders, friends and family. This also made it difficult for patients to transfer between programs within the hospital or to access resources allocated for a specific category of sick person. For example, in 2010 a program was in place to supply pregnant women with free mosquito nets. At the same time, Jonah, a six year old boy on ART at Temwa, was suffering from dangerous bouts of malaria. His mother was a tenant farmer from Southern Malawi; during an interview she described to me how their house was made of bamboo and they lived very close to a river (see Figure 20). She explained that the “mosquitoes are so bad at night” they could “barely sleep.” Since as tenant farmers they had no cash to purchase a net (see Chapter five) I made my way to the maternity ward to request a net for Jonah there. The HSA on duty initially refused. “They are for pregnant women only,” he insisted. I pointed out
that this was a boy on ART, so malaria would be dangerous for him. I asked him if the reports destined for the Ministry of Health were more important than Jonah’s health. He agreed, but wrote for the record that Jonah’s mother was pregnant.

Standardized treatment guidelines are meant to reduce error, increase transparency and increase access to ART. I anticipate that the people involved in the creation of these guidelines would (rightly) argue that these guidelines are what makes treatment roll-out possible in resource-poor contexts. While these guidelines have clearly increased the number of patients on treatment, my findings also indicate that they unintentionally introduce bureaucratic barriers to care by introducing unnecessary delays and preventing horizontal movement within the hospital. Since HIV disease progression in children is so much faster than in adults, these delays are often deadly for children, who need to be identified early to benefit from treatment. Underlying these standardized guidelines is also an assumption that the sole purpose of biomedicine is to bring about diagnostic closure that will ultimately lead to correct life-saving medical intervention.

Next I consider how the Gaze operates in context where the physicians imagined by Foucault are largely absent.

“We motivate, but we cannot help”: The Medicalization of Community Health Care workers

*Me: So how did you come to be an HSA?  
Mr. G: I was just interested maybe…. to work with the community.  
Me: So you wanted to be an HSA? 
Mr. G: Ahhh... nooo... It was not my choice to be one. You know this country. You graduate [secondary school]... and you search around to find something you can do.  
Me: If you had a choice, what would you have done?  
Mr. G: I wanted to be an [airplane] pilot (he laughs at himself).*

- Interview with an HSA, May 2009

The above conversation sums up the ambivalent feelings HSAs have about their job. HSAs were originally intended to be “community health care workers,” or an imaginary bridge between the formal (biomedical) health care system and the rural communities where most
Malawians live (Ommundsen 2011). As Malawi’s frontline civil servants, they have the most direct interaction with patients and their families all over the country. Their role as “community health care workers” is often touted as beneficial since they can act as intermediaries between the norms of the community that they serve and the standardized treatment guidelines formulated from afar, softening the Gaze and humanizing clinical encounters. In their role as community health care workers, HSAs perform the bulk of Malawi’s primary health care delivery services, such health promotion (i.e. telling parents about hand washing), weighing babies and giving vaccinations (see also Justice 1983). On the other hand, Malawi’s weak health care system has necessitated a reframing of their work (Bemelmans et al. 2010). Increasingly, they are expected to act as front-line clinicians (see also Druetz et al. 2015). Their roles in Malawi’s national HIV treatment programme illustrate the shift towards a more pragmatic, medically centred use of HSAs. They now perform diagnostic tests (HIV, Malaria), measure children for malnutrition, provide counselling services and help professional health care workers run HIV clinics. Yet, unlike the professional healthcare workers imagined by Foucault, such as physicians, nurses and clinical officers, HSAs have no formal medical training. Formal levels of training varied greatly among the HSAs at Temwa. What I call “Senior HSAs” were hired and trained as community health care workers more than a decade before my fieldwork. However, most of the HSAs at Temwa were hired in recent years with funds provided by the Global Fund (see Chapter one); by the end of my fieldwork in 2010 most only had on-the-job training with Senior HSAs. A few Senior HSAs had additional training for specialized tasks at Temwa. For example, Mr. J had been certified by the Ministry of Health to do HIV tests after a three week training course (Bemelmans et al. 2010). Mr. G was also certified to run the ART clinic. Mr. K had been certified to do microscopy for malaria testing. The medicalisation of HSAs with the advent of ART roll out raises important questions about both how the Gaze operates in a context with few trained medical professionals and the role of community health care workers like HSAs in large-scale global health interventions such as ART scale-up. While the “scale up” of HSAs was facilitated to enable rapid ART access for a large number of patients, as per the standardized guidelines discussed above, their lack of medical training and authority within the clinic setting hindered patient-centred care at Temwa.

HSAs have been a part of the Malawian health sector since the smallpox eradication campaign in the 1960s. However, “task-shifting” arrangements to make up for acute health care
worker shortages in recent years, to enable access to ART in rural areas, have more than doubled their number since 2006 (Nyirenda and Flikke 2013; WHO 2004). Task shifting, or delegating tasks normally performed by medical professionals to staff with lower-level qualifications, was considered the only feasible means of expanding ART treatment programs in areas with acute health care worker shortages (Callaghan et al. 2010). In rural areas like Temwa, where there are no physicians, HSAs far outnumber trained medical professionals, making them responsible for the vast majority of all medical care taking place outside of district hospitals (Alfsen 2011). At Temwa during my fieldwork, for example, there were six HSAs for every trained nurse and clinical officer employed by the hospital.\footnote{168}{Statistics here: 2:100,000 physician to patient ration; 38:100,000 nurses; 83:100,000 HSAs. The ratios are higher in rural areas where nurses and physicians do not want to work (WHO/world bank report on human resources for health).} They are also the lowest ranking worker in the Malawian health bureaucracy, with poor salaries, heavy workloads, high mobility and poor job security (Nyirenda and Flikke 2013). Many of the HSAs I talked to had so many tasks they failed to list them all without prompting when I interviewed them. Senior HSAs, such as the very busy Mr. G, had duties including the supervision and training of new HSAs in addition to his regular duties running the ART clinic. All of the HSAs I spoke to felt frustrated by their poor pay and overburdened by the number of tasks that were continually assigned to them. Many, like Mr. G, spent their free time upgrading their credentials (i.e. completing secondary school) to either qualify for university or to find a more lucrative job in the non-profit sector. However, with poverty and unemployment rates high in Malawi, even their low salaries ensured that they lived a better life than most in the surrounding area.

Although HSAs largely lack any formal training, some research suggests that good, and sometimes even better, health outcomes can be achieved through task shifting (Zachariah et al. 2007; Lehman and Sanders 2007). These findings raise a number of intriguing questions that demand further exploration. How exactly could better health outcomes for HIV patients be achieved by non-professional health care workers and why? Zachariah et al. hypothesize that these benefits may be achieved because non-professional health care workers are more likely to “adhere more strictly to simple clinical practice guidelines” (2009:551-553). However, my findings suggest the opposite: that strict adherence to standardized treatment guidelines undermines treatment outcomes by excluding many children from HIV care and treatment.
services (see also Druetz et al. 2015). Pediatric HIV testing and treatment initiation at Temwa was more effective when the rules were broken, largely because most children develop HIV related symptoms before they are even eligible for treatment. To understand this dynamic I examine the roles and responsibilities of HSAs at Temwa and how this influenced the timing of pediatric ART initiation.

Daily tasks at Temwa were strictly divided between the different cadres of health care workers. While COs and nurses occupied themselves with the physiological aspects of disease, by delivering babies and prescribing medicines, HSAs spent most of their time on administrative tasks (filling out registries, handing out ART patient cards) or health promotion campaigns aided by local volunteers and Chiefs. In the words of Mr. N, a senior HSA, his key role was to “motivate” the community, but he could not “help them.” He explained:

Mr. N: Some women are not coming [to deliver their babies at the hospital] because they have some cultural beliefs, some religious beliefs and some are saying ‘the health workers are coming late to the hospital so I’m not going to deliver there.”… *Our job as health workers is to motivate them to come to the hospital... because the government does not allow them to give birth at home [there is no actual law, but it is strongly discouraged by health care workers].*

Me: How do you motivate them?

Mr. N: Well, many times, we HSAs are also parents, maybe some have already given birth just at home with TBAs [traditional birth attendants] but we are just telling them [to come to the hospital]. *We cannot help them. We are just going there to motivate them, nothing else apart from this.*

Me: Can you explain to me how you tell them?

Mr N: We have got health committees. That committee is moving around the villages telling mothers, and chiefs, so that they should not deliver at home. That committee is together with we HSAs. Volunteers I could say. We’ve got volunteers moving up and down telling women: “Don’t deliver at home!”

Mr. N’s distinction between “motivating” and “helping” patients hints at both a sharp distinction between the roles and responsibilities of HSAs and professional health care workers and their relative authority within the hospital. In short, HSAs had no power to diagnose or recommend
ART for children at Temwa. Their lack of authority to intervene in the treatment trajectories of their patients is a fundamental flaw of Malawi’s national treatment programme.

HSAs have the largest number of interactions with patients at the hospital by far. In most cases they are the only cadre of health care worker in many of the positions at Temwa. HSAs occupied all but one of the alternative entry points into HIV care and treatment services identified in Malawi’s national treatment guidelines. Yet only one of the HSAs at Temwa had any specific training on pediatric HIV. In fact, when I interviewed most of them, they had a vague, and sometimes incorrect, ideas of when children should be tested for HIV and when they should start treatment. For example, the guidelines identify “under-five” clinics as an alternative entry point. Infants and children are weighed and signs of malnutrition are measured using standardized growth charts in a child’s health passport. However, since HSAs do not have the authority to clinically evaluate patients, they do not make any clinical recommendations at these entry points. Rather, caregivers are supposed to note the child’s weight on the health passport themselves and are “motivated” by HSAs to go to the OPD and see Mr. N if they notice any weight loss. I personally witnessed dozens of malnourished children pass through these clinics undiagnosed; but, like the HSAs at Tewma, I lacked the medical authority to test and diagnose children with symptoms of HIV.

Due to the nature of their work, HSAs also had intimate knowledge of many of their patient’s social lives. Each HSA at Temwa was assigned to a small number of villages (two to seven on average), where they conducted mobile clinic and outreach activities including routine post-natal visits, vaccinations, child health campaigns, “village inspections” (census taking, sanitation and water) and a variety of pilot initiatives by government and NGOs. For example, as a part of a new government initiative to help reduce the number of maternal and neonatal deaths, Mr. G did at least 30 home visits per month with pregnant women and newborns in his village area alone. During one home visit Mr. G observed:

This child is not doing so well, he is malnourished as you can see [he had orange hair and a distended belly, which he thought might mean the boy had an enlarged spleen]. Just last week his mother started shouting with the second wife through the walls [who lived in a house so close to her own that we could see into it from her sitting room] over how the husband [who was a truck driver] was dividing up the money between the houses.

This statement indicates that after more than a decade of experience Mr. G was very capable at making clinical observations and diagnoses, yet his authority did not extend into the biomedical
realm, or in a way that would allow him to test patients for HIV he thought might be at risk. He was also privy to social knowledge that could contextualize his observations.

Hospital hierarchies were also very clear at Temwa. I rarely witnessed any social or professional interactions between HSAs and the professional medical staff at Temwa (nurses and the CO). They did not, for example, socialize outside of the hospital. There were also no weekly staff meetings, or any forums for HSAs to bring their concerns or observations to the attention of the CO in charge of the hospital. In Tanzania, Hutchinson et al. (2014) also found that professional medical personnel in Tanzania tried to maintain hospital hierarchies by resisting the efforts or input of community health care workers whom they considered untrained and untrustworthy. So, even when HSAs had information that might be relevant to a patient’s treatment trajectory, such as the likelihood of an HIV infection in a sick child, it was unlikely to be shared higher up the hospital hierarchy, largely because HSAs lacked the authority and training to do so. To understand how things might have gone differently at Temwa if there was a physician present, I asked a pediatrician volunteering at a district hospital in Malawi how she used the standardized guidelines given the exclusions I was witnessing. She replied:

This is how I interpret the guidelines: I put every child under 18 months I meet with chronic diarrhea on ART…. The nurses do not like it... They think I’m just wasting the medicines, but I figure it’s better to treat children who may have HIV rather than let the infected ones die because I can’t be sure…. People used to worry that putting children on treatment if they weren’t positive would be bad for them, but now we know that it’s not really a major problem as long as we keep testing them and take them off treatment if it eventually turns out to be a false positive (emphasis mine).

As Smith et al. (2003) argue in relation to their research with anaesthesiologists in Britain, physicians recognize that there are limitations to standard guidelines and procedures and use their expertise and experience to make clinical decisions based on the information available. Dr. A expanded on the statement above by citing new research (that she said was not published when the official guidelines were developed) and that with new evidence, which with her training she could access and interpret, her actions were both medically sound and ethical. Clearly HSAs lack both the skill and latitude to act in a similar manner. Thus, there are clear limits to the effectiveness of task shifting arrangements in resource-poor contexts.
Conclusion

My analysis of Temwa Rural Hospital as medical space where the Gaze operates from afar indicates that an overemphasis on the physiological aspects of pediatric HIV infection excludes children in a number of ways. While standardized procedures and task shifting arrangements were meant to speed up the process and ensure universal access to treatment, they came with their own “anti-politics” (Ferguson 1994; Taylor and Harper 2013). The Gaze at Temwa is apolitical because it deflects attention away from the broader social and political-economic conditions that lead to pediatric HIV infections in the first place, such as underfunded and poorly run PMTCT programs, and instead focuses on the physiological experience of pediatric HIV infection. Standardized protocols and task-shifting arrangements are meant to move large numbers of patients through the system, but by doing so they introduce exclusionary practices that result in premature deaths of infants with HIV. Although symptom checklists are technically accurate, in practice they are often ineffective because the technical (rapid antibody tests), biological (high rates of comorbidities in uninfected children) and socio-economic context at Temwa differs greatly from the settings where they were designed. The priority placed on bureaucratic efficiency and eligibility also prevented health care workers from acting when they knew death was likely imminent, perhaps occasionally out of fear of losing their job, but mostly because they lacked the skill and authority to reinterpret guidelines for their patient’s benefit. More broadly, strict adherence to standardized protocols stunts the development of practical solutions to local problems and prevents moral reflection on the causes of the epidemic in the first place.

In many ways the Gaze operated at Temwa much as described by researchers in North American contexts, but there were also fundamental differences. A notable exception was the total absence of any imaging technologies or laboratory results, such as x-rays, glucose readings, blood pressure, or urine tests that allow health care workers, in more affluent contexts, to see “into” the human body. As Street (2003) argues, in many settings biotechnologies help physicians reach “diagnostic closure,” yet in Temwa this was largely impossible. While clinical algorithms, or what are sometimes called “decision support technologies” (Greenhalgh et al. 2013: 2), are designed to fill in for critical resource shortages (both human and technological), moments of stability required for treatment eligibility remained elusive. Instead, guidelines meant to facilitate access to treatment created new bureaucratic hurdles leading to treatment
delays and denial, which in some cases resulted in death. Although the Gaze is a helpful concept for understanding how standardized guidelines operate in practice it does not shed much light on health and healing as a social, as well as a medical practice. The Gaze often fails to acknowledge the interpersonal aspects of the clinical encounter (see also Lupton 1997). For example, my observations at Temwa suggest that the age, gender, and ethnicity of a patient, as well as lack of obvious social support, influenced whether or not a health care worker would suggest an HIV test for a sick child. The concept of the gaze also does not adequately account for the emotions and desires that motivate behaviour. “Caring” activities, such as comforting a sick patient, or offering a starving child food, fall outside the clinic’s purview, yet these are all practices I witnessed alongside standardized medical procedures at Temwa (see also Livingston 2012: 6-7). The health care workers I observed were often very worried about their patients. Many went beyond their job descriptions to help patients in need, and offered non-medical advice and encouragement to those in trouble. Yet their desires to help were often subsumed by the need to accomplish medical tasks and procedures quickly and accurately in a structurally constrained and bureaucratized work setting.

Despite being the lowest cadre of health care worker and despite their lack of medical training, HSAs are still courted by patients as gatekeepers and key resource people in the constant struggle to access limited resources, such as antibiotics, mosquito nets and food supplements. While Nyirenda and Flikke (2013: 34) assert that most HSAs live in the villages “among the communities they serve”, I found that nearly all of the HSAs at Temwa used their salaries to live in town, making them a part of the local community around the hospital (see also Kyandoddo and Whyte 2003). HSAs attended church, were in debt to local shopkeepers, bought and sold tobacco from local landowners (who were also patients), employed tenant farmers and ran small shops in town to supplement their salaries. Their homes were often full of relatives and neighbours from their home villages, who stopped (some for considerable amounts of time) to get medical treatment, give birth, or attend the local secondary school. Many of the HSAs hired after 2006 were unmarried young men just out of secondary school, and they were often in relationships with young women in the surrounding communities. As such, distinguishing between their roles as health care workers and the competing roles they occupied in their personal lives – as concerned family members, fellow Church-goers, or neighbours – presented them with particular moral and practical quandaries given that the technocratic exigencies of
their jobs left little room for flexibility. For instance: What do they do when a relative insists that their six-month child be tested for HIV? What do they do when they run out of money to feed the tenant farmers they employ? What do they do when they notice a neighbour’s child is severely malnourished? What do they do when their reverend asks them to help out a family with a sick child who belongs to the same Church? The demands placed on HSAs are often contradictory: follow rigid hospital procedures and guidelines designed by policymakers in far distant settings, or bend the rules to help a friend, colleague, relative, or business partner. I discuss these dilemmas in more detail in the following chapter.
Chapter 5: “Dirty Like a Tenant”: Universal Access, Migration and Health Disparities

A blue plastic scale marked in black sharpie “UNICEF” swung inside an open doorway signalling that an “under five” clinic was underway at Temwa rural hospital. The long line swept away from the open doorway and at least 100 children and their mothers, aunts, and grandmothers (but never fathers) patiently waited for their turn in the sun. Local farmers were escorted by older female relatives while tenant farmers, seasonal migrant labourers working on tobacco farms in the area, were either alone or clustered in groups with fellow workers or neighbours. When I first arrived I could not differentiate between local landowners and tenant farmers so easily, but more than a year into fieldwork, I could readily tell them apart: perhaps most notably, tenant farmers never greeted me and were much less likely to look at me directly – an attitude they told me came from being “visitors” (mulendo) to the area and “not feeling free.”

The scene on that day was indistinguishable from the dozens of under-five clinics I attended, and I was familiar with the ritual.169 Typically, two Health Surveillance Officers (HSAs)

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169 To increase treatment access and uptake for children in particular, Malawi’s national treatment guidelines identified under-five clinics as key “entry points” in HIV care and treatment programs (HIV Unit, Ministry of Health). Although under-five clinics were originally designed to increase vaccination rates and monitor child growth, research on children with HIV also indicated that a quarter of all children presenting with chronic and severe malnutrition are also HIV positive, making routine screening for HIV at these sites a logical and cost-effective way to increase treatment uptake (Thurstans et al. 2008). Under five clinics designed to monitor children’s growth were adopted in Malawi in the 1980s as part of a global turn to ‘Selective Primary Health Care’ as Comprehensive Primary Health Care was deemed unfeasible and not cost-effective (Walsh and Warren 1979). According to Unger and Killingsworth (1986), SPHC selects a limited number (usually 5-10) health interventions by prioritizing diseases of importance on the basis of prevalence, mortality, morbidity and ‘the feasibility of control’. This approach has been distilled into UNICEF’s prominent program called ‘GOBI’ which focuses on ‘growth monitoring’ (or ‘under-five clinicals’), Oral Rehydration, Breastfeeding and Immunization. Despite limited empirical evidence that this approach is effective at reducing morbidity and mortality in children, it remains a key strategy of child survival initiatives worldwide (Ashworth et al. 2008). In particular, criticisms have highlighted how politically and economically motivated these approaches are (Unger and Killingsworth 1986) and how the emphasis on education and behaviour change overlooks the underlying causes of child mortality such as poor sanitation, food
suspended each child, in a pair of overalls meant for that purpose, from a hook on a weigh scale (see Figure 21). After the arrow stabilized they loudly called out the child’s weight in the direction of the mother, who was expected to mark the weight on a growth curve in the child’s health passport later herself. At least a few children, at every clinic, had visible signs of severe malnutrition, including orange hair or listless bodies, yet they always passed through the clinic with few comments. Many more had less visible, but equally serious signs of malnutrition.

One child’s age was hard to tell since he was so malnourished that he was unable to stand on his own. His mother gently put him into the overalls, while Mr. K, the HSA on duty that day, yelled out his weight in the general direction of his mother: “5.5kg!” Afterwards his mother hastily moved out of the way for the next person in line. Characteristic of these encounters, the mother left without a single word between her and the HSA, but the child looked sick enough that I felt compelled to intervene: “Isn’t there anything we can do for that one? He does not look good.” With some pity, but finality the HSA replied: “That one is a tenant.” I protested, but he insisted that “there [was] nothing to be done.”

Mr. K’s dismissal of a tenant with a severely malnourished child with a strong indication of pediatric HIV infection, exposes two fundamental problems with design and implementation of Malawi’s national pediatric HIV treatment programme. The first is that beyond providing free ART for patients at Temwa, there were few “extra resources,” such as ready-to-use therapeutic food supplements or mosquito nets, to extend and improve the quality of life for children with HIV. As Mr. K noted when I pushed him to intercede, what would be the point in advising this mother to “feed her baby the four food groups” – the only intervention at his disposal - when the issue was that “tenants have no food at home” (see Chapter Six for more details). 170 The second

security and inequality (see Kent 1991 for a comprehensive criticism; Pfeiffer (2004) and Janes (2004) on more recent efforts to privatize primary health care).

170 A few months into my fieldwork UNICEF also started to host a clinic for malnourished children on Friday mornings. This clinic provided RTUF food supplements (better known as “plumpy nut”) for children who qualified (see Redfield 2012 for a detailed description of plumpy nut). Children with HIV were not allocated any additional resources. However, this programme did not run in conjunction with Tuesdays and Thursday Under-5 clinics, which, frankly, would have made much more sense. Rather, health care workers “cherry picked” patients they thought could benefit from the food supplements and would refer them to the Friday clinic, which was not common knowledge. Health care workers did this because the UNICEF clinic did not have enough supplies to treat the volume of children who would qualify. Stocks often ran out the second Friday of every month, and sometimes in the first week. I routinely referred patients to this clinic, but only one family I know was ever successful at
issue, which I want to focus on in this chapter, revolves around how a global commitment to provide “universal access” to ART rarely considers that both access to treatment and the therapeutic benefits of treatment are distributed along socioeconomic fault lines (Makombe et al. 2006).\textsuperscript{171} My findings, for example, indicate that migration remains a poorly understood factor affecting treatment access and long term health outcomes for children with HIV (Barninghausen 2007; Bhatasara 2013; Lima et al. 2009).\textsuperscript{172} In nearly two years, only one of the 38 children started on ART was a tenant’s child at Temwa Rural Hospital. Given that worldwide, far more people migrate within, rather than across, borders, the lack of information about migration and access to ART is striking (IOM 2005).\textsuperscript{173} Most research to date on the barriers to universal access emphasizes the logistical and financial barriers typical of most people in resource poor settings, such as severe health care worker shortages (Makwiza, et al. 2006; Stillwell, et al. 2004); weak health infrastructure (Coovadia et al. 2005; Ginsburg et al. 2007) that in some cases is being “cannibalized” by ART roll-outs (Nguyen 2007); and the hidden costs of treatment, such as transport costs for patients travelling monthly to and from the clinics (Greene 2004; Hardon getting these resources. Aside from the UNICEF clinic, severely malnourished children could be admitted to the district hospital’s “Nutrition Rehabilitation Unit” (NRU). However, this requires a referral by a clinical officer, and they were never present at the US clinics, and admittance places a huge burden on families especially during the farming season. Tenants, for example, would lose their job if they were admitted to the district hospital. Thus, HSAs were trained to advise parents to feed their children “the four food groups.” As they noted, this was often pointless advice when the underlying problem was a lack of food, not knowledge about the quality of food to feed a child. How to find ‘good food’ was also the number one question asked of me by informants during the course of my research.

\textsuperscript{171} The WHO defines “universal access” as “80% coverage of those in need” (Therien 2012). “In need” refers to evolving clinical criteria used to determine a patient’s eligibility for treatment. In 2010, an estimated 170,000 children with HIV lived in Malawi and 100,000 were defined as “in need” of treatment according to the WHOs 2010 guidelines (UNAIDS 2013). Since the WHO’s (2013) most recent recommendations all children under five are started on treatment if sick. Thus, at the end of 2012 the estimated coverage for children was 36%, but at present it is much lower (UNAIDS 2013).

\textsuperscript{172} National guidelines have no specific provisions for internal migrants, beyond the provision of “transfer papers” which allow patients to exit treatment at one center and enter into another. However, since there is no national database for patients there is nothing preventing patients from simply leaving, retesting at another site and then initiating treatment again somewhere else. Malawi, however, does identify some groups of people as “most at risk” for HIV infection, including sex workers, truck drivers, youth, teachers and men who have sex with men (HIV Unit, Ministry of Health 2010). But, again, migration remains a severely poorly understood factor in Malawi and throughout the region.

\textsuperscript{173} 2007 data on internal migration in Malawi indicate that more than 287,000 people migrated within the country – or 2% of Malawi’s total population. Half these people moved from a rural area to an urban area, some from an urban area back to a rural area and others, like tenant farmers moved from a rural area to another rural area (NSO 2008). However, this census was conducted from 8-28 June 2008, or when the tobacco season has finished and many tenant farmers had already returned to their home villages, even temporarily. Thus, it is very difficult to accurately identify the number of tenant farmers working in Malawi.
While these issues undermine the quality of care that everyone receives at decentralized HIV treatment centres like Temwa, most of these studies also assume that the targets of HIV interventions, and perhaps especially rural targets, are a homogeneous group and that everyone seeks and uniformly receives biomedical care. Unfortunately, this “trafficking in generalizations” (Allen 2004) leads to blanket policies and programs that presume what works for one person works for another, often glossing over the reality that there are very real social and economic disparities among people seeking HIV care in rural areas. Therefore, the specific pathways through which certain categories of people, such as tenant farmers, become underrepresented in HIV treatment services remain unclear.

Following Pierre Bourdieu (1984) and others, I use the concept of “social fields” and “habitus” to help expand our understanding of health disparities beyond the obvious material constraints to the relational and distributional aspects of health inequalities (Coburn 2004; Gattrell et al. 2004; Stoebenau 2009; Veenstra 2007). For Bourdieu (1984), each individual occupies a position in a multidimensional social field; their position in this field is not just defined by their social class, or their economic capital (or command over economic assets), but by their ability to mobilize networks of influence and support (social capital); the authority or prestige granted to them based on their race, ethnicity or employment (symbolic capital); and the forms of knowledge, skills and education that they may have (cultural capital). For example, tenant farmers have limited economic capital since they neither have access to the means of production (land, or cash for farm input like fertilizer) nor do they have much social capital as new and temporary residents in a region far from their usual support networks. Moreover, they have little cultural or symbolic capital since tenant farming is considered to be both dirty and demeaning by the wider community. Thus, my analysis of how the tobacco social field in Temwa works sheds light on how hierarchical relations of power in Temwa shape access to HIV care and treatment services (Bourdieu and Wacquant 1992).

The second concept I draw on, to shed light on the social relations of power in Temwa, is the concept of “habitus.” For Bourdieu (1984), each social position, such as tenant farmers or absentee plantation owners is associated with a set of corresponding “dispositions” (i.e. style, grammar, taste, attitude), which is learned over time and taken as “natural.” Bourdieu calls this

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174 The exception perhaps would be a growing body of research looking at the higher mortality rates among men on treatment than women (see for example Callaghan 2015; Cornell et al. 2012).
“practical sense” the “habitus,” and he argues that it guides individuals and groups (beyond consciousness) in how to act, what to say, and how to say it (Bourdieu 1990). This is why, after a year in Temwa, I learned how to distinguish between tenants from landowners, based almost solely on their comportment (i.e. they did not greet me). Bourdieu’s analysis of social fields has been used to map the social determinants of health in other contexts (Gattrell, et al. 2004; McMichael and Manderson 2004; Rojas and Carlson 2006; Stoebenau 2009; Veenstra, 2007; Yip et al. 2007) and “habitus” has been successfully used to show that seemingly irrational behaviours are, in fact, socially structured (Bourgois and Schonberg 2007; Cockerham 2000; Dixon Woods et al. 2006; Holmes 2011). Drawing on these insights, I argue that an important, yet often overlooked, factor influencing universal access to ART is the way that intrarural inequalities result in the underrepresentation of specific social categories of HIV infected children in HIV treatment programs. Through an analysis of the “social field” of tobacco labour in Northern Malawi, I am critical of standardized biomedical approaches to paediatric HIV treatment that fail to address the specific needs of disadvantaged populations and the wider aspects of sickness and ill health that extend beyond the individual (Young 1982; Kleinman 1988). More broadly, my findings contribute to insights about the specific pathways through which health inequalities become inscribed onto individual bodies (Bhalla and Lapeyre 1997; Nguyen and Peschar 2003). I end by reiterating a key finding that migration powerfully affects some children’s ability to access timely ART, contributing to uneven chances of health and survival for HIV infected children.

Embodied Inequality: Tobacco Farming, Migration and Health Care in Northern Malawi

Embodied inequality is an interdisciplinary concept emphasizing how our material and social worlds result in uneven population patterns of health and disease (Krieger 2011:672; Nguyen and Peschard 2003). However, most researchers have not agreed on the mechanisms behind differential health outcomes, or on what to call them. Quesada et al. (2011: 342-3) detail a list of terms used by anthropologists to grapple with the effects of embodied inequalities. Of the two dozen they list, a few terms are relevant here including: “the social determinants of health” (Strathdee et al. 1997; Kawachi and Kenney 1999; Marmot 2005; Marmot and Wilkinson 2006), the “political and economic determinants” (Singer 2001; Navarro and Muntaner 2004;
Hamdy 2012), “zones of abandonment” (Biehl 2005), “structural violence” (Farmer 2004), “social exclusion” (Shucksmith 2012; Spangler 2011), “discrimination” (Ferrie et al. 2003; Smedley et al. 2003) and “structural vulnerability” (Quesada et al. 2011). Each of these terms could be used to explain different aspects of tenants’ children’s underrepresentation in HIV care and treatment services at Temwa, but none is sufficient on their own to explain the processes I witnessed.

One of the most influential concepts over the last two decades is the concept of “structural violence” generally attributed to Johan Galtung (1969) but developed further by Paul Farmer (1996, 2004). Farmer argues that “suffering is ‘structured’ by historically given (and often economically driven) processes and forces that conspire – whether through routine, ritual or… the hard surfaces of life – to constrain agency” (2003: 40). Farmer (2004) used the concept effectively to highlight how historical and economic processes, such as the slave trade in Haiti, result in present day health inequities. While this idea is very helpful for understanding how historical, political and economic determinants shape health disparities, it has been criticized for being too linear and deterministic (Bourgois 2004), for ignoring how individual agents interact with inequality to produce different health outcomes (Schepers-Hughes 2004), and for failing to explain how and why individuals might participate in their own oppression (Kirmayer 2004).

For example, studies have shown how symbolic and cultural attributes, such as appearance and affect (Allan 2014), education (Rojas and Carlson 2006), race/ethnicity (Duke 2012; Harrison 1994; Levy 2014) and gender and age (Braveman 2006; Currie 2012) all interface with larger political and economic structures in unexpected, but critical ways. Thus, while structural violence helps explain how global political and economic asymmetries produce conditions in which specific groups of people migrate and accept risky living conditions for economic and social mobility, it does not explain why health care workers think tenant farmers should wait to start ART until they return to their home villages, or why many tenant farmers agree with them.

Social exclusion is another concept used to think about how different categories of people have different health outcomes. Shucksmith (2012: 378-80), for example, argues that the concept gained popularity in Europe among academics and policymakers because it focuses attention on the multidimensional, rather than solely economic processes underlying inequality (see also Reimer 2004). For example, researchers have used the concept to explore how both youth and the ageing are excluded from political and economic processes in rural areas in Europe.
(Shucksmith 2004; Walsh et al. 2012). Recently Spangler (2012) used the concept of social exclusion to argue that poor women and sex workers are more likely to have unsupervised births at rural hospitals in Tanzania: poor women were excluded because they are unable to pay the bribes demanded by health care workers or to bring their own supplies for the birth, such as a razor blade to cut the umbilical cord. Sex workers had the money to pay the bribes, but because their social status was low, health care workers often excluded them from care. Critically, exclusionary tactics at health centres not only limited the care of those who sought their services, but also led to self-exclusion by women who claimed that “modern medicine is not for people like me” (Spangler 2012: 490); poorer women in particular preferred to risk giving birth at home rather than face possible ridicule and discrimination by health care workers.

In a parallel example, Whyte and Whyte (2006) also note that health care workers in Uganda used “the blanket sign” - that is, whether or not the patient was able to bring a blanket to the hospital -- to decide whom to inform about ART programs. Patients who could not afford to bring a blanket were considered too poor to benefit from ART due to the hidden costs, such as transportation and the importance of eating good food while on treatment. As in Tanzania, Whyte and Whyte (2006) also note that patients self-excluded from treatment when the financial burden placed on their extended care networks was too great. For example, one man diagnosed with HIV committed suicide rather than burden his family with his life-long care. Thus, the concept of social exclusion includes criteria that extend beyond economic criteria when defining disadvantage by highlighting how exclusion from quality biomedical care intersects with other context-specific social hierarchies, such as age, ethnicity, occupation, education, sexuality and the quality of a patient’s social support.

Despite its usefulness for explaining the social determinants of embodied health inequalities, social exclusion remains a contested concept. For example, Shucksmith points out that some consider it a theoretically weak, technocratic concept originating in anti-poverty action, while others argue that it is a euphemism that diverts attention away from wealth redistribution efforts, or worse, code for cultural explanations of poverty or poor health (2012: 379-380). Savage (2002) also argues that it places too much emphasis on rigid social categories like youth, race and gender, without considering how class might intersect with each of these social categories. Moreover, by focusing our attention on a single social category (like poor women, or indigenous Mexicans), the concept of social exclusion actually undermines efforts to
unite different categories of people who may be vulnerable to the same broader political and economic inequalities (Murard 2002; Savage 2002). For example, Duke (2011) argues that an emphasis on ethnic difference and legal status among migrant workers in the US actually prevents efforts to unite them and improve labor conditions for everyone. Thus, while structural violence focuses our attention on the political and economic determinants of health, social exclusion focuses our attention on the social determinants of health. While both of these perspectives offer valid insights into embodied inequalities, neither is able to offer a comprehensive approach that successfully incorporates each of these points of view.

Perhaps one of the most promising concepts for understanding embodied health inequalities is the idea of “structural vulnerability” recently proposed by Quesada et al. (2011). To address the criticisms lobbied at structural violence, they suggest that the word “violence” should be replaced with the more neutral and inclusive term “vulnerability.” They argue that the concept of structural vulnerability draws attention to how both the political and economic determinants interact with the social determinants of health, or things like gender, race and age. For them structural vulnerability highlights how specific individuals are located within a local hierarchical social order and how that might affect their health practices (2011: 341-2). Structural vulnerability has been used productively to examine how race and citizenship in particular shape health outcomes for Latino migrants in the US. Duke’s (2011) study of migrant labour on a shade tobacco farm in Connecticut is a good example. He argues that racially informed perceptions of what constitutes a “good worker” shape labour practices on the farm and that the ethnic division of labour is sustained because the workers internalize racialized tropes and take them as “common sense” (2011:412-3).

Holmes (2011) also uses the idea of structural vulnerability to analyse how farm labor on a berry farm in the US is structured according to a segregated continuum from white US citizens, to Latino US citizens to undocumented mestizo Mexicans, to undocumented indigenous Mexicans. He argues that those at the bottom of the hierarchy, in this case undocumented indigenous Mexicans, have increased rates of many chronic and infectious diseases (Holmes 2012). However, the immediate applicability of the concept to tobacco farm labour in Malawi is not so straightforward; tenant farmers are neither undocumented nor racialized the same way that Mexican workers are in the US. As Malawian citizens they are legally entitled to care at the Temwa Rural Hospital, yet they are still severely underrepresented in HIV care and treatment.
services. Thus, while Quesada et al (2011: 341) argue that structural vulnerability aims to illuminate the positionality of specific individuals or groups along different “symbolic taxonomies of difference” (Bourdieu 2000)… “historically distinctive discourses of difference” (Foucault 1984)… and “individual pathology and biography with social exclusion” (Biehl 2005)” I do not really see how the concept sheds any more light on the non-material aspects of embodied inequality than more nuanced approaches to structural violence.

Rather than try to incorporate disparate theories of embodied inequality into one overarching concept like “structural vulnerability,” I turn to Bourdieu (1984, 1999) to explain the underrepresentation of tenants’ children in HIV care and treatment services. For Bourdieu, society is made up of a network of social fields shaped by different forms of capital: economic (access to means of production), social (various kinds of social relationships with valued others), symbolic (prestige, legitimacy and value) and cultural (culturally valued taste and consumption patterns) (Williams 1995). The relative importance of each form of capital is shaped by the local, historical context (Bourdieu and Wacquant 1992: 17). Malawi is the largest tobacco-producing country in the world per capita (Conroy and Sachs 2006; Harrigan 2003; Wilson 2010). As the tobacco growing and transport hub in the Northern region of Malawi, tobacco planting, growing, harvesting and selling was and is the defining feature of life in Temwa in every way. Most of the farmers growing tobacco told me that it was their only source of cash, which they needed to pay for fertilizer, to pay for their children’s secondary school fees, kitchen pots, food, school uniforms, transport, medicines, clothing and building supplies for houses – especially cement and iron sheets used for roofs. Thus, I draw on Bourdieu’s concepts of social fields to problematize the concept of “universal access” more broadly by exploring how intersecting and mutually reinforcing systems of social, symbolic, cultural and economic inequality operate.

Bourdieu’s approach to inequality has implications for the design and implementation of pediatric HIV treatment programmes in Malawi and beyond. Three key aspects of Bourdieu’s theorizations of social inequality are of particular importance for understanding embodied inequalities in Temwa. First, Bourdieu’s emphasis on the empirical analysis of any given social field facilitates the discovery of locally relevant social categories, rather than predetermined axes

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of difference. For example, when I first arrived in Temwa I knew that tenants were an important social category; however, I had no idea that other categories, such as “renters,” existed at all. If I had designed a survey trying to understand the underrepresentation of children in HIV treatment services, I would have missed them entirely. This is especially crucial when the social categories at hand are not immediately visible through more commonly described axes of difference such as skin colour, language, gender and age. Rather, they only became visible to me (everyone else could see them clearly) over time through extended participant observation as I learned how to decipher subtle differences in dress, demeanor and linguistic style which divided tenants from landowners.

Second, Bourdieu’s concept of “habitus” helps contextualize patient-provider interactions at Temwa Rural Hospital. For Bourdieu (1977; 1984), social categories are associated with a set of “dispositions” (i.e. style, accent, comportment) structured by the “habitus.” For example, in North America the term “manspreading” is used to refer to a phenomena where men (unconsciously) take up too much space on crowded public transit. Habitus emphasizes how bodily practices, such as how a person sits, holds eye contact and even walks, is reinforced over time by participating in different social locations (Holt 2008: 232; Bourdieu and Wacquant 1992). Or, put another way, habitus is the embodied materialization of individuals’ capitals, or their “internalized capital” (Bourdieu 1984: 114). Thus, habitus is essentially a way of being in the world that seems natural, or taken for granted. At Temwa Rural Hospital, access to ART was mediated through a patient’s social position in the community, which was rendered legible through their habitus. The result was that health care workers facilitated access to ART for those that they felt could “make it” (or those with the financial and social resources to survive on treatment), while letting others go home undiagnosed, (since the social and economic conditions of their lives made death likely from their point of view). These assessments were made during very brief clinical assessments, a fact which I will discuss in more detail below.

Finally, habitus also helps explain individual actions that initially seem uninformed or irrational from a public health perspective. As Holt argues, Bourdieu offers a more nuanced understanding of agency via habitus, which emphasizes the beyond conscious, habitual,

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177 Although it was rare for health care workers to recommend HIV tests (an issue I take up below), after testing they encouraged some patients more than others to start treatment rapidly.
embodied and non-reflexive elements of everyday practices (2008: 232). One of the challenges I faced when trying to interpret my findings is that my data seemed to contradict itself; on the one hand, I had evidence that health care workers were deliberately excluding tenants from care, while on the other, I had evidence that tenants were avoiding HIV care and treatment services themselves. One of the main contributions of Bourdieu’s analysis is to overcome the dichotomy between “structure” and “agency” by emphasizing how dominant relations in society become incorporated into everyday practices (Holt 2012). For Bourdieu, individual decisions by either patients or health care workers may be subconscious and governed by dispositions and choices that defy rational reflection since they reflect the internalization of the social order (Holt 2012: 234; see also Dixon-Woods et al. 2006; Cresswell 2002). Thus, habitus helps illuminate how the oppressed, in this case tenant farmers, participate in their own oppression (by delaying ART initiation in this case). As Webb et al. (2002: 25) explain:

Agents are subjected to forms of violence (treated as inferior, denied resources, limited in their social mobility and aspirations) but they do not perceive it that way; rather their situation seems to them to be ‘the natural order of things’.

To illustrate the importance of these points I describe the social field of tobacco farming in Temwa Rural Hospital’s catchment area. The hierarchies I describe, from tenant farmers up to absentee plantation owners, produces differential health outcomes for children with HIV. These complex intrarural inequalities result in the underrepresentation of tenant farmers’ children in HIV treatment programs. Through an analysis of the “social field” of tobacco labour in Temwa, I challenge oversimplified approaches to ART rollout by describing how complex rural hierarchies are. In the final section of this chapter I examine two specific, but interrelated, pathways towards health inequalities for HIV positive children.

“Dirty Like a Tenant”: The Social Field of Tobacco Labour in Northern Malawi

*I feel so sick from the smell I don’t even feel like having dinner! [Laughter]. Why can’t tenants wash their genitals before coming to give birth here?*

- Nurse M to Nurse L at Temwa Rural Hospital in front of patients

We were sitting in the shade under a *gafa*, surrounded by the pungent aroma of drying tobacco. *Gafa* are the low lying structures built each season to dry tobacco. A half dozen tenant
farmers and their children graded (sorted by quality), “sewed” (tied leaves together with dried corn husks) and hung small bundles of leaves over our heads. Issa, a former tenant farmer, but now manager of a 100 acre tobacco estate owned by an absentee landowner working for a major NGO in Lilongwe, was telling me why thousands make their way to Temwa every year to find work in the area. He explained:

Here is different from Mangochi [Southern Malawi] because of poverty. Here you can find money because tobacco farms are like the [gold] mines [in South Africa]. Here I can find money to help our friends at home and then when it is time I will go back.¹⁷⁹

Like so many other tenant farmers using their earnings to build a house in their home villages, his ultimate goal (which he accomplished the next year after 12 years as manager of this estate) was to rent his own land and grow his own tobacco, rather than work for someone else, before retiring where he “belonged” [in his home village].

On our 10km journey back to Temwa town from Issa’s house, the rhythm of tobacco season’s ending was our constant companion. One and two tonne trucks filled with tobacco bales spewed dust and diesel exhaust into our faces as they lumbered past on their way to auction floors in Mzuzu. Fields of tall luscious green tobacco plants topped with large beautiful pink flowers (both a sign that the season was over or that the tenant responsible had failed to harvest the crop on time) filled the fields on either side of the dirt road I negotiated slowly on my small Yamaha DT motorbike. Once back in town, dried loose tobacco yet to be baled, sat in large piles on every other front porch. Even the porch of the town’s post office was filled with dried tobacco as the local postman weighed and baled his tobacco while on duty. I dropped my motorbike at home and went straight to the market to pick up food for dinner. Food choices were very slim in Temwa; since

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¹⁷⁸ Although Malawians use metric weights and measures for most things, including kilometers for distance, the British colonial era means that all land is measured in acres.

¹⁷⁹ Tenants told me that they bought materials to build homes, fertilizer, clothes and set up small businesses for family members in their home villages. In a longitudinal study conducted by Peters (2006) in Southern Malawi she found the same pattern.
tobacco instead of food dominated local agriculture, the only things for sale were some sad looking tomatoes and a few piles of pumpkin leaves. There were, however, lots of cheap plastic buckets and Made in China polyester clothes for sale. Back home I found my landlord’s children playing outside. Like so many ten year old boys in town, they were busy playing “tobacco truck driver”; they made one tonne truck Lorries out of mud and were piling them with imaginary tobacco bales made out of old bricks (see Figure 22). They told me they hoped to one day become tobacco truck owners – a lucrative business among the town’s wealthier residents. I moved to the back of my house and started a fire to boil water for my bath and watched the sun set over the tobacco fields behind my house. I hummed along to the music blaring from the town’s many brothels.\(^{180}\)

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My interest in tenant farmers often confounded, and sometimes angered, local landowners. Most could not understand why I would be interested in people “who are not even from here.” The general gist of their arguments was that as visitors (mulendo) to the area, they had no rights to resources that were meant for people who belonged (wachikaya/wakukaya). To understand the dynamics between “mulendos” and “wachikayas”, or visitors (tenants) and “those who belong” (landowners), this chapter draws mainly on results from Phase 1 of my research, where I spent the majority of my time familiarizing myself with the role of tobacco in everyday life. To that end I accompanied four HSAs on their duties in the first three months of fieldwork. On these trips, either made on foot or by bicycle up to 15km from town, I observed village inspections, maternal and neonatal health follow-ups, sanitation workshops, mobile clinics. In each of these areas I also organised and sponsored “recipe days” to gather people from these areas to talk about health challenges in their areas.\(^{181}\) These village areas were selected by health care workers at Temwa Rural Hospital when I asked them to pick areas they felt represented the

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\(^{180}\) Prowse (2009) noted that condom sales went up by a factor of four during the tobacco harvest season in Kasungu town – the tobacco growing center in Central Malawi. Although it is impossible for me to confirm this, since as a woman I never had access to these male dominated social spaces in town, the number of condom wrappers strewn outside the sex workers’ windows in the morning clearly increased during this time of year. One important implication of the link between sex work and tobacco is that the HIV infection rate in Temwa might be much higher than aggregated regional statistics suggest.

\(^{181}\) These recipe days were modeled on ones I participated in while I was an employee of the Soils Food and Health Communities project at Ekwendeni hospital. Essentially, HSAs and village headmen recruited women from the community to prepare a locally available and nutritious food item for the community so that everyone could learn how it was made and to taste it. I contributed by providing cooking oil, tomatoes and meat to feed everyone who participated. The response was very positive and I had many requests to conduct them in all the village areas supervised by HSAs but did not do so because of time constraints.
variety of livelihood strategies and living conditions within Temwa hospital’s catchment area. Health care workers expanded my understanding of the social field in Temwa beyond just “tenant farmers” and “landowners” to include “renters,” “self-employed farmers” and “bwanas” (big men, bosses or more colloquially “the big bellies”) or the local elites, which in this context included religious leaders, plantation owners, civil servants (teachers, police officers, health care workers), tobacco truck owners, Chiefs and village headmen. I will discuss in detail each of these social categories below in relation to the different forms of capital outlined by Bourdieu (1986).

**Forms of Capital in the Tobacco Social Field**

I consider the community-named categories tenant, renter, self-employed farmer, landowners and bwanas as collective social positions within a tobacco social field structured around symbolic, cultural, economic and social capital. Economic capital in this context represents primarily an individual’s access to land, and, by extension, the resources derived from land, including food and cash from tobacco sales or rental income. Land in Malawi is obtained through customary land tenure, which essentially means that in the Northern region (which is patrilineal), men inherit land in their father’s village area. In the Southern region (which is matrilineal), women inherit land via their mothers. Thus, landowners in Temwa are boys and men living in the village of their father’s birth. A few notable exceptions included women living in their mother’s home villages who were given land by the village headmen in their mother’s village, and while this was fairly common, it was not a universal practice. For example, widowed or divorced women were sometimes given land in the village of their birth or their mother’s birth. Also, some local women married tenant farmers, and eventually were given land in the village of their birth. However, in general the quality of the land that these women were given was poorer – for example they were given smaller parcels of land with sandy soil with no access

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182 Of note here but beyond the scope of this chapter is that local elites also avoided the ART clinic at Temwa rural hospital. I was told that they obtained their medicines at night from health care workers or collected them at distant hospitals while doing business out of town. In particular, I was aware of a number of HIV positive “big men” (bwanas) and Chiefs who obtained treatment elsewhere to protect their privacy and reputations.

183 Of note is that while Temwa is a rural area, primarily populated by smallholder farmers, the dominance of the tobacco industry meant that most people purchased their food, rather than growing it themselves.
to a “dimba” (river bed used to plant tobacco nurseries or vegetables). Significantly, all but one of the tenant farmers I talked to had land in their home villages, but they had no way to “find cash” (or grow a cash crop) on that land; hence, they migrated to a tobacco growing region. Thus, economic capital in Temwa was mediated by gender, migration status, customary rules governing inheritance and occasionally decisions made by individual village headmen.184

Distinctions in economic capital provide only partial insight into the tobacco social field in Temwa. Symbolic and cultural capital associated with occupation, education and ethnicity also shaped dispositions, identities, opportunities and health strategies for sick children. Perhaps most importantly is that in everyday life, migrants in Malawi are not entitled to the same benefits or resources as non-migrants. All migrants, whether tenant farming or doing business, are assigned the socially meaningful category of “visitors” or “mulendo.” The “mulendo” is a category of person referring to people staying in a place where they do not “belong” or a place that is not their “home village” (wakukaya). For example, one of the first questions a person in Malawi asks you is “where is your home village?” A person from the North will always respond with the name of their father’s home village – even if they have never lived there in their lives. This is also the place where their body will be buried when they die. Customary laws and social customs restrict access to valuable social and economic opportunities for mulendos. As one HSA explained: “You know there is a problem in the villages because in most of the activities the tenants are being sidelined by village headmen saying... ‘no you are visitors to this village’ so that’s why most of them they do not express their views.” By “sidelined” Mr. J was referring to the exclusion of migrants from many aspects of community life that could benefit them in some way. For example, each village has a volunteer run Village Development Committee (VDC), which decides how government or NGO resources will be distributed. During my research the government provided each village with a limited number of fertilizer coupons, and each committee decided how they would distribute these coupons; some decided to distribute them to widows, others to their friends and neighbours, while others focused on HIV/AIDS affected households. However, tenants are not entitled to any of these resources even if, for example, they have HIV. As one tenant explained to me: “Life is very difficult here because we have no rights.

184 It is important to note that large areas of land in this area were not farmed by anyone. An example is that one village area was very “underpopulated” according to the village headman governing the area. Thus, he was renting land to tenants who wanted to farm “on that side” - over time he said they could “have” the land if they wanted to stay.
We are *under* the authority” (emphasis mine). Other examples I was told of were tenants who tried to start small businesses (i.e. shoe mending, fixing bicycle flats) and were told to desist because someone who “belonged” was already doing that business. Tenants were also rarely allowed to purchase land (in fact there was a minor political movement to destroy the migrant neighbourhood in Temwaw town while I was there) or lay claim to any NGO resources that might target vulnerable populations.\(^{185}\) The logic behind these decisions was that if they wanted access to these limited resources they should do so in their own home villages. This is important for HIV/AIDS care since in the context of resource shortages at the hospital, HIV/AIDS medicines, health care services and food supplements were all limited resources.

Symbolic and cultural capital intersected with ethnicity in unexpected ways. Landowners are from the Tumbuka ethnic minority, whereas most tenant farmers are from Southern Malawi. There are no visible differences in skin colour or facial features to distinguish one ethnic group from another in Malawi and there is little antagonism between different ethnicities; intermarriage is widespread and daily interactions are amicable.\(^{186}\) However, the fact that many tenants came from Southern Malawi was significant because it was used by landowners to make broader conclusions about regional variations in education, taste and religion, which were considered significant. The Northern region is distinct from the central and southern regions in a number of important ways. While Northern Malawi has been economically and politically marginalized since independence from Britain in 1964 (Friedson 1996; Vail and White 1989), Rumphi district has the highest levels of education in the country. For instance, 70 percent of Tumbuka women are literate, compared to only 12% of Yao women; 93% of Tumbuka men are literate whereas only 41% of Chewa men report that they can read and write (Poulin 2007). These rates are a historical remnant of the Livingstonia Mission, which favoured the Tumbuka by providing free education during the colonial era (McCracken 1997). Many of Malawi’s most educated

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\(^{185}\) For example, both World Vision and the Norwegian Development Fund (NDF) had food security projects in the region. However, since VDCs select the children to be sponsored by World Vision none of these children are migrants (Bornstein 2001, 2003). Also, when I asked the NDF how they incorporated tenants into their projects, they were not even aware that there were migrant labourers living in the region. Tenants’ children were also underrepresented in school; some told me it’s because their children could not speak chiTumbuka (the language of instruction in the region until secondary school). However, in heavily populated tenant areas the schools were atrocious. In one area in particular the school had two teachers for hundreds of children and it was a mud room with a grass roof. Thus, even government resources directed at tenants were pitiful.

\(^{186}\) Although for the most part this was true, I was told there are a few minor distinctions worth noting. Tongans for example are generally described as being shorter than other Malawians because historically they intermarried with the “Akafulas” or first people of Malawi who were pygmies. Tumbukas tend to be considered taller than some Malawians on average with “wider foreheads”. The size and shape of the forehead, along with the hairline is something that many Malawians used effectively to recognize kinship ties. For example, people were able to discern who my research assistant was related to based on the shape of her forehead – this happened repeatedly during our home visits.
(university professors and medical doctors for example) own and manage tobacco estates in Temwa’s catchment area. This fact was cited to me repeatedly by landowners as they considered it to be one of the most salient differences between Tumbukas and the rest of the country. As one prominent Chief said to me, “We Tumbuka value education. The first free school for boys and girls in Malawi was opened here by my father in 1912.” Significantly, these differences in cultural and symbolic capital were used by health care workers to make distinctions between those who “could and could not make it” on HIV treatment at the rural hospital, which I discuss below.

Many tenant farmers are also either Lomwe, Chewa or Yao from Southern Malawi, who are generally considered to be “ignorant” (less educated) and therefore “less refined” by Northerners. For example, a widely cited difference between Chewas and Northerners is that the former eat rats and monkeys, while the Tumbuka do not. Another is that Yaos, an ethnic minority from Southern Malawi who make up most of the country’s practicing Muslims, make good tenant farmers because they do not drink alcohol, and are therefore more reliable labourers. Also, since tenant farming was generally considered a demeaning form of labour, Tongan people, an ethnic group who rely on fishing along Lake Malawi, are the only ethnic group not represented in Temwa; most landowners in Tumbuka argued that this was because Tongans are “too vain” and “too proud” to labour for food.187 Notably, a quarter of the renters and self-employed farmers I spoke to were actually from further North in Malawi and many of them were also Tumbukas, a fact that initially surprised me and the health care workers at the hospital. However, unlike tenant farmers from the South, they had an easier time accessing land to rent and were typically charged less for it when they did, often because they had the cultural capital (language, education) and social capital (distant kin networks through the Tumbuka clan system) to draw upon. While the division of labour within the tobacco social field was loosely stratified according to ethnicity, there was a lot of movement between each of these social categories. For example, some tenant farmers were able over time to accumulate capital and run small businesses in the migrant neighbourhood BusyBusy.

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187 An example I was told by many people to explain this fact was that Tongans like to carry a handkerchief with them wherever they go; people would pretend to be Tongan walking with their head held high and wipe off every speck of dirt that touched them as they went. Tongans embraced these ideas wholeheartedly and told me many times that “for Tongans there is no weather.” Often referring to the fact that Tongans like to dress very well (including wearing suits and jackets) even in the hottest weather.
A key feature of symbolic and cultural capital is that they are contingent. In other words, what is considered worthy and worthwhile, is not determined by an objective measure but in social context. As Bourdieu argues, capital is also embodied in “long-lasting dispositions of the mind and body” (1986: 243). By this he meant that norms of appropriate identity performance are unconsciously inculcated into everyday practices (Holt 2008: 237; Butler 1999). Although these norms exist beyond a person’s individual control, they must also be reproduced by individuals in their social practices (Kelly and Luis 2006: 834). This is where Bourdieu’s concept of habitus is important, since how a person behaves in the clinic provides clues about their overall volume of capital. For example, tenant farmers kneel on the ground when making requests of those considered their superiors, including health care workers, their employers and village headmen. In the ART clinic, wealthier men typically took their place first in line on the benches, while women and tenants sat on the floor and went last. Women, for example, are not supposed to have their heads above more senior men; male tenants in many ways are expected to behave like women with their landlords. Those with more capital overall could also cut the long lines in the outpatient-department by using a “back door” (a door on the other side of the building) meant for that purpose. In more everyday settings, women remove their shoes when entering a house, while men do not. More broadly, then, Bourdieu’s insights into the internalisation of social expectations and value systems into bodily dispositions and practices helps transcend the divide between structure and agency, by examining how actions are both constrained by, but at the same time constitutive of, a deeper structure.

Social capital also structures the social field of tobacco farming. Broadly speaking, social capital illuminates the value of social relationships and networks to individuals. For Bourdieu, “the volume of the social capital possessed by a given agent… depends on the… volume of the capital (economic, cultural, symbolic) possessed” (1986: 250). In other words, social capital is accumulated and/or lost alongside other forms of capital. For example, most tenants have little or no education and do not speak chiTumbuka (low cultural capital); thus, they are unable to develop social capital in Temwa. Renters and self-employed farmers, on the other hand, were more likely to be Tumbuka speakers – often because they could more easily integrate into the community and cultivate the relationships necessary to rent land. Another key issue is that the structure of tenant farmers’ social capital is fundamentally altered during migration. All tenants migrated without the grandparents, who are often a crucial form of support in their home
villages, an issue I took up in more detail in Chapter two. Through migration they lost extended
kin networks, neighbours and friends. For example, during the survey at Temwa Rural Hospital I
asked each informant about food sharing practices. While landowners routinely shared food with
neighbours and relatives (mangoes, fresh maize, pumpkins) tenants only ever shared salt with
fellow tenants. Or, as Jupiter, a renter from Northern Malawi explained to me when I asked him
if anyone had helped them since they arrived:

[Laughing very hard at my question…] No. I have not shared anything with anyone and
no one has shared anything with us because of how we stay here in this village. We don’t
belong here; we are visitors (mulendos) so it is not common for us to get visitors. It is not
common…

This is critical for tenant farmers whose total volume of capital often declines with migration;
their economic capital (land) is out of reach while in Temwa, their cultural and symbolic assets
(such as Chieftainships, religion, language) do not have the same value across these contexts,
and their social capital is often weakened (Kelly and Luis 2006: 835). However, as Jupiter and
other tenants explained, these changes were not always bad. For him, migration was a way of
escaping the negative demands placed on him by his social networks (see also Moore 2009). As
he said:

To my side, where you were born and where you grow up you meet a lot of problems…. For you to be okay, for example, to become rich where you are born is difficult because of jealousy… it is difficult to do business or to farm a lot… Or, if you build a good house with iron sheets, people will become jealous of you. There are some bad people [witches] and they will start making your children sick… The only way to protect yourself is to change places [migrate], like I have done here.

While many migrants framed their loss of social capital as a good thing, the addition of a “boss”
or a “bwana” was often considered a major detriment, especially for men who were used to
being “the heads of house,” but now suddenly were “under the authority.” Most did not like
being subordinate to their bosses and considered tenancy a temporary arrangement for long term
economic gain and social mobility in their home villages. Moreover, both health care workers
and tenants felt that temporary alterations in a tenant’s social capital during the tobacco season
made treatment delays both logical and beneficial for infected children since treatment required
significant inputs from extended family networks in terms of both time and money. Thus, both perceived and real changes in social capital helped reproduce embodied inequalities (Holt 2008).

The Social Organization of Tobacco Labor: Tenants, Renters and Self-Employed Farmers

Thousands of tenants, either single men or young families with small children, migrate from all over the country to find work in early August every year. Most find work through their social networks, such as relatives, fellow churchgoers or former neighbours already working in the area, while some find work by going to the “chirabu” (men’s drinking area selling locally brewed beers) to meet potential employers. Extra labour is required because tobacco is a very labour intensive crop: tobacco nurseries need to be watered constantly before the rains start, and then transplanted to fields that have all been cleared and ridged by hand. Regular weeding, two fertilizer applications, continuous harvesting as the plants mature and “topping” (chopping off the flowers at the top to prevent the tobacco from getting bitter) are time consuming and gendered tasks. As the tobacco is harvested, leaves are graded then “sewn” together so they can be hung and dried in a tobacco shed or “gafa” built by hand each year by men from bamboo. Most tenants are also responsible for building their own houses at the beginning of the season; usually these bamboo and mud structures are only strong enough to last one season (see Figure 23). The overall result is that within individual villages tenant farmers are easily distinguishable from local landowners: their housing, language, lack of extended kin networks and livelihood strategy all make them identifiable on a day to day basis.

188 The Center for Tobacco Control Research and Education (2006) estimates that there are nearly 2 million Malawians working directly in the Tobacco industry in Malawi. Nearly 80,000 are children less than 14 years old and 55% of these are between the ages of 7-9. Labour on tobacco farms is also strictly divided by gender. Men are responsible for building the gafas, procuring fertilizer, applying fertilizer, negotiating with the landowner, watering the tobacco in the nurseries and baling the tobacco after it has dried. Women (and children) on the other hand are responsible for most of the daily labour including weeding, harvesting and sewing. However, when I suggested to a group of female tenants that maybe landowners should pay men and women equally they felt that this would do irreparable damage to their marriages and instead suggested that landowners pay women a smaller amount of money, but give the bulk of the year’s payment to their husbands. The implications of these labour arrangements are manifold, but notably while single men can find employment on farms women cannot. The result is that some female tenants found ‘husbands’ for the season [see narrative below].
The average tenant household (husband, wife and young children) is capable of farming 1-2 acres per year for either a smallholder landowner or on a larger tobacco estate. The total amount of tobacco harvested each year varied widely for a number of reasons. Fertilizer is very expensive and not all landowners could afford it; a freak hail storm destroyed some crops; a few tenants got sick, limiting their farm activities, while others’ yields were far higher than the average since they had years of experience with tobacco farming.\textsuperscript{189} Soil quality and rainfall also varied greatly throughout Temwa’s catchment area, providing a distinct advantage to some.

Tenants are paid monthly with maize (one to two tins of maize per household was the average)\textsuperscript{190} and then a lump sum after the tobacco is sold at auction between April and September every year. However, food rations stop as soon as the harvest is complete, often by the end of March. Thus, most tenants often wait months for the tobacco to be sold at auction. This lag in time between the end of rations and receipt of the lump sum payment creates an annual hungry season for tenant farmers only. For local landowners this is the post-harvest season and their access to food increases. This highlights how intrarural inequalities within Malawi also differentially shape health and food security for different social groups.

Payment arrangements also varied widely, and there is no way for tenants to enforce agreements with landowners.\textsuperscript{191} There were widespread reports of landowners failing to pay the pre-agreed amount, perhaps in some cases because they knew that the agreement could never be enforced but also because the cost of farming tobacco often put landowners into debt, forcing them to pay back loans rather than tenants at the end of the season. For example, some tenants were paid by “agreement” or an amount per bale decided on ahead of time, while others were paid per kilogram harvested and processed. Landowners and estate managers did not like this process since tenants would put stones in the bales or get the tobacco wet to make the bales heavier than they really were. Whatever arrangement was agreed upon, the tenants I spoke to were paid between 25,000MK-100,000MK, or around 100-400USD per household for eight-twelve months of labour. Aside from the monthly maize payments, tenants were not provided with any money or food, making them extremely vulnerable until the tobacco was sold at auction.

\textsuperscript{189} Weeding is critical for the proper management of tobacco and maize crops alike. For example, I was unable to find anyone to weed my maize at the right time leading to the loss of a ¼ acre to termites.

\textsuperscript{190} A tin of maize is approximately 12kg. A tin of maize lasts approximately one month for a small family of four.

\textsuperscript{191} An exception was that a large paprika estate owned by British investors hired tenant labor in the catchment area. Farmers protested in 2009 against their low pay; they were dispersed by police from Rumphi.
(Bezner Kerr 2005). In addition to the work they did for their bwana, most also did a form of inter-household labour exchange for food called “ganyu” to survive on a month-to-month basis. Examples of ganyu labour included harvesting the maize field of a farmer who did not grow tobacco or weeding a maize field for food, money or other household essentials like soap.\footnote{Ganyu is a good indicator of relative poverty in rural Malawi (ref). Significantly, women are paid far less than men for ganyu labour. For example: a man might be paid 3500MK (25$CAD) to harvest an acre of maize, whereas a woman might be paid 500MK (3$CAD) to shell a tin of maize.}

Some tenants were also able to secure cash loans (plus interest owed) from wealthier landowners against their future earnings. Despite this extra work, most tenants had little to no cash for most of the farming season, which made transport costs to and from the hospital prohibitive for those too far away to walk.

Although there are important economic differences between tenants and landowners, each of these social categories was also imbued with different levels of social, symbolic and cultural capital. Health care workers, local landowners and tenants alike used the category of “matenant” (the plural of tenant) to reflect upon poverty, or “mpawi,” in Malawi. Mpawi was generally used as a broad category to highlight how inflation affects the price of commodities (petrol in particular), and how labour shortages partially attributable to the HIV/AIDS pandemic had led to poorer living conditions and increased rates of food insecurity since democratization in 1994 (deWaal and Whiteside 2003; Englund 2002). In everyday conversations, tenants embodied everything that was wrong with Malawi: food insecurity, poor living conditions, lack of educational opportunities, unpredictable inflation, and disease. At the same time, many also characterised tenants as the agents of their own destruction: ignorant, overly fertile (fertility rates are higher in the south than the north) and “only interested in finding money for today”, never thinking of their futures. Others, however, portrayed tenants as subjects to be pitied: victims of Malawi’s unstable economy and greedy landowners. In everyday practice, commonly accepted ideas about tenants were also used to discipline children or tease friends and neighbours. For example, children who refused to bathe were often teased for being “dirty like a tenant,” which often persuaded even the reluctant toddler to get in the tub.\footnote{Another favorite is to tell children that if they don’t bathe a “mzungu” (white person) will bite and/or eat you.} While playing, children re-enacted these small dramas during kudimbika – a game played by children similar to “house” in North America. The child playing the role of the tenant put on torn clothing, mussed up their hair, rubbed dirt up their legs, and avoided eye contact with their playmates, thereby recreating local
social hierarchies (see also Hirschfeld 2002 on “cootie lore” on North American playgrounds). The ideas circulating around tenants placed them somewhere between grinding poverty and recent historical shifts that allow everyone the opportunity (in theory) to escape poverty through tobacco farming.

Yet a tension existed: despite the decline in living conditions associated with tenant farming, it was also imagined as a route to social mobility. That is, through tobacco farming some tenants eventually achieved their goal of starting a small business or renting land and growing their own tobacco – some even hiring their own tenants in time – which within Temwa’s catchment area was interpreted as a sign of personal achievement and respectability. Renters were farmers who rented unused land from local landowners to grow and sell their own tobacco; self-employed farmers also rented land to grow tobacco, but usually ran a small-business on the side to pay others to do the actual farm labour. Many tenants who stayed on for years aimed to raise enough capital to farm tobacco on their own or to start a small business, which they used the profits from to pay others to farm tobacco for them. Unlike tenants, renters and self-employed farmers do not have to share their tobacco sale profits with anyone, and they therefore make much more money than tenants. For example, while the average tenant agreement was 8,000MK/bale during my research (50$/bale), the average bale sells for over 100,000MK (600$/bale) at auction and an acre of maize yields between 1-4 bales. However, both renters and self-employed farmers needed a considerable amount of money saved to buy fertilizer (100$ or more per acre), and food (20$/month), and pay for ganyu labour during the time sensitive weeding and harvest times. Thus, while renters had the potential to make a lot of money from tobacco, they often made tremendous sacrifices in the short term to acquire it. While many tenant farmers initially planned on returning to their home villages after two or three seasons of tenant farming, many, like Jupiter, stayed much longer than they intended because the economic capital that they accumulate while farming as a tenant puts them at risk in their home villages. Some feared that the financial demands placed on them by kin when they returned home would be so great they would lose all their accumulated wealth, while others worried that their new wealth would incur the jealousy of others. As I explained in Chapter two, jealousy leads to witchcraft attacks, which could result in death.

Simple characterisations of the “matenant” also often obscure important socioeconomic disparities between tenants, as well as similarities between them and local landowners. For
example, tenant farmers and many local landowners alike rely heavily on ganyu labour to survive because of the high costs of fertilizer and high rates of food insecurity throughout the region (Bryceson 2006; Bezner Kerr 2005). While standard representations of the tenant describe them as “the poorest of the poor,” this narrative also masks the variety of factors that motivate tenants to search for work far from home and the economic resources that are usually necessary to do so. As Englund noted with rural-urban migrants in Malawi, migration often involves considerable expense, but is offset by the potential of migration to improve living conditions in the home village. In this sense, Englund is arguing against most depictions of rural-urban migration which characterise it as a “pathological… phenomenon that would not exist if the socio-economic conditions were right” (2002: 139). Instead he says it is critical to remember that migration is often expensive, and only undertaken by individuals who have the economic (transport money) and social capital (networks in the host area) that could lead to social mobility and material benefit. While most rural-rural migrants in Temwa did cite “poverty” as a reason for leaving their home villages, when asked to explain what they meant by this they did not frame their migration as a strategy to cope with land shortages, grinding poverty or desperation, which is how it is often characterised. Rather migrants framed this decision in terms of their aspirations for social mobility through migration: to build a house with iron sheets, open a small business, or farm tobacco themselves at a later date after they gained the skills working as a tenant.

“Poverty” for tenants therefore did not connote suffering or a lack of food or land, but an inability to obtain powerful forms of capital in their own home villages: experience, clothing, houses and businesses. Many felt that this was only possible in areas far from kin and extended family networks because of the social obligation to share any material gain with relatives. That is, while far away from family obligations they could amass material wealth without fear of repercussions —in this context, fear of being poisoned or bewitched by a resentful and jealous relative, or the social pressures to share material wealth with poorer relatives. In addition, the concept of “poverty” not only refers to material constraints but also a lack of social capital at home. Nearly every tenant I spoke with referred obliquely to “problems” at home as one of the reasons for moving away. One woman decided to move after her sister became very jealous of her loving relationship with her husband, and she feared for her life (because of witchcraft). Many young male tenants also said they were trying to avoid living with their in-laws, a common practice in the matrilineal South. As one newly married man said succinctly:
Ah… To live with my wife’s family! They will be saying to me all the time: ‘Why are you drinking beer, in-law? Why haven’t you brought us good relish [food], in-law? You see that is why it is better for us to stay here, so when we move back we can build our own house.

Others also euphemistically referred to their recent HIV diagnosis, a recent divorce or widowhood as major motivators for leaving home (see also Anglewicz 2012 on how HIV positive individuals are more likely to migrate in Malawi). Therefore, tenant farmers come from all over Malawi (and beyond) and often migrate for complex socioeconomic reasons that do not easily sit with their characterisation as “the poorest of the poor.” While local landowners characterise tenant farmers as the “poorest of the poor” and highly mobile and temporary residents, most of these characterisations are objectively incorrect. Rather, commonly held ideas about tenants are based on social evaluations of their collective volume of capital (Bourdieu 1984), and these ideas in turn reproduce privilege and disadvantage which are concealed under these taken-for-granted assumptions about tenant farmers and their place in Temwa. As I will show below, these over simplified characterisations of tenant farmers result in the underrepresentation of HIV positive tenants children in HIV care and treatment programmes.

Prestige, Authority and Tobacco Farming: Landowners and Bwanas

Tobacco growers (both smallholder farmers and large estate owners) are typically wealthier than most local landowners since tobacco requires expensive investments in fertilizer, seed, and food. Tenant farming for smallholder landowners and rental agreements between migrants and local landowners are reflective of major historical shifts in Malawi. The right to grow tobacco was once restricted to the rich and influential, through the procurement of expensive government regulated “special licenses” (Bezner Kerr 2005; Kydd and Christiansen

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194 In addition, at least one third of all tenants are from similar linguistic and cultural groups from nearby and further North in Malawi and not Southern Malawi. Notably however, many of these tenants seek out labor on tobacco farms far from their home villages to avoid the social stigma attached to tenant farming. However, Tumbuka-speaking tenants have significant advantages over migrants from Southern Malawi since they share a language and some distant kinship ties via marriage or clan affiliation. For example, Tumbuka tenants pay less to rent land from local landowners than migrants from Southern Malawi.

195 Many local landowners grow tobacco without the help of tenants; however without extra labor most can only grow a small amount to raise money for school fees or buy household supplies, such as ¼ acre.
Following Independence from Britain in 1964, President for Life Kamuzu Banda increased labour intensive agricultural exports. From 1970 to 1993 large agricultural estates grew from 2 percent of the total cultivated land to 19 percent (Msukwa 1994). During this time there was a decline in customary (or kinship based) work parties and an increased reliance on a quasi-feudal tenancy arrangements under which smallholder farmers supplied labour to plantations for food or income (Bezner Kerr 2005; Englund 1999; Kydd and Christiansen 1982). A catastrophic drought, the loss of transport routes through war-torn Mozambique, and a fall in export prices at the end of the 1970s, followed by a series of structural adjustment loans from the 1980s onwards, made smallholder farmers even more reliant on informal labour or tenancy agreements for food than ever before (Englund 1999; Peters 1996). Structural adjustment policies in the 1980s and, later, the liberalization of burley tobacco after 1990, opened up burley tobacco to thousands of smallholder farmers (Ellis et al. 2003; Takane 2005). However, while these policies aimed to reduce poverty and stimulate development in rural areas, they inadvertently exacerbated rural inequalities and increased food insecurity instead (Conroy 2006; Harrigan 2001).

While some smallholder farmers benefitted from the liberalization of the tobacco market through small scale production for household supplies or school fees, larger scale production requiring tenant labour is beyond the financial reach of most (Orr 2000). Bryceson (2006), for example, argues that the increasing number of local landowners renting land to their wealthier neighbours or to tenant farmers from different regions of Malawi highlights how rural inequality is rising throughout the country. Therefore, since only a few smallholder farmers, political elite and salaried civil servants (teachers, health care workers, police officers) have enough surplus cash and food to hire tenant farmers, tobacco farming remains a powerful symbol of upward social mobility and prosperity among rural Malawians (see also Prowse 2009 on tobacco farming and social status in Central Malawi). Many of the landowners I spoke to, for example, also aspired to raise enough capital to grow tobacco in the future.
The production and sale of tobacco in Malawi involves a great many people. As I’ve shown, most of the farm labour is done by migrant labourers, while the capital to grow tobacco (seed, fertilizer, labour, land) is provided by local landowners. Local elites, or “bwanas”, also play critical roles in the tobacco social field. Most large scale tobacco growers or plantation owners are village headmen and chiefs, a result of historical practices which originally limited tobacco farming to those granted a special license. These plantations are about 100 acres each and employ between 10 and 20 tenant farming households. All are managed by an estate manager, while the owner lives elsewhere, either in town or in one of Malawi’s major cities. Also, a handful of local elites, including professional health care workers at Temwa Rural Hospital, owned trucks that they used to transport tobacco to the auction floors in Mzuzu; Tobacco farmers paid on average 5000MK (35$) per bale to send their crops to Mzuzu. Most civil servants in Temwa who worked for the police, the local schools, the post office or the hospital also grew or bought and sold tobacco as well. Some, for example, rented land and paid for ganyu labour to farm it. I for example, was given two acres of land by my landlord but I chose to grow maize (to everyone’s mild consternation). In line with local practices, I paid a tenant farmer living nearby specific amounts per task: for example, 7,000MK (35$) to weed an acre. Many civil servants used their monthly salaries to buy tobacco directly from local smallholders, bale it themselves and then send it to the auction floors in Mzuzu. For example, Figure 24, shows a government house for a primary school teacher in Temwa with a stick near the edge of the road. There are a few tobacco leaves tied together perched on top of the stick, a sign used by individuals that they are buying tobacco. Both of my research assistants also used the monthly salary I paid them to buy tobacco from farmers we met during our research activities. This was an extremely lucrative and risk free practice since this buying and selling occurred once the auction floors were open and that year’s
tobacco sale prices were established. Landowners and tenants took tremendous risks growing tobacco since they could not predict at the outset that both sale prices and weather conditions (i.e. rainfall) would be sufficient to make a profit. Thus, bwanas typically benefit the most from the tobacco industry, largely because they accrue the most profit with the least amount of risk.

Although there is a great divide in symbolic capital between bwanas, landowners and tenants, differences in economic capital were less distinct, which highlights how important it is to understand the connections between economic, cultural and social processes when examining health disparities. For example, the anthropometric and dietary diversity data I gathered at Temwa Rural Hospital, which are indicators of chronic and severe malnutrition in children, suggest that tenants’ children and landowners’ children actually have similar rates of malnutrition. One explanation for this surprising fact is that many local landowners have very high rates of food insecurity and run out of food months before the harvest, creating what is called the annual “hungry season.” However, as employees of relatively wealthier landowners, tenants are guaranteed at least one tin of maize until the harvest season begins, which delays the food crisis for many. Referring to Southern Malawi, Englund (1999) also argues that economic transactions between wealthier landowners and labouring tenants are framed as a form of altruism rather than as a means to acquire personal wealth. In other words, the relationship between tenant and landowner is framed as mechanism to redistribute wealth rather than accumulate it. In Northern Malawi this tension plays out between landowner and tenant through food sharing practices and financial or social support for sick tenant family members. In particular, while it is considered bad manners for a child to eat food at a non-kin member’s house, I noticed that tenants working for smallholder farmers often sent their children to “play” at the bwana’s house around lunch time. As one landowner said to me as she put out lunch for her own children as well as their tenants: “In Malawi, this is very bad behaviour. But how can I refuse?” Another striking finding is that while renters have more symbolic capital than tenants, the child health data suggest that they have very high rates of severe malnutrition among their children. This was initially a surprising finding to both me and health care workers at Temwa

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196 I should also add that many foreign NGO workers in Lilongwe bought tobacco directly from farmers’ fields in Kasungu in the central region using a middle man. I know of at least one PhD candidate from an American university who used her profits to pay her tuition.

197 Interestingly, it seems like children raised in their mother’s home village and not their father’s home village have the highest rates of malnutrition. This highlights how important care giving arrangements are in child health and not just economic markers.
Rural Hospital since renters are generally considered “better off” than tenant farmers. However renters are very low in social capital; not only are their systems of social support altered during migration, but they do not have a bwana to appeal to in times of trouble. Thus, the pathways to embodied inequalities are multilayered and transcend arbitrary distinctions between economic, cultural and social processes.

**The Tobacco Social Field Map**

As I have shown, the social field of tobacco labour is hierarchical, with tenant farmers firmly on the bottom and bwanas at the top. Hierarchies within the tobacco social field are imbued with different, but intersecting, forms of capital, which ultimately result in differential access to HIV treatment programs for infected children. Figure 25 is a visual representation of the tobacco labour social field, which I have just outlined in detail. The X, Y coordinates on the map below are relational: they illustrate what Bourdieu described as importance in the social field. The vertical axis marks the total volume of capital a position holds in the tobacco social field; those at the top hold the most capital. The horizontal axis marks the ratio of symbolic, cultural and social capital to economic capital; the right end of the spectrum holds the highest volume of economic capital.

Characteristics on the map describing bwanas are clustered in areas holding relatively high overall capital. In terms of symbolic capital, they are spoken to with deference by those considered to have less capital; they are educated, speak English, own land or businesses and, in the case of Chiefs are even considered royalty. Bwanas also have more economic capital: mobile phones, motorbikes, bicycles, shiny polished shoes and brick houses with iron sheets and solar panels. Characteristics describing landowners indicate that landowners have higher volumes of symbolic and cultural capital than tenants, but less than bwanas. However, what is significant is that within the category of “landowners” there is great economic variability. Some, especially those wealthy enough to employ tenants, are relatively much better off than others who are not even able to grow enough food to feed their own families for a year. Renters and self-employed farmers also have more total capital than tenant farmers, but less economic capital for most of the year. They are also more vulnerable to economic downturns and bad weather because of the huge risk of investing all their savings into tobacco. They are considered resourceful, upwardly-
mobile and hard-working. Characteristics describing tenant farmers are clustered in areas with the lowest overall capital and relatively lower symbolic capital. For example, they are “dirty”, “poor” and “ignorant”; while they are also considered “hard workers,” many also characterize them as “wasteful” and “careless” by citing examples related to drinking all their earnings away in one night at local bottle stores.

### Figure 25: The Tobacco Social Field, Temwa Hospital Catchment Area, 2009

<table>
<thead>
<tr>
<th>Total Volume of Capital</th>
<th>Symbolic &lt; Economic</th>
<th>Symbolic &gt; Economic</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Renters:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Entrepreneurial, hardworking”</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Tobacco Growing Landowners:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Bosses, wealthy, educated”</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Tenants:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Dirty, uneducated, pitied”</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Local Elites:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Chiefs, royalty, educated, absentee landowners”</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Poor Landowners:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Belonging, at home, but struggling”</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

“Maybe they don’t come to the hospital?”: Tenants in Temwa Rural Hospital

Disturbed by the noticeable absence of tenant farmers’ children from HIV care and treatment services in particular, I asked several health care workers why, and their response was always “maybe they don’t come to the hospital.” To counter such arguments I conducted a survey at Temwa’s under-five (U5) clinics and the out-patient department (OPD) to gauge tenants’ use of Temwa’s health care services. Of the 460 patients surveyed over a 10 day period during two separate seasons (the post-harvest and hungry seasons), 64% (n=274) were local
landowners and 36% (n=166) were internal rural-rural migrants from all over Malawi. These migrants can further be subdivided into three categories: 99 were tenants working under “tenancy agreements” with local smallholder farmers or working on large estate farms. 41 were former tenant farmers who had raised enough money to rent their own land and grow tobacco independently. While, as I pointed out above, this is a socially more desirable position, and something tenants often strove to achieve, dietary diversity and anthropometric data gathered at the same time indicate that their children are the most malnourished and their households the most food insecure. Finally, 26 were migrants mostly from the far Northern region of Malawi (a few from Burundi and Zambia) living in a crowded migrant neighborhood near the hospital that I call “BusyBusy”.198

<table>
<thead>
<tr>
<th>Social Category of Patient</th>
<th>% of patients (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Landowning Farmer</td>
<td>64% (274)</td>
</tr>
<tr>
<td>Tenant Farmer</td>
<td>22% (99)</td>
</tr>
<tr>
<td>Renter</td>
<td>9% (41)</td>
</tr>
<tr>
<td>Self-employed farmer</td>
<td>6% (26)</td>
</tr>
</tbody>
</table>

Although it was impossible to know what the ratio of tenant farmer/landowner is in the area, since no official records are kept, these findings indicate that tenants do, in fact, come to the hospital (see Table 5). Moreover, most of these tenants are from the Southern region, where HIV infection rates are almost double those in the Northern region; thus, one might reasonably anticipate that their children would receive an HIV+ diagnosis at a higher rate than the children of local landowners.199 However, this was not the case. During my research, only one tenants’ child initiated ART at Temwa Rural Hospital, and only after the interference of her employer, an

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198 This survey was conducted over three days in November 2009 and again in April 2010 with over 500 caregivers and their children at Temwa’s U5 clinics.

199 The NSO (2010) estimates that the HIV rates by region are: Northern 8%, Central 9% and Southern 17.6%.
issue I take up in more detail below. Two other tenants’ children were already on ART in their home villages, and transferred into care at Temwa with official transfer papers; in each case the child had been on treatment for more than a year before they moved to Temwa. My findings indicate that a disproportionately low number of tenants’ children were on treatment at Temwa, or only three of 35 children on treatment. My attempt to understand why tenants’ children with HIV remain untreated, even after they visit the hospital for HIV-related symptoms, is the focus of the final section in this chapter. In particular, I ask how so many tenant children can remain undiagnosed, despite repeated use of free and accessible biomedical health services that are ostensibly designed to identify early warning signs of HIV infection in children.

My examination of tobacco production as a “field” indicates that Temwa Rural Hospital’s catchment area is symbolically, culturally and economically divided and that rural inequalities are rising. Tenants in particular are perceived as highly mobile, uneducated and food insecure. Yet objectively many of these characterisations are incorrect. Many landowning families, for example, share the same characteristics as tenant farmers. Nevertheless, my findings indicate that these perceptions are strongly related to the underrepresentation of tenants’ children in HIV care and treatment services. But how exactly are children excluded from care? I start with a case study to illustrate how health inequalities are embodied through intrarural social inequalities.

“I thought it was a disease from God”: Two Pathways to Embodied Inequalities

My research assistant Maggie had a knack with kids, so when two and a half year old Mpatso cried when Maggie tried to chat with her, we knew that Mpatso was very sick indeed. Her mother, Diana, shook her head and said: “she just refuses everybody, but she was not born like this.” While we were accustomed to seeing behaviour changes in children with HIV as their symptoms got worse, Mpatso’s lethargy disturbed us. Later, on our way home, Maggie told me (shaking her head sadly) that “that one [Mpatso] cannot make it” – by that she meant that she did not think Mpatso had long to live.

Mpatso’s mother Diana was a tenant farmer from southern Malawi. She had arrived four months earlier to find work on a farm. Diana followed her older sister, who worked on a farm nearby, from Mulanje district in the far south of Malawi to “find money for food and clothing” soon after her husband died. Half-way along the journey, she found what she called a “road
husband.” Since single women cannot work without a husband, she had to find a husband to work. The logic behind this seemed obvious to her; she asked me quite seriously: “without a husband, who would build the *gafa* [tobacco shed] used to dry the tobacco?”

Diana did not know her age, but guessed that she was around 22 years old. Diana looked thin and worn out; her hair was cut short and a little bit matted (or basically she looked like a tenant). But overall Diana was happy with her situation. She explained that “so far my *bwana* is *akuzisunga*” [taking care]. When I asked her to explain what she meant, she told me that when her *bwana* saw the way Mpatso was looking – swollen, orange fuzzy hair and failing to walk - he gave them small fish for *dende* [relish] and *nkunde* [local bean variety] to plant around the house. Both of these are foods that are high in protein and recommended by the hospital to help with malnutrition in children, but are not foods most tenants can afford to buy themselves. Diana went on to explain that like herself, her *bwana* first assumed Mpatso was suffering from a lack of food associated with being a tenant. However, after a few weeks with no signs of improvement, Diana’s *bwana* decided that it was best if Mpatso went to the hospital to see a doctor. Diana noted that he went out of his way to help by driving them to the district hospital (not the rural hospital) in his police vehicle. At no point during this process did Diana ask her sister for help, since, as she explained, her sister would have no food or money to give her.

According to Mpatso’s health passport, the clinical officer on duty diagnosed her with severe malnutrition and prescribed eight pots of fortified peanut butter as part of Malawi’s national ready-to-use therapeutic food supplement program. All children diagnosed with malnutrition at the district hospital were tested for HIV as part of routine provider-initiated care at district hospitals. As Diana explained:

I found out Mpatso and I had HIV the time she was swelling and we were receiving *food groups* [the counselling at the hospital advising mothers to feed their children good food].... I did not think of getting her tested myself. I was just thinking it was just a disease from God.

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200 I did not know this at the time, but I had already interviewed her sister at Temwa, who had a nine year old boy with HIV on treatment. They had transferred into care at Temwa the year previous.

201 Mpatso weighed 8.5kg at the time of our interview. According to UNICEF’s RTUF rationing table Mpatso qualified for a total of 8 pots per week for a total of 16 pots since it is a two week treatment. Therefore it seems like she was only given half of her prescription, a fact that I suspect came from huge supply shortages for this in demand resource.
In other words Diana did not suspect her daughter had HIV leading up to her diagnosis. Instead she felt sure it was just a “natural” illness related to their poor living conditions in Temwa. Maggie later commented that Diana didn’t realize Mpatso was so sick “because she was a tenant” and tenants “lack understanding because they don’t go to school,” a sentiment I heard directed at tenant farmers in Temwa many times.

Although both Diana and Mpatso tested positive for HIV at the district hospital, neither started ART. Yet Mpatso’s CD4 count of 278, which was recorded in her health passport the same day, meant she was eligible according to national treatment guidelines. Instead, Diana was advised to feed Mpatso “good food” (beans, fish, meat, nuts, milk) and to take her to Temwa when her daughter “stopped swelling”, or when the signs of serious malnutrition went away.

After they returned to Temwa, Diana and her husband did ganyu labour to find money for “good food” for Mpatso. They found a bit of work weeding a maize field nearby and bought some margarine to put in Mpatso’s porridge. For a week or so Mpatso seemed to be doing better, but then she started to swell again. She also stopped eating, developed a fever and chingwenya, a type of severe chronic diarrhea where “the anus comes out of the body” [prolapse]. Diana decided that it was time Mpatso started the medicines, and we met her for the first time the day she tried, unsuccessfully, to initiate ART for her daughter. Diana explained that they went to see the clinical officer. He told her that Mpatso could not start treatment. She was not told the reason why, nor she did she ask for a reason. Although Mpatso’s signs of malnutrition had also returned, she was also not admitted to the district hospital, where there was a nutrition rehabilitation unit.

I was determined to figure out the rationale for this decision. I escorted Diana and Mpatso back to the clinical officer for an explanation. From across the expanse of his desk Mr. K looked briefly at Mpatso’s health passport and then told us to see the other clinical officer next door. We dutifully left the room and waited outside Mr. N’s office. However, after thirty minutes or so I grew impatient, knocked and let myself in, and I found that the room was empty. I went back to the ART clinic and was told that Mr. N was actually at a training workshop (surely Mr. K knew this when he told us to go there) and that we had to see Mr. K again. I returned to his office and explained Diana’s situation again (she said nothing and stood in a corner in the back of the room). He shrugged, and without explanation told Diana to report for ART counselling the
following day, an act that prevents me from knowing what would have happened to Mpatso if I had not been present.

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This experience stayed with me for the duration of my fieldwork as I continued to be bewildered by the absence of tenant children from HIV care and treatment services. How exactly were tenants being excluded from care? Was Mpatso excluded from treatment based on her mother’s obvious tenant status? Did Mr. K worry that Mpatso’s advanced symptoms of severe malnutrition made her a likely candidate for an accelerated death after treatment initiation; a process euphemistically referred to in the clinical literature and in national treatment guidelines as “immune reconstitution syndrome”? Given that the hospital was experiencing drug shortages at that time, which meant that patients had to come and collect their medicines every two weeks rather than once a month, was he worried about the drug supply for patients, mostly landowners, already on treatment? Would Mpatso have started treatment if Diana had arrived at the hospital with someone who had more authority to speak on her behalf, like a grandparent or her bwana? If her boss had not intervened so quickly, would Mpatso have remained undiagnosed and died soon after, with her death attributed to the poor living conditions commonly associated with tenant farmers instead?

I suggest that there are two different pathways to embodied inequalities at Temwa. The first pathway I describe focuses on how perceived deficits in capital are both managed by patients and “read” by health care workers at Temwa to limit access to care for those who they feel “will not make it” – or have insufficient capital to ensure that a child can indefinitely survive on treatment. The second pathway describes how tenants recognize their deficits in capital. In other words, I explore how tenants learn to embody their new habitus after migration, and that this new habitus increases their ambivalence towards HIV testing and treatment initiation for children. These pathways reveal how embodied health inequalities are socially structured and extremely complex. These findings challenge conventional assumptions in global health interventions that a “one size fits all” approach to treatment roll out will ensure “universal access” targets are met (see also Pennazato et al. 2014). Rather, they indicate that pediatric HIV treatment programs need to be sensitive to context-specific forms of capital that intersect with health-seeking practices.
Maggie and I found ourselves 15km east of Temwa on a one hundred acre tobacco estate owned by a local chief living in town. The landowner’s wife led us there by motorbike through scrub and sandy river beds – which meant we often had to stop and push our motorbikes through and let ox carts carrying tobacco pass by us on the narrow path. When we arrived at the plantation, we found two dozen tenant farmers, all from the same village in Southern Malawi, chatting amicably in the shade of a large, two-story gafa. Some were grading the dried tobacco, while a few men used a hand cranked metal press to bale tobacco into large burlap squares for transport to Mzuzu. At least a dozen young boys stood around watching the baling process, but most of the children were out “playing”: hunting rats or gleaned harvested maize fields for “leftovers” they could sell for sweets in town.

A few hours into our visit, there was a commotion behind the estate manager’s large house and a small crowd rushed towards me carrying a young girl. As they approached, her father held his daughter’s hand outstretched for me to see the blood dripping from a wide open wound at least five centimetres long on her inner palm. Father and daughter kept their eyes trained on the ground as the estate manager stepped in front of the pair and explained to me: “This child was out hunting for rats and her friend cut her hand with his hoe. What should we do, doctor?” I explained that I was not a doctor, but that the girl might need stitches or medicine to prevent infection and that they should go to the hospital. He nodded in agreement, but what happened next was not what I expected.

The child, named Lucy, sat down next to me, and wrapped an old piece of fabric around the wound. Her father borrowed the estate manager’s bicycle, and returned more than an hour later with 20 litres of water for a bath tied to the back of his bike with strips of old rubber tire. The child’s mother appeared and called out: “Lucy! Atabwela [come here in chiChewa].” Forty-five minutes later, mother, father and daughter appeared in clean clothes, hair combed and skin shiny (lotion applied). All three got on the bicycle and headed for the hospital.
After this incident I paid better attention to what patients wore to the hospital. I noticed that most patients wore their best outfits, often the clothes reserved for Church on Sundays, or market days in their areas. The preceding incident illustrates the great lengths patients, and especially tenants, go to improve their self-presentation and thus try to ensure better care at the Temwa Rural Hospital. It is often argued that the power relations implicit in these situations are generally hidden from the participants (Contandriopolous 2004). Bourdieu and Wacquant (1992) describe this process as a form of “misrecognition”, or a form of symbolic violence where individuals are complicit in their own subordination. My findings suggest, however, that many tenants were hyper aware of their social position in relation to health care workers at Temwa. As Dixon-Woods et al. (2006) argue in relation to women who consent to surgeries they do not want in the UK, their apparent complicity derived not from their failure to recognize the power relations at work in the hospital, but from their sensitivity to the “rules of the game” and their deficits in capital. In practice this often meant that tenants struggled to make up for perceived deficits in capital by dressing well and by being polite, compliant patients.

Health care workers were routinely derisive towards tenant farmers. Health care workers often ignored them if they appeared disheveled or dirty, or assumed they were “mad” or “immoral” (Durham 2004). Patients’ clothing was often commented upon, and hair styles, for women in particular, were used to gauge relative wealth: shaved, braided, wool hair extensions, plastic hair extensions, chemically straightened hair and “weaves”, or full-on wigs, made determining a women’s wealth and occupation relatively easy. Short hair was most often seen on the poorest farmers, and weaves or chemically straightened hair usually indicated nurses, midwives and teachers with salaried employment (Nyamnhjoh et al. 2002). The quality and type of shoe often provided the same social cues about men. For example, one man came to the hospital wearing only one shoe rather than come barefoot. In the briefest of interactions health care workers were able to discern the smallest gradations in social and economic status through minute differences in physical appearance and bodily comportment (Hansen 2000b). More importantly, this information was used to explicitly separate patients into categories of those who “can and cannot make it” on ART.

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202 As one chief said to me: “If my friend doesn’t notice my new shoes, I greet him loudly waving my feet in the air in front of his nose until he takes notice!” This phenomenon likely explains why in friendly conversations men often complement each other’s shoes soon after greeting each other and how the exchange of shoes between men is a sign of friendship.
Unfortunately, despite their best efforts, the constellation of indicators that tenants carried with them into Temwa Rural Hospital undermined their treatment access. More importantly, their capital deficits did not coincide with the “social criteria for ART eligibility” outlined in Malawi’s national treatment guidelines. In particular, the national guidelines emphasized that patients on treatment should eat a balanced diet (*manga kudya koyenera*), manage their stress (*kutchotsa nkhawa*) and keep their bodies “fit” (*olimbitsa thupi*). Health care workers considered tenants incapable of fulfilling any of these requirements since tenants are, as I have discussed above, assumed to be extremely food insecure, overworked and lacking in social support. Aside from physical appearance alone, standardized patient cards and checklists dictating clinical encounters allowed health care workers to gather detailed information about a patient’s education, social support and employment status that was then used to determine their suitability for HIV testing and ART initiation. As Mr. J explained to me one day about the process of enrolling patients into ART programmes:

> These days it is hard to tell “this one is poor” or “this one is rich” just by appearance alone because of *salaula* [second hand clothing market] since they are all dressing well... But we ask them their occupation, so this one is saying “I am a farmer” or “I am a teacher” then you know.... Of course, most of the times tenants are only speaking chiChewa so it is easy to tell that this one is a tenant farmer, but also most of them haven’t been to school and they don’t know how to write. For example, sometimes they are also failing to know their age or even lose count of how many children they’ve had! This one day I asked a woman “what year were you born?” She said “2005.” “No,” I said, that means you are three years old.” “Yes,” she said, “I am three years old”. *Asenthena* (you see)? That’s how we can tell [laughs].

Universal access to HIV treatment is mediated through health care workers who parse out those who “cannot make it” on ART treatment. By saying “that one cannot make it” they were not just saying that the child was a strong candidate for “immune reconstitution syndrome,” they were commenting on how real and perceived deficits in capital would undermine long term treatment success. Pervasive characterisations of the *mtenant* as poor, food insecure and highly mobile, which as I have shown are not always accurate representations of tenants’ realities, further influenced health care workers’ perceptions of tenants’ abilities to ensure ART adherence among their children. As a result, health care workers deliberately withheld information about HIV testing and treatment initiation from tenant farmers.
Although health care workers deliberately excluded tenants from HIV care and treatment, none considered their actions discriminatory or problematic. Rather, they framed these exclusionary practices as beneficial for all HIV positive patients, tenants included. Health care workers argued that by screening out potential defaulters before treatment initiation, they could maintain high ART retention rates and thus increase the chances that global health funding for free ARVs would be sustained in the long term. Most could remember a time when patients did not have access to treatment, when patients “were just dying all around.” These memories of crowded hospital wards were compounded by many by their own personal losses: nearly everyone had lost a close family member, some their own children, to HIV/AIDS prior to the national roll out. The global financial crisis in 2008 only heightened their certainty that funding for HIV treatment would one day be eliminated, especially if patients did not “make it.” Their concerns might seem pessimistic, but recent failures by the Global Fund to secure the funds they need to keep global HIV treatment programmes running suggest that their fears may be justified (see Chapter One).

A second factor underlying the underrepresentation of tenants from HIV treatment by health care workers was a genuine concern that ART might accelerate, rather than prevent, the death of HIV infected tenants and their children. From the perspective of health care workers, diagnosing a tenant with HIV, when they are far from their families and living in precarious circumstances, was actually very cruel. As Mr. J went on to explain: “To be told that you have this disease, while living the way they live here [alone, and in poverty]? No, it is better for them to find out when they go home.” Health care workers were very aware that many of their patients, especially those that were already malnourished, were dying through a process called “immune reconstitution disorder” - most within three months of starting ART - and were keen to avoid this unfortunate side effect (MOH 2007). Health care workers often thought it was more prudent for tenants to start treatment at “home,” where food was more varied, living conditions were better and family and friends were nearby to offer support. Like the “blanket sign” Whyte and Whyte (2009) noted in Uganda, being a tenant often discouraged health care workers from recommending HIV tests for children. Unfortunately, children with HIV develop serious symptoms much more quickly than adults. Therefore, while treatment delays are dangerous for adults, any treatment delay for children is far more likely to result in an early death.
Finally, as I discussed in Chapter Four, health care workers rarely strayed from national treatment guidelines, even when it seemed practical and ethical to do so. However, in a few rare cases, health care workers did stray from the national guidelines. These exceptions highlight how social criteria are used at Temwa to determine treatment eligibility. For example, three infants accessed ART services before the 18 month age cut off followed so closely in most cases. Although subtle, there are key social differences between these children and Mpatso described above. For instance, before treatment is initiated, national guidelines insist that the “primary caregiver must understand the implications of ART,” yet the guidelines go on to say that “it is beyond the scope of this document to discuss social criteria for eligibility” (HIV unit, Ministry of Health, 2007: 37-39). In this way the guidelines gave health care workers some leeway to come up with their own social criteria for eligibility. Mr. J, the HSA in charge of testing, elaborated when I asked him what kind of social criteria were considered relevant by health care workers when deciding whether or not to recommend an HIV test or initiate treatment:

They need to know the goodness of testing. Ah you know, these people [tenants] are just ignorant. They need to be encouraged because they don’t know the goodness [of knowing their status].

In all three cases where the exceptions were made, a mother repeatedly and proactively insisted that her child be tested for HIV. One mother named Brenda, for example, secured a PCR, or virological test, from the Rumphi District hospital when her daughter was 11 months old. She told me that this was the best way for her to “take good care” of her daughter. Brenda was one of the few to not just “know the goodness” of testing her daughter, but to use the language used by health care workers to achieve her own ends. Diana, on the other hand, never suspected her daughter had HIV, and the only reason she found out was because she tested positive during a routine screening test at the district hospital facilitated by her boss. It was also only my interference that resulted in a decision by the clinical officer on duty to start her on treatment. Thus, deficits in capital were used by health care workers to make decisions about who they would funnel towards HIV care and treatment services. The fact that only one tenant child initiated treatment at Temwa, after being diagnosed at another hospital, highlights how profoundly exclusionary Temwa Rural Hospital was for tenant farmers.
“We are not free. We are just being kept here like chickens”: Treatment Avoidance by Tenants

I hear “the visitors” a lot when people talk about tenants. Can you tell me what it means to be “a visitor” in Malawi?

...Well, mostly it means we can’t keep you here.

You mean, they can’t be buried here?

Ehe! (Yes!). They are saying you are not of our clan [mtundu wawo].

So for HIV testing, what do you think that means?

Ahhh! It is better to test at their home villages, because it is difficult for them to come for testing... Aaaaaiii! It is very difficult.... Because most of them they are here, they are tenants, and they don’t want maybe to........

Die here?

Ehe! Exactly [laughing].

- Mr. J. (Senior HSA at Temwa)

Although health care workers rarely recommended HIV testing for tenants’ children, HIV testing and treatment was also not always perceived as a good thing by tenants at risk. As Kaler and Watkins (2010) also found in Southern Malawi, a positive HIV diagnosis is often considered a death sentence. Although treatment access has improved in recent years, many tenants were ambivalent about the efficacy of ARVs given their capital deficits. Many people told me that a positive HIV diagnosis leads to lethal levels of worry, anxiety and fear, which would hasten the inevitable death from AIDS. This issue was especially problematic for tenants because, as “mulendos,” they are very far from their home villages and their usual social support networks.

As the conversation above indicates, the fear of death far from home also raises some serious concerns about burial after death. In my entire time in Malawi I never witnessed anyone buried

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203 The Tumbuka have a very informal clan system, meaning that it rarely comes up in casual conversation and is usually a system only understood by elders. However, in this context “clan” is juxtaposed with the idea of “mulendos”.
in a village where they did not belong, although I was told that it does occasionally happen.\textsuperscript{204} For the newborn deaths I recorded among tenants, they were buried in a special graveyard only known to elders. However, in the case of an adult or child death, most tenant farmers preferred to borrow money to arrange transportation for the body back to the home village. Landowners in these cases often helped pay to get the body back home. However, death away from home was actively avoided. Most people who felt close to death returned to their home village.\textsuperscript{205} However, this is not always possible and some tenants do die far from home. However, burial in a village area not your own is undesirable, even dangerous; the ghost of the dead could, I was told, haunt the surrounding area for generations. This was another factor that encouraged landowners to help pay for transport to the home village.

All of this had important implications for the integration of tenants’ children into HIV care and treatment services. I have already shown how a child’s relative social, economic, cultural and economic capital shape access to treatment at Temwa Rural Hospital. In the last section of this chapter I focus on how this process was partially patient driven. I do not want to suggest that tenants in Malawi are somehow less likely to be informed about the benefits of treatment, or “in denial” about their HIV status, than their landowning neighbours, as much public health literature might suggest (Nieuhaus 2014); rather, I want to consider the ways that some people feel entitled to or more receptive to biomedical care while others forgo it. To do this I draw on Bourdieu’s (1980) concept of habitus discussed above. Habitus explains the orderliness of social life – or how social actors internalise the rules of conduct, including the ways that people become imbued with a sense of their “place” relative to others. For Bourdieu and Wacquant, the “order of things” is taken for granted, and considered natural by all members of the social field (1992: 167). By drawing on these insights I will demonstrate how the underrepresentation of tenants in HIV care and treatment services is reproduced over time with the collusion of tenants themselves.

\textsuperscript{204} In these cases they are buried in a part of the village graveyard reserved for “newcomers”. I was told that these were usually people who no longer had any relatives in their home villages. Instead of being “visitors” they are considered “new arrivals” – an important distinction.

\textsuperscript{205} For example, the small Malawian community living in and around Toronto (less than 100 families) have a joint bank account set up to raise funds for funeral expenses. Each family donates a small amount each year and if someone dies that money is used to ensure that the body is returned back to Malawi. This is the only kind of fundraising that this community does.
For Bourdieu (1990), habitus is about the internalised rules of conduct relative to one’s social location. However, through migration, tenant farmers move from one social field to another, and in the transition they often learn to consciously embody a new habitus. Suddenly, a man who may have been considered a smart, socially mobile farmer in his home village is expected to show deference to his landowning neighbours. For example, nearly every tenant I interviewed mentioned that “not feeling free” was the hardest part about living in Temwa. As Harrison, a tenant farmer from Mangochi explained to me:

We are not free here. We are just being kept like chickens. The problem is that we are not respected. As a grown up person, with all your energy you farm tobacco for someone else, but for them you are like a lame person. Like a low class person who is useless…. The rudeness happens in many ways when someone is not at liberty. You are afraid. Maybe you ask someone ‘how does this thing work’ but you are answered in a different way, so that makes me unhappy and I feel it is better to just sit at home.

Tenants were very aware that they were considered socially inferior to their landowning neighbours as migrant farmers. Although most expressed deep anger and frustration about their social positioning, within their daily interactions with landowners they behaved passively. In everyday life tenants learned to inhabit their social position: they did not welcome or greet visitors passing through their fields or on the roads near their farm. Through various interactions and established rules, they learned that they were not entitled to the same resources as those who “belonged.”

Understanding how tenants’ health strategies for sick children intersect with social hierarchies is important for challenging conventional assumptions that these behaviours result from individual choices or deficiencies alone (see also Stoebenau 2009: 2046). For tenant farmers, in particular, health strategies for sick children are shaped by transformations in social capital related to migration (Kelly and Luis 2006; McMichael and Manderson 2004). In Chapter Three, I discussed in detail how the composition of a child’s therapy management group (TMG) influences the treatment trajectories of children infected with HIV. In particular, I described the important role grandparents played in helping children start treatment. Here I want to focus on how transformations in social capital alter tenants’ receptiveness to treatment initiation for children. For example, when I asked Vonex, a thirty-something year old tenant farmer with three children under five, about his life in Temwa, he complained bitterly about the lack of support:
The badness comes from having no one to advise us… Eeeeeeee… I find that I am sick or my child is sick and while if it were home you have grandparents around may be they can teach you, or they can tell you ‘take the child to the hospital,’ but here because there is no one, I have found badness in the tobacco fields.

To compensate for the lack of grandparents, tenants are encouraged to “treat their bosses like grandparents.” Richard, for example, consulted his employer’s wife when both of his children fell ill, and she gave them *panado* (a mild analgesic) when they developed fevers and diarrhea. Others, however, worried that they might lose their employment if they fell sick, and so preferred to keep their HIV diagnosis secret from their *bwanas*. Tenants working on large-scale estates are also at a disadvantage since landowners often leave the management of the farm to an estate manager, usually a former tenant with seniority. Managers have fewer resources on hand, but more demand, since they are responsible for a much larger group of farmers. Thus, although *bwanas* are supposed to act like grandparents by advising and supporting tenant farmers as trusted elders, in practice this was complicated by the power imbalances between employer and employee.

The leap from uneven patterns of ART access for children to embodied inequalities is not hard to make. There are two pathways to embodied inequalities at work: health care workers avoided telling tenants about HIV testing and treatment, while at the same time tenants avoided going for an HIV test. Actively seeking out testing and treatment was interpreted as a sign of “readiness” for ART. Unfortunately, tenants’ children are perceived as patients unable to “make it” on ART because of real and perceived deficits in their total volume of capital. This process is further complicated by the ways that the political economy of tobacco farming alters TMG networks (or social capital), excluding individuals who are instrumental in securing ART for children (such as grandparents), while including others who are more likely to obstruct treatment initiation (such as fathers and *bwanas*). Rather than the rational, independent decision-makers envisioned by policy-makers, TMGs trying to get sick children healthy are social beings embedded in social fields that are marked by intense, but often ignored, intrarural inequalities. These issues converged to limit tenant access to quality biomedical services by reducing their sense of entitlement and self-worth. “Not free” to express their opinions, few demanded treatment from health care workers, who were in every way their social superiors. These findings highlight how important it is to consider how material constraints operate alongside many other
collective forms of identity. In this case, different degrees of “belonging” to a community undermined efforts to achieve universal access. Borrowing Bourdieu’s concepts of field, habitus and capital facilitates an analysis that highlights how complex and multidimensional embodied inequalities are.

Conclusion: Embodied Inequalities and Universal Access at Temwa

My analysis of the tobacco social field at Temwa indicates that migration reduces a tenant’s total volume of capital while away from their home villages. Most tenant farmers willingly accept short term deficits to achieve long term gains. Migration is a strategy used by tenants to build economic and symbolic capital. However, at Temwa Rural Hospital, deficits in capital are used to stratify patients into those “who can” and those “who cannot make it.” Health care workers associated tenant farming with poverty and poor social support and therefore conclude that ART would be a burden for tenant farmers. Tenant farmers, in turn, learn to embody their new low social status, or their new “habitus,” and feel unentitled to demand good care at the hospital, or access to what are considered scarce resources.

These findings have implications for pediatric HIV treatment programs striving to achieve “universal access.” Standardized ART guidelines rarely benefit disadvantaged groups. In this case they directly undermined tenant access to treatment since they introduced vague and discriminatory “social criteria” that health care workers used to parse out those they felt were deserving of treatment. Since HIV treatment programmes aim to provide universal coverage to those in need of treatment, finding ways to integrate internal migrants and their children into HIV services is critical for the effectiveness of ART programmes throughout sub-Saharan Africa. By employing Bourdieu’s concept of the “social field” and “habitus,” we can trace how two pathways to embodied inequality operate and expand. This approach also helps us understand how standardized national ART care and treatment programmes may not work in regions where different kinship systems and political economies fundamentally alter the composition of TMGs. Research on ART outcomes indicates that the long term benefits of treatment are unevenly distributed along social and economic fault lines (Mills et al. 2010). Thus, my findings provide critical insights into how social dynamics, power relations and economic circumstances produce these disparities. The treatment trajectories discussed here
indicate that embodied inequalities are structurally produced; they are not the product of individuals making poor health choices. Given that children are still far less likely to access ART than adults (UNAIDS 2012), understanding the social dimensions of HIV diagnosis, treatment initiation and adherence will provide useful information for service delivery organisations to improve their programmes.
Chapter 6: “He is almost like other children”: Local Biologies and Precarious Futures for Children Living with HIV

“The pathogen is nothing; the terrain is everything”
- Louis Pasteur

Nine year old Lionel is dancing. His classmates in my weekly English class at the primary school surround him, clapping to cheer him on as he wows us with his expert moves and joyful personality. Lionel also has HIV. According to his mother Martha, Lionel started “falling sick often” around the same time his father died in 2006. His health records indicate that she visited the hospital more than thirty times and was repeatedly prescribed antimalarial medicines and antibiotics for his chronic fever and diarrhea. After nearly two years of this, when Lionel’s “body was really finished,” she decided to take him for an HIV test. He started adult fixed-dose combination antiretroviral treatment (ART) the very same day at a regional hospital (O’Brien, et al. 2006). This was more than two years before ART was “rolled-out” for children at no-cost to decentralized HIV treatment centres across Malawi in 2008 (Bong, et al. 2007). By late 2012, Lionel and more than 33,000 other children under the age of 14 had access to split-tablet, adult-dose ART regimens throughout the country (HIV Unit, Ministry of Health, Malawi).

ART significantly reduces mortality and morbidity for those who get access, enabling many children with HIV to resume an “almost normal” life (Moyer and Hardon 2014; Russell and Seeley 2010; UNAIDS 2013). After nearly three years on treatment with few complications Lionel is the living embodiment of this possible reality. His mother explained:

At first I started to notice that he was just getting fat. Then we stopped having to go to the hospital all of the time…. Now I see that he is almost like other children (emphasis mine).

Yet, while ART medicines are often touted as “life-saving” miracle drugs, considerable challenges remain for children trying to grow up with HIV (Bernays et al. 2015; Edmonds et al. 2011). Martha’s relief at Lionel’s sustained improvement on ART, for example, was tempered by
serious doubts about Lionel’s ability to survive into adulthood. Her concerns were strongly shaped by the treatment experiences of others, which diverged substantially from their renderings as “life-saving” miracle drugs. As she explained when I asked about Lionel’s future:

What do I think about his future? Nothing.... I just think nothing. I encourage him with school, but I just have thoughts about... well, whether he will live very long… The way he is now in his body, he is almost like other children, but sometimes I am worried that he will not reach the stage of marriage.... Sometimes I think he will live a long time, and then you find that other people who are [also] getting the medicines die without any reason... even others of his age. So sometimes I feel that... maybe that he will die just like the way our friends die.

Concerns about children on ART were further shaped by the social and economic realities of caregivers’ everyday lives. For example, later in our interview, when I asked Martha to explain why she felt Lionel might not live into adulthood, she emphasized her lack of social resources as a barrier to Lionel’s long term treatment success. Martha highlighted how Lionel’s father’s death, her own HIV infection and potential early death, as well as the lack of financial resources of her relatives to provide adequate support for Lionel if she died as the biggest challenges to his long term survival. For Martha, the long term efficacy of ART for Lionel was profoundly shaped by the precariousness of their daily lives in rural Malawi.

This uncertainty about the future is at odds with global health discourse that surrounds ART roll-out. Supporters maintain that they transform a deadly disease into a “manageable chronic condition” (Bernays et al. 2010; Bernays et al. 2015). My research among patients, caregivers and health care workers at Temwa Rural Hospital indicates that few children with HIV are experiencing this asserted shift of HIV from acute crisis to a “manageable chronic condition” (McGrath et al. 2014; Moyer and Hardon 2014; Philbin 2014). Nearly all of the caregivers and health care workers with whom I spoke remained unconvinced that pharmaceutical intervention alone could prevent early death or illness from HIV infection. Primary caregivers, in particular, routinely expressed doubts about the ability of ART to overcome medical, economic and social barriers to successful life-long treatment. Do such doubts deny the “scientific fact” that ART “works” or that it alone is capable of transforming a
deadly disease into a chronic condition in resource poor contexts? Are doubts about the therapeutic efficacy of ART merely reflective of low levels of “therapeutic literacy” that could be improved by adherence counselling and education? Or are these doubts remnants of a “fatalistic attitude” or “AIDS based stigma” commonly ascribed to non-compliant behaviours?206

I am convinced that reservations about the therapeutic efficacy of ART in the life-long treatment of infected children are not the direct result of a lack of education about the benefits of treatment or fear of HIV related stigma (see also Niehaus 2014). Nor do they reflect a “fatalistic” or denialist attitude commonly ascribed to people living with HIV/AIDS who do not seek or comply with medical regimens prescribed to them (Marsland and Prince 2012: 457). Rather, I argue that reservations about the ability of ART to extend children’s lives indefinitely reflect deep structural inequalities between those who design HIV/AIDS interventions for children and those who are expected to follow them. My perspective draws heavily on Margaret Lock, who developed the concept of “local biologies” to counter the notion of a universal biology to explore the “ongoing dialectic between biology and culture” (1993: xxi). Local biologies is a concept that was developed to help explain the range of human physiological differences (Lock and Kaufert 2001; Lock 2001). Lock developed the concept to explain both the experience and incidence of menopause in Japan and North America and concluded that as a disease category it was “neither a fact nor universal event but an experience that we must interpret in context” (1993: 370). Following Lock and others, I challenge the assumption of a “universal” context free body (Butt 2013; Fullwiley 2011; Hamdy 2014; Horton and Barker 2010; Koch 2011; McCullough and Hardin 2013; Towghi 2014). However, while Lock focused on cultural practices, such as diet and exercise, to explain physiological differences, I emphasize the role of precarity, food insecurity and the cumulative effective of infectious disease assaults on local biologies. I argue that both the course of the HIV/AIDS virus in children’s bodies, such as the speed of disease progression, and the rate and kind of opportunistic infections they contract, influences their potential for long term survival on ART. In other words, as Louis Pasteur famously said on his deathbed: “the pathogen is nothing, the terrain is everything.”

Questioning the idea of a universal body has many implications for global health interventions (GHIs) targeting young children with HIV. My findings indicate in particular that relying on Western-generated “best practices” and protocols to treat children with ARVs may

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206 For examples of this kind of approach that “blames the victim” see Harrison (1985), Lewis (1966), Ryan (1971).
actually undermine HIV treatment programs in the long term. As Martha noted, and I observed, children just like Lionel can and do go from relative health to death even while on treatment. New research also suggests that ART may also be the cause of permanent developmental delays and reduced mental functioning that impact the quality of life for children on treatment (Donald et al. 2014). Local biologies embraces the idea that disease phenomena vary across locales both quantitatively and qualitatively. This is important because it means that “biological difference can influence individual experience as well as [the] cultural interpretations of experience” (Nichter 2008: 165). In this context, caregivers raising HIV positive children experience and give meaning to the uncertainty of adult-dose ART regimens for children. In Malawi, the possibility of death is an ever-present reality that cannot be fully avoided through pharmaceutical remedies. In particular, delayed HIV treatment initiation, undiagnosed disabilities among HIV infected children, food insecurity, and death among elderly and HIV positive caregivers highlight how impossible it is to disentangle biology from history, culture, politics, environment and – ultimately – the uncertainty surrounding children growing up with HIV (Lock and Nguyen 2010: 90). My overall findings indicate that a longer-term vision for ART scale-up must be broadened to go beyond pharmaceutical intervention to incorporate community interventions that support children’s social and economic realities and aspirations (see also Russell et al. 2007).

My aim in this chapter is threefold: First, by examining how primary caregivers understand and engage with the ART regimens prescribed to the children under their care, I seek to draw attention to the social, economic and medical realities of children on treatment, which are all too often sidelined in efforts to scale-up treatment access in resource poor settings. Through an examination of the daily grind of ensuring life-long treatment for children with unique medical needs, I want to demonstrate how the normalization of HIV discourse prevents serious analysis of the problems faced by caregivers trying to raise children with HIV. My second aim is to examine the “terrain” where HIV/AIDS flourishes. I ask, how do the “body counts” (Epstein 2008: 213-228) of “lives” and “years of lives saved” match up with the gradations of HIV treatment success experienced by children on treatment? In other words, are

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207 Three children died while on ART during my fieldwork. Two died within a few weeks of treatment initiation – likely due to late treatment initiation or immune reconstitution syndrome. Another died after a year on treatment from a presumed meningitis infection. Many more children died, but their deaths were part of the larger “invisible epidemic” I described in the Introduction. Also, adult deaths on ART were extremely common and were often mentioned during interviews by caregivers reflecting on their child’s future.
children on ART experiencing a return to “normal life” as envisioned by the GHIs trying to help children with HIV grow up into adulthood?

Finally, I aim to explore how assumptions about a universal biology, embedded in transnational pediatric HIV treatment programmes, obscure real problems with the long term safety and efficacy of ART treatment for children. As I outlined in Chapter Four, Malawi’s pediatric HIV treatment program was designed in Geneva for implementation in many different social, political and economic contexts, and these protocols are based on assumptions of a universal biology. Like Lock’s most provocative assertion that menopause is quantifiably different in Japan than in North America, I want to consider the implications of excluding human differences when designing HIV treatment programs (2007: 217-21). As emerging research in epigenetics, or the study in cellular trait variance that influence health and human behaviour illustrates, inter-individual variation is proving to be massive compared to inter-group genetic differences, highlighting how the physiological mechanisms behind local biologies remain both quantifiable and poorly understood (Engle 2011; Lloyd 2014; Lock et al. 2007; Lock 2013). More importantly in relation to Malawi, most research on the efficacy of pharmaceutical interventions leave out “non-white” or “non-standard” bodies (Epstein, 2007; Fullwiley 2011; Pollock 2012; Vaughn 1991). For example, most of the “evidence based data” used to design Malawi’s pediatric HIV intervention is derived from clinical trials conducted in North America and Europe using pediatric drug formulations (see Mills et al. 2012). This distinction is particularly important in the era of “universal access” to ART. While GHIs focus on mechanisms and technologies to speed up ART roll-out, relatively little attention has been paid to differential treatment outcomes from context to context. This issue is critical given that Malawi has the lowest ART retention rates in the world, with nearly half of all patients who start treatment either dead or “lost to follow up” five years later (HIV Unit, Ministry of Health, Malawi, 2010).208 By focusing on the interplay between precarity and biological processes, my

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208 The Global Fund estimates that by 2011 they have ‘saved 2.9 million lives’ (ref: 21). They base these estimates on the assumption that after 12 months 86% of patients who start ART are still alive (excluding anyone who died within first 8 months of treatment). However, in Malawi after 12 months only 74% of children on treatment are still alive and after 60 months (or five years) only 55% of patients (adults and children) are alive (UNGASS 2011). Moreover, when compared to other countries it is clear that there is great variation in the relative success rate of ART treatment by gender, age, country and socioeconomic status. For instance, in India the rates for children are much higher than Malawi with nearly 90% of children who start treatment alive after 12 months (R. 2009). Moreover, these numbers exclude the fact that between 2-5% of all patients who start ART treatment die within the first 3 months. Therefore, these celebratory statistics mask inequalities on many levels, including large
findings provide insights into the formation of local biologies influencing pediatric HIV/AIDS treatment outcomes in Malawi.

“Even Children His Age Die While on the Medicines”: ART and Local Biologies

Why was the medical argument that children could live into adulthood so unconvincing to TMGs and health care workers in Malawi? Is it not universally the case that being on treatment transforms a life threatening disease into a chronic one managed through simple therapy? One where you could “almost” have a normal life? To understand these dynamics I adapt Margaret Lock’s (1993) concept of “local biologies” that she first developed in Encounters with Aging to explore qualitative and quantitative differences in menopause experienced between women in Japan and women in North America. Her findings illustrate how cultural practices, such as diet, exercise and the environment altered both the experience of and prevalence of menopausal symptoms across cultural contexts. Her analysis reveals that the supposedly “universally biological” symptoms of menopause, such as hot flashes, mood changes or constipation, are not equally experienced among women. Her most provocative assertion is that this difference cannot be explained by cultural constructions of illness alone; rather, that Japanese women’s symptoms of aging are based on the entanglement of biology and culture – or that cultural practices produce population-based biological differences (Lock 1993: 38-39, 373). These observations reveal how contingent biological processes are on historically and culturally specific practices, such as what we eat, where we live and how often we exercise. Even if the exact mechanisms behind these processes remain unclear, there is enough evidence linking health outcomes to social, political and economic forces to conclude that the “universal body” is a fiction (Leibing 2013; Lock and Nguyen 2010: 90).

More recently, anthropologists have taken up the idea of local biologies to include the interplay between the body and shifting socioeconomic, environmental, political and historical contexts. For example, Horton and Barker (2012) show how the dental health of Mexican migrant farm workers children differs not just due to cultural variation in diet or infant feeding practices. Rather, they highlight how the structure of farm work made bottle feeding necessary

variations between countries, success rates between adults and children and they never discuss high mortality rates in the first few months of treatment. However, as Martha notes, just because these inconvenient exceptions are excluded from statistics does not mean they go unnoticed by the people targeted by HIV interventions.
for working mothers, which, in turn, led to an inadvertent increase in infant tooth decay. Dental health was further compromised by poor dental health coverage for migrants. In Papua province, Indonesia, Butt (2013) also found that regional political conditions and intrarural inequalities intertwined, leading to HIV treatment delays and rapid onset of AIDS and death. Hamdy (2008, 2013) also broadens the original concept of local biologies beyond bio-cultural dynamics to consider Egypt’s kidney failure epidemic. She challenges assumptions about the universal safety of living organ donations by pointing out that kidneys are failing in Egypt due to a range of environmental, political and social factors, including toxic waste exposure and unregulated pharmaceutical markets that undermine the safety of kidney transplants. The value of these new approaches to local biologies is that it avoids what Wardlow has called the “‘etiologization’ of culture in the context of the AIDS pandemic” (2002: 153), or the dangerous tendency in GHIs to conflate differential health outcomes with cultural practices and differences. Rather, my use of the term “local biologies” draws on these insights to focus our attention on how shifting cultural practices, political economies and local biologies are intertwined (Fassin 2007; Fullwiley 2011; Koch 2011).

By shaking the foundations of a universal biology, are thrown open to question common assumptions about the therapeutic efficacy of pharmaceuticals can be everywhere and in everybody the same. Lock and Kaufert (2001) argue that because women do not experience menopause in the same way from place to place, the rationale for standardized medical protocols recommending hormone replacement therapy seems impractical at the very least, and perhaps even dangerous in some cases. In another study, Koch (2011) demonstrates how an overreliance on pharmaceutical interventions for TB infected prisoners in the Republic of Georgia actually increased the number of multi-drug resistance cases of TB, since it did not address any of the social conditions (such as overcrowding and poor nutrition) that facilitated TB transmission in the first place (see also Nguyen 2013) and Towghi (2013) questions the rationale behind recent efforts to globalize the HPV vaccine to prevent cervical cancer in India. Given that cancer causing genotypes vary substantially between India and North America, immunologists worry that a vaccine developed for North American markets might not be as effective in different contexts. More worryingly, immunologists have expressed concerns that a vaccine that does not consider the specific epidemiological particularities of the Indian context may inadvertently strengthen other cancer-causing HPVs. Although these findings complicate the idea of
therapeutic efficacy, the concept of local biologies is not about individual variability. Physicians are aware that not everyone responds to pharmaceutical interventions in the same way. For example, some people are allergic to penicillin while others are not; some people respond to antidepressants while others do not. However, I am not using local biologies to refer to individual variability or even to imagined or even real genetic variability that may impact an individual’s ability to absorb the benefits of pharmaceutical interventions (Fullwiley 2011; Pollock 2012). Rather, I use the term local biologies to highlight that in Malawi population-based biological differences are shaped by complex relationships between a precarious social and economic environment that are widely shared. As many TMGs and health care workers noted, sometimes local biologies were embodied by children as a negative response to ART. Many therefore had very realistic fears about their ability to sustain ART adherence in the long term. The unusually poor ART retention rates in Malawi highlight how these processes operate at the population level.

“I wonder if he will live very long”: Temwa’s Local Biology

Talking to various members of a child’s TMG in Malawi, I came to realize that they were the ones questioning the suitability of ART for their children given the lack of food and support they faced in their daily lives. However, it is not that caregivers questioned the therapeutic efficacy of the treatment per se (although a few did), but whether the social and economic conditions of their everyday lives made treatment as effective as it could be (see also Hamdy 2013). Using the concept of “local biologies” to reconsider the rhetoric behind the “HIV is a manageable chronic condition” involves taking seriously the concerns raised by those ensuring that HIV positive children take the medicines as intended. Drawing on the concerns raised by the health care workers and the TMGs that I talked to, this chapter argues that programs advocating pharmaceutical intervention need to more seriously consider the dynamic biomedical, physical or social factors particular to Malawi that constitute local biologies.

Despite assertions that ART transforms a once-deadly disease into a manageable chronic condition, the life expectancy for children on treatment in resource-poor contexts remains mostly speculative (Mills, et al. 2011). Even in the United States, the mean age at death of children on treatment is 18 years, which is still 10-30-fold higher than in similarly aged uninfected
populations (Mofenson et al. 2008; FIF 2008). Although this is a dramatic decline from the pre-ART era, improvements in life expectancy and quality of life are contingent on a number of biomedical resources that did not travel to Malawi with the medicines – such as physicians, pediatricians, laboratory monitoring technologies, alternative drug formulations, early testing technologies or a range of medicines to treat opportunistic infections or side effects from drug complications. For example, the vast majority of children in Malawi rely on rapid testing technologies, which means that most children are diagnosed after they are 18 months old and already symptomatic (see Chapter Three). However, biomedical research measuring therapeutic efficacy indicates that ART is far more effective in the long term if children initiate treatment immediately, rather than waiting until they satisfy clinical or immune criteria (i.e. CD4 counts) (Kiboneka, et al. 2008; Violari et al. 2008). Hazra et al. (2010), in their review of children on ART in North America, also note that while children on treatment are now less likely to die of opportunistic infections related to HIV infection (such as pneumonia), they are more likely to be affected by complications related to ART resistance and toxicity, including cardiovascular disease, renal failure, bone loss, central nervous system and metabolic disorders. Moreover, they also found that children on ART are more likely to suffer from cognitive deficits, problems with attention and psychiatric disorders, although to this day we do not know whether these problems are due to the medicines and/or HIV infection or to something completely unknown (see Scharpe 2014). To carefully manage and monitor these conditions, children on treatment in high resource countries are regularly screened using laboratory technologies that are generally unavailable in Malawi, including basic urine tests (Hazra et al. 2010). Treatment resistance, or the failure of the medicines to reduce viral loads over an extended period of time, is also a serious problem in children on treatment for many years, often requiring complicated – and costly – “salvage therapies” (Parsons et al. 2006). Unlike high resource countries, children in Malawi do not have access to any alternative therapies when they develop treatment resistance, yet some like Lionel have been on treatment for a number of years and may already require new regimens (Kebe et al. 2013; Wadonda-Kabondo et al. 2012).

Although some of these concerns are undoubtedly sidelined as part of a calculated effort to keep public support and donors on board, they also reflect the techno-medical limitations of current pediatric HIV treatments – there is after all no “cure” for HIV (see also Closser 2008 on optimism in polio eradication initiatives; Robins 2004). For years children with HIV were denied
access to HIV treatment since no affordable or feasible pediatric formulations existed for a resource poor context.\textsuperscript{209} Given the lack of treatment options for children, Medecins Sans Frontiers (MSF) felt “morally obliged” to provide children with adult-dose split tablet regimens where there were no paediatric formulations available, despite the lack of evidence about their therapeutic efficacy or safety for children (O’Brien et al. 2006: 1956). Preliminary results, which measured the safety and efficacy of adult medications for children on treatment after six months, were encouraging (Fassinou et al. 2004). As a result, in 2006 the WHO amended their international treatment guidelines to recommend adult dose regimens for children as an “interim solution” (O’Brien et al. 2006: 1955) until more appropriate pediatric drugs could be developed for resource-poor contexts. In Malawi, national treatment guidelines adopted these international guideline changes in 2006, and by 2008, a national roll-out was initiated after health care workers were trained in paediatric HIV diagnosis, treatment and management (Bong et al. 2007). This means that until August 2010, when pediatric formulations became available in Malawi for the first time, approximately 20,251 children were alive and on adult dose split-tablet ART regimens in Malawi (HIV unit, Ministry of Health, Malawi). In practice this meant that during my research caregivers “split” or “broke” adult-dose tablets into halves or quarters dependant on their child’s weight (see Figure 26). While research was “encouraging,” the situation was described as “far from ideal,” even by its proponents, and serious questions remained about the safety and efficacy of this policy (O’Brien et al. 2006). For example, split tablet regimens are linked to under-dosing and decreased efficacy in children (Menson et al. 2006), which can also cause treatment resistance later in life (Chokephaibulkit et al. 2005). In addition, pediatric formulations are approved for use on the basis of efficacy data extrapolated from adult studies, and there is very limited information on the pharmacokinetic effects

\textsuperscript{209} For a description of the years and paediatric ART treatment denial and neglect that preceded 2006 see Rollins (2006) and The Committee on Pediatric HIV/AID (2007. For a description of how adult treatment regimens became available in resource poor contexts (see Biehl 2008; Mills et al. 2006; Nguyen 2011).
and safety of treatment in children (Hazra et al. 2010; O’Brien et al. 2006). Therefore, while children on adult-dose ART regimens do better than their peers who do not get treatment, the therapeutic efficacy of their treatment regimens are delimited by the limited biomedical resources surrounding their roll-out.

The physical body of the child on treatment is another important factor influencing therapeutic outcome: the body, as Lock noted, “is the product of individual lived experience in specific environmental, historical and sociopolitical contexts” (2013: 292). Unlike the United States where the long term efficacy of ART has been measured under ideal conditions, children in Malawi are exposed daily to poor living conditions, endemic viruses and infections such as TB, malaria, dengue fever, and parasitic infections such as schistosomiasis. Yet the cumulative impact of these diseases on a child’s body, how they affect a child’s immune response or their ability to absorb and mobilize chemical agents in medicines, is only partially understood (Bustinduy et al. 2014; Edmonds et al. 2011). Thus, their effect on the therapeutic outcomes of ART and HIV disease progression among children is unknown and rarely taken into account in program implementation. For example, Malawi has one of the highest rates of malaria infection worldwide, and malaria infection is linked to increased HIV viral loads, or compromised immune systems, and a decreased immune response to pharmaceutical intervention in adults, including ART (Whitworth et al. 2000; Stillwagon 2006). Health complications related to long term ART, such as renal disease, may also be amplified by Malawi’s poor water supply, leading to diarrhea and dehydration, as well as by toxic exposure to nicotine through tobacco farm labour, which all pose particular stresses on kidney function (McKnight and Spiller 2005). High rates of anemia and undernutrition (a more specific type of malnutrition) in Malawi are also strongly linked to accelerated disease progression in children, especially in the first few months of treatment initiation (Bolton-Moore, et al. 2007; Marazzi, et al. 2008; Paton et al. 2006). These problems complicate biomedical notions of a universal body, undermining recent assertions that ART turns HIV infection into a manageable condition for everyone, everywhere.

Children’s bodies undergoing HIV treatment are also subject to social phenomena, such as the health of their primary caregiver, and the gendered and generational structuring of authority within their TMGs (Bezner Kerr 2005, 2008; Hejeoka 2009; Kamat 2006; Messer 1997; Munthali 2006; Quissumbing & McClafferty 2003). Research conducted in two different regions in Malawi on food distribution within households highlights how complicated these
issues are. For example, Kennedy and Peters (2002) found that children living without their
fathers in female-headed households had substantially better nutrition that those living with both
parents. However, researchers working in Northern Malawi, which practices patrilocal residence,
found the exact opposite – that children in female-headed households were the most likely to be
severely undernourished (Bezner Kerr et al. 2011). In Zimbabwe, Parsons (2010) also noted that
children living with extended kin after the death of one or both of their parents were often the
recipients of reluctant hospitality, and were more likely to be food insecure than other children
sharing the same home (see also Wolf 2010). Hampshire et al., (2009) also found that some
children in Niger were the “victims of non-discrimination”; by that they meant that efforts to
ensure that every child was treated the same irrespective of their age, gender or orphan status led
to poor health outcomes for children who had additional nutritional requirements due to illness.
Combined, these findings highlight how important it is to consider not just the economic means
of a child’s TMG to realize long term treatment adherence, but how resources are distributed
within these groups to better understand how HIV positive children may or may not gain access
to valuable resources, such as food or money for transportation to the hospital when they fall sick
that could exten their lives.

Arguably these issues affect children more than adults since they are completely
dependent on an adult or older sibling for all of their health needs. This was a huge source of
concern for all of the primary caregivers I spoke to, since most were either HIV positive
themselves or very old. Even brief disruptions in treatment, such as the absence of the primary
caregiver when he or she might be away visiting relatives or at a funeral, can be very dangerous
for children on treatment (Haberer et al. 2011). Research indicates that the transition from
childhood to adolescence also poses significant challenges for children on treatment. For
example, research in Zambia suggests that as children age, their treatment adherence decreases
(Haberer et al. 2009) and that processes of HIV disclosure may lead to confusion and discrepant
perceptions about a child’s level of responsibility for medication (Dolezol et al. 2003; Hejeoka
2009). Children on ART transitioning into adolescence may interrupt their treatment regimens to
satisfy their own life projects (Mattes 2011; Mutumba et al. 2015; Smith and Mbakwem 2007).
By highlighting the various ways that biomedical, physical and social phenomena interact with
the pharmaceutical regimens administered to HIV positive children, I found that an array of
actors, from global health donors to health care workers, are at best overstating the benefits of
ART for children. It is also significant that the drive to scale up HIV treatment for children is taking place at the expense of promoting other basic health care measures that have been proven to improve health for all children, not just those who are HIV negative (Nguyen 2009). In the next section I draw on specific concerns of various primary caregivers to answer two questions. First, to what extent are these caregivers experiencing a “return to normal life” after a child starts ART in Malawi? Second, what factors enable or hinder this process of transition for children living with HIV? Finally I conclude by considering how current renderings of the “normalization of HIV” may obscure what challenges lie ahead for children on long term treatment.

**Negotiating Precarious Futures: The Limitations of HIV Interventions to Facilitate an “almost normal” Life**

There is massive global investment, symbolic and material, in the promise of scaled-up HIV treatment (Schwartlander et al. 2006). As President Clinton declared, HIV treatment gives “hope for the future” because treatment turns “AIDS from a death sentence to a chronic illness” (Clinton 2003: 1800). Despite the limitations of HIV treatment in Malawi described above my observations support these assertions in many ways; the early effects of treatment initiation for children were often very dramatic. Health care workers and caregivers alike witnessed such visible and rapid improvements in infected children’s health that most expressed renewed hope for the child’s recovery and re-engagement with normal childhood activities. For example, caregivers often expressed intense relief soon after treatment initiation:

> Just two weeks ago he was not walking or eating! Now he is chatting with his friends and I can see a great change.
> - (Julie, grandmother of five year old Chimwemwe)

> I was very sad. I thought I had ruined my son’s right to have peace in life, because it was me who gave him this disease. But now I can see that maybe he will become a child.
> - (Judy, 18 year old mother of Vitu)

These changes also encouraged primary caregivers to resume everyday activities and pursue their own life goals. Many noted that since their child had started treatment they were now able to attend church again or visit with neighbours, since they no longer had a “kumeka,” or fussy,
infant to worry about. Others also expressed a desire to pursue their own marital and reproductive aspirations (see also Smith and Mbakwem 2007). For example, after a few months of successful treatment, some mothers asked me about the possibility of remarriage and having HIV negative children in the future.

As I discussed in Chapter Three, positive feelings about the potential of ART to return children to an “almost normal” life were strongest soon after treatment initiation. This was largely because for nearly everyone the stage immediately before and after treatment initiation was often characterised by intense uncertainty and loss. More than half of all the treatment initiations were preceded by an ongoing illness or death of at least one family member, either another child or a parent, usually the father. A third of all the children on treatment had already lost at least one sibling to HIV prior to their treatment initiation. One mother had lost all six of her older children “before the stage of walking.” Although the cause of many of these deaths remained unknown, since most of them occurred prior to the availability of treatment for children in 2008, most came to believe that HIV infection was the culprit. As one mother explained:

My children were just dying one after another. All [four] died just before the stage of walking. I thought there was just something wrong in my body… The doctors were not explaining it very well, telling us it was things like malaria or diarrhea. Now I can say looking back that that maybe they had this disease like this one [the one starting treatment].

As their children’s symptoms intensified prior to their eventual diagnosis, so too did their struggles. The intensity of the symptoms often led to long term hospital stays, which required time and money that many caregivers borrowed from relatives or did ganyu labour to find. The visible signs of HIV infection also led to derision by neighbours and other members of the TMG, who sometimes assumed that this was related to carelessness or ignorance on behalf of the mother. Thus, visible signs of improvement soon after treatment initiation provided an immediate sense of relief and renewed hope for a return to normal life for both caregiver and child. While over time caregivers grew less concerned with their child’s immediate survival and symptom relief, other concerns emerged surrounding long term treatment adherence and HIV-related complications.
This transition, from crisis intervention to long term management of a child’s HIV related symptoms, was far more precarious in the long term. While most children improved rapidly on treatment soon after initiation, the effort put into long term symptom management and treatment adherence was fragile, and often vulnerable to diverse forms of interference (see also Russell and Seeley 2010). In at least three cases, HIV treatment initiation sped up death rather than preventing it, a process referred to as “immune reconstitution” by health care workers, and these children died within weeks of starting treatment. This refers to immune reconstitution inflammatory syndrome whereby the infected individual begins to recover but then the immune system responds to a previously acquired opportunistic infection (such as TB or pneumonia), making the HIV infection much worse. Ramadhani et al. (2013) note that this is particularly the case with children who are also moderately to severely malnourished. While these cases were a minority, they stood out in caregivers’ minds as reminders that the treatment does not work for everyone at all times. However, even for those children who improved on treatment, none recovered completely. Nearly every caregiver also noted that the child on treatment was smaller than others the same age and more likely to fall sick than their siblings or friends. Many had minor reoccurring skin problems, coughs and developmental delays, which I discuss in more detail below. Therefore, despite growing confidence in their child’s health, no one was entirely secure in the long term efficacy of ART, especially in the face of daily challenges finding food, of staying healthy (especially for HIV positive caregivers) and ongoing health problems that persisted among children on treatment.

Doubts about the long term efficacy of ART for children were compounded by negative experiences with ART over time. Everyone knew someone who had died while on ART, some soon after treatment initiation, others years later. For example, one grandmother caring for her five year old granddaughter was very worried about treatment initiation since her own daughter had died just a few weeks after starting treatment. As I discussed in Chapter Two many children initiated ART soon after their father’s death – often soon after they started ART themselves. Some primary caregivers found out that they were also HIV positive on the same day as their child and were worried about the implications of their possible deaths on the long term survival and happiness of their children. These issues were compounded by a general suspicion that foreign donors and the Malawian government would be unlikely to provide the medications at no-cost indefinitely. Therefore, despite rapid and sustained improvement on ART in most cases,
few caregivers experienced the “normalization” of their child’s HIV given the long term challenges to treatment success in this context. The rest of this chapter focuses on areas where treatment success and local biologies intersect, such as food insecurity, mobility, barriers to long term treatment adherence and drug toxicity.

“She goes to school every day, but she just fails her exams”: Disability and Mental Health

Everyday challenges caring for HIV positive children are compounded by undiagnosed cognitive and mental health problems (Malee et al. 2011), hearing loss among infected children (Torre et al. 2012) and higher rates of comorbidity, all leading to school delays or early drop out. Although research to date has not determined the frequency of these problems among perinatally infected children, or their exact cause, they clearly impact the child’s quality of life and future potential to independently care for themselves. Rhoda, a mother of a nine year old girl named Bridget explained:

Bridget is just repeating Standard One for the fourth time. She is failing to pass the exams, even though I encourage her in school and she likes to go to play with friends. Before she started the medicines she was just intelligent. But now I think they [the medicines] are giving her troubles at school. You can see her mind is not alright.

While Rhoda was sure that the medicines were the cause of her daughter’s loss of intelligence, others felt that the medicines helped with their child’s development. For example, 8-year old Chuma’s grandfather explained:

After he started the medicines, he at first lost his memory. He would forget things that happened… For example, you would tell him to take a bath but he would forget to take one. Because of this he has been disturbed at school… because he was falling sick all of the time he was not keeping things in his head and he did not write his exams well. He was intelligent in Standard Two, but now he is repeating Standard Three. But now I can see he is coming back to normal. He is becoming intelligent again” (emphasis mine).
Determining the cause of these developmental health delays is critical, since attributing them to the treatment themselves will likely influence ART treatment adherence over time.

Compounding these problems are disabilities and HIV-related co-infections either related to HIV infection or ART drug toxicity (Govender et al. 2011; Scharko 2006; Van Rie et al. 2007, 2008). For example, two children, like 14 year old Lubbock, were also partially deaf. His aunt’s worries about Lubbock’s future highlight how a “local biology,” or the intersection between HIV, ART and the possible cumulative effects of living in a precarious environment all render Lubbock’s future insecure:

He is just in Standard Four, but should be in secondary school like his sister now. He is failing to hear in class – you see [shouting loudly at his back]– you have to speak very loudly for him to understand. The teacher just has a small army [150 students] – so what is he to do? We do not know where the father is, so since he is staying here in his mother’s village, this is a very big problem for me [because he will not be able to get land and farm]. I worry about his future.

Even without obvious signs of mental health problems or physical disabilities, every school aged child on ART at Temwa Rural Hospital was behind in school at least one year and many had stopped going after a year or two. Some, like Lionel and Chuma, fell ill during exam time and were not able to write the exams, forcing them to repeat a school year. As Martha explained:

The only difference I see between him and other children is in education. He should be in Standard Four, but he’s in Standard Three because he was sick during exam time and couldn’t write his exams so he has to repeat.

Others missed extensive class time due to HIV-related illnesses that caused them to miss too much material to pass the mandatory exams. As Lubbock’s aunt points out, without an education many children will have few opportunities in the future. This issue was particularly pronounced for children being raised with maternal kin, since as adults they will have a very limited claim to land through their maternal family (Wolf 2011). As Rhoda noted earlier, without an education there will be few opportunities for uneducated children outside of farming, and without access to
land this poses serious long term challenges to their well-being. More generally, the impact of undiagnosed mental health and developmental problems on the quality of life and the capacity for independent functioning (or long term treatment adherence) into adulthood is potentially profound.

“Good food is scarce”: Food Insecurity and Therapeutic Efficacy

Malnutrition and food insecurity are persistent cofactors of the HIV/AIDS pandemic; ART increases resting energy expenditure (Shevitz, et al. 1999), increases the physiological need for food (Kalafonos 2010) and can hasten disease progression in children (Marazzi, et al. 2008). To mitigate these complications health care workers encourage primary caregivers to provide ‘good food’ to improve the therapeutic efficacy of ART medicines. During the initial adherence counselling sessions that I observed, the nurse slowly flipped through a cardboard slideshow on her desk showing how ‘good food’ acts as a shield protecting the body from the virus. “Good food” in these diagrams included eggs, meat, beans, pineapples, and fish. Unfortunately, nearly all of these foods are either unavailable in this region (such as pineapples) or beyond the financial reach of most households, such as eggs, meat, fish. Fruit, in particular, was hard to come by in this tobacco growing region because of the sustained time and energy that fruit trees often require to survive dry seasons, when migrant labourers are not around to water them. Tenants are also only given land to grow tobacco, and are rarely provided any space to grow vegetables or beans. For example, during my fieldwork the bean crops in my area failed both seasons due to sporadic rainfall and could only be purchased in the market. Therefore, rather than reassure caregivers, the counselling slideshow had the overall effect of creating feelings of anxiety and frustration that they were failing to meet these expectations. Contributing to this anxiety was the fact that “good food” for all of these caregivers were foods that had to be purchased, and not ones that could be collected in the wild or grown close to home. As Jennifer, an elderly grandmother caring for two HIV+ grandsons, noted:

The problem now is that we are old and we are having troubles finding money for good food. These ones [her two HIV positive grandsons] need good food. Sometimes you can find it, but sometimes good food is scarce.
Mpatso, a 16 year old girl helping with her brother’s care, elaborated on the concept of “good food” having to be purchased:

Lubbock’s refusing his vegetables because we are cooking them without cooking oil and we have trouble finding tomatoes for soup. But he is eating good food when we find it…. When we find meat, or eggs he is eating that. Sometimes my mother’s brother [asibweni] does ganyu [farm labour for food or money] to buy stork [margarine] or milk or sugar to put in his porridge.

Efforts to obtain good food often required complex negotiations within TMGs. Many families engaged in ganyu, a form of farm labour for food practiced by the poorest families in the region (Bezner Kerr 2005). However, both financial and labour contributions made by various members of the TMG were often only reluctantly given:

Mostly my brother [who lives next door] is helping us with money for good food, but sometimes he shouts at me, that we should go back to my husband’s village and let his family take care of us.

- (Mavis, mother of a two year old on treatment, living in her own, rather than her husband’s home village)

Good food was also used by senior members of TMGs to remove children on treatment from their mother’s care:

I took my granddaughter to stay with me when my daughter remarried. The new husband would not be interested in spending money [on the good food] he needs to keep his body strong.

- (Ruth, Grandmother caring for a two year old on treatment)

Finding food, either through extra labour or small businesses, depended heavily on one’s social status within the community. Women, for example, had few opportunities to find money on their own. Some grew vegetables to sell in the market, others brewed beer and a small number
engaged in transactional sex to find the food they needed (see also Bryceson & Foncesca 2006). This sometimes caused problems with extended family members, who did not approve of beer brewing or “prostitution” (mahules).

To find money for food I brew beer and sell at the chirabu [men’s drinking area in town]. My in-laws saw this and tried to take the house away from me and send me back to my village, but in the end they only took all the things from inside [the house].
- (Patricia, widowed mother of five year old Judy on treatment)

I am just moving around… [working as a prostitute] so that my son can stay strong on the medicines. Everyone at home is dead. There are no grandparents, and no parents that could be helping me.
- (Molly, mother and sex worker caring for three year old on treatment)

As I discussed in detail in Chapter Five, by their status as “visitors”, tenants in particular had few means of finding good food.

How do we find food apart from maize? I should not lie. We only eat maize because we are under the authority. As tenants we are not free to go somewhere and do ganyu to find necessities. The landowner has not even given us one tambala [less than 1cent USD] in advance. Sometimes I mend shoes to find maybe 100MK [25cents]. But to be honest, that is why we Chewas [referring to his ethnicity] eat rats. Not because we like them, but just after some months your body longs to taste something other than vegetables. That has a bit of oil in it.
- Vonex, tenant farmer with a two year old diagnosed with HIV but did not present with the clinical symptoms to qualify for free treatment)

The landowner gave us some soya beans for Margaret’s porridge when he saw how she was looking [orange hair, failing to walk]. But other than that we have not found anything.
- (Lucy, mother of a two year old on treatment)
The ability to find good food for HIV positive children did not only depend on the household’s relative wealth, but also on the composition of the therapy management group. Nearly every family in this region experienced some form of food insecurity over the course of the year, and some TMG members resented “hunting” for good food at the expense of other members. Other families with HIV positive children had fewer resources to draw on, either because family members that would normally help, such as grandparents, were already dead, or because they were migrants in the area without the usual kin networks that could help them. Aside from the initial adherence counselling given at the hospital, caregivers were not given any information about locally available foods that might improve the therapeutic efficacy of their children’s medicines, nor was there any nutritional support available for HIV positive children. The lack of “good food” also undermined caregivers’ confidence in the therapeutic efficacy of ART medicines, so much that most had doubts that their children would live “to become children.” Thus, taking local biologies seriously by considering how social (TMG composition) and biological processes (food security and drug efficacy) are inextricably linked draws attention to potential vulnerabilities in global health treatment plans for HIV positive children.

“This disease ends in death” – The Permanent Ambiguity of Therapy Management Groups

The long term therapeutic efficacy of ART is predicated on the willingness and ability of the patient to take the medicines every day for the rest of their lives. However, the extensive mobility of children between households – for reasons ranging from the divorce or death of a family member to providing companionship and labor to an elderly relative – may undermine long term treatment adherence (see also Young and Ansell 2003; Wolf 2010). To prevent dangerous treatment disruptions, primary caregivers reported giving up paid employment in towns to be near family members in case they died of their own HIV infections. 36 year old Esther explained:

My husband died when I was only two months pregnant with Happy. At the time we were doing business in Mzuzu. Buying things in Mozambique and selling them in town. It was there I found out my husband had HIV because he was admitted to the hospital and
the nurses were saying he was positive, that it was marked in his health book, but he never told me. But looking back, I can see the signs in how his body was and I accept that he died from this disease. He went to get tested on his own, I guess, but I don’t know why he never told me. Sometimes I think it was because he was afraid I would refuse to move to Mozambique because we are sick, that I would not want to be far away from my home village."

I tested positive soon after he died during antenatal care. I know my husband gave it to me, because he is the only man I ever slept with…. After my husband died I wanted to go back to Mozambique. Before we came here for business I was staying very well with my mother in law, but my parents were not understanding. They said it was too far, they were worried I would have problems, so I didn’t go because of the wish of my parents. But myself I wanted to go there because my children will have problems in future, especially if I die then my children will not have peace because in our culture nephews cannot have land. So if God can keep me with good life like this and with good health and farming then I can find time to go there with the older [HIV uninfected] boy one to show him his home village. Otherwise he should just be going to school or doing business, but that you need to find money so that is the difficult part for me because my children will be in problems if I can die quickly.

Elder members of the TMG, such as grandparents or fathers-in-law, were often able to assert their authority over mothers in particular, by insisting that they return home after being diagnosed with HIV. Of note is that this pressure ensured that most HIV infected children were being raised by matrilineal kin, which has longterm consequences for their access to land and school fees into adulthood. Thus, while caregivers needed the help of their relatives for food, housing and clothing, many worried that this arrangement would negatively impact the future aspirations of any children as they grew up.

Like Lionel’s mother Martha, many primary caregivers worried about what would happen to their children if they died, either from old age for grandparents or from their own HIV infections.
The biggest problem for me bringing up Lucy is that I am looking after her alone. The time she was born I started having problems. I have been admitted in the hospital twice, even with the medicines, so this is something which is worrying me very much because her father is remarried and his relatives are there but when Lucy is sick they are not helping me. If I die, I don’t know who will be caring for her.
- (Rhoda, mother of a six year old on treatment)

With my mother in the hospital I am very worried. She has been there for six weeks but the way she is looking…. [She starts to cry]. Now I am the one making sure that Lisa takes her medicines. But finding food… the grandparents are old so that is a challenge.
- (12 year old sibling, caring for her two year old sister on treatment during her mother’s hospitalization)

The death of a primary caregiver was particularly dangerous since it often led to treatment disruptions and modifications. Katherine, a five year old girl with HIV, was improving slowly after initiating ART treatment; after years of debilitating illness she was finally able to play outside with friends and go to school. However, soon after her mother’s death from HIV-related complications, Katherine was sent to live with her father’s family in another village. In less than a month, Katherine’s health deteriorated so rapidly that another paternal aunt became so alarmed that she carried Katherine to hospital on her back where she was admitted and treated for advanced symptoms of HIV infection. The first aunt, who had gained custody after Katherine’s mother died, did not know the reason Katherine was taking the medicines and abruptly stopped her treatment, with potentially deadly complications. Although the other aunt Maria re-initiated ART a month later, by the end of my research nearly a year later Katherine still had not recovered enough to attend school with her peers.

While for Katherine a sudden transition in her TMG had severe health consequences, the responsiveness of TMGs to sudden change or crisis also enabled another aunt to step in and take over Katherine’s care when her health deteriorated. Other changes within the TMG, such as the loss of a father, either from death or divorce, also led to an HIV diagnosis and ART treatment initiation. In this context, child care responsibilities are strictly organized around a marked division of labour and authority by gender and generation (see also Foley 2008). Although wives
and mothers are responsible for everyday responses to disease and health promotion, such as vaccinations, bathing, finding food, sanitation, and obtaining amulets and charms to ward off malevolent forces, health strategies for acute illness are often left to the father or other senior members of the TMG. I do not want to suggest that fathers have no interest in maintaining their child’s health; rather, I want to point out that the gendered division of child care labour places a different kind of burden on fathers than on mothers. For example, since serious illnesses tend to require more cash, time and mobility, fathers must often grapple with the difficult decision to purchase fertilizer that will help provide food for one or more households for an entire year rather than pay for transport to the hospital for one sick child. These tensions are exacerbated by the exclusion of men from most child health services, which have historically focused only on maternal health to promote child health improvements.

“He will understand when he gets the medicines himself”: Facilitating Treatment Adherence for Children into Adulthood

Disclosing to a child that he or she has HIV is considered one of the critical steps for ensuring long term treatment adherence. Research suggests that delayed disclosure has many long term health consequences for children on ART. It is associated with reduced treatment adherence (Arrive 2012; Bikaako-Kijura 2006; Lara et al. 2010), increased treatment resistance, psychological trauma, (Hazra et al. 2011) and disruptions at home, at school and with friends (Mattes 2014). For example, in 2010 a 15 year old boy in Southern Malawi found out he had HIV and the same day attempted to kill his mother for infecting him. The transition to adolescence, in particular, presents a new set of challenges for caregivers as youth take over the responsibility of obtaining and adhering to ART without the daily supervision of an adult (Hazra et al. 2010). As children become their own caregivers, some choose to stop treatment on their own for reasons ranging from peer pressure, to a preference for faith based healing (Mattes 2011). However, given that most children with HIV start treatment as infants, disclosure often occurs over time rather than as a singular event (Lesch et al. 2007). While the research on HIV disclosure to children in sub-Saharan Africa is sparse, it suggests that formal disclosure rates between caregivers and children are very low (9%), with health care workers and caregivers often disagreeing about how and when this process should take place (Moodely et al. 2006).
How exactly primary caregivers in Malawi were supposed to manage the disclosure process was unclear during my research. I suspect that this was largely because until the roll-out in 2008, very few HIV infected children lived beyond early childhood. On a national level there were no guidelines in place to help health care workers, schools or primary caregivers navigate this tumultuous terrain. Nor were there any psychosocial support services in place designed for children and adolescents in my area. When I asked caregivers how and when they intended to tell their child that he or she had HIV, very few had given the idea any thought. Most were surprised to find out that he or she might live “to become a child” and were more concerned with the child’s immediate survival. However, after a few months of sustained health improvements, caregivers began to ask me for guidance about the process of HIV disclosure: Should we tell the headmaster at his school that he has HIV? What happens if his friends at school tell him he has HIV? How will he know to come and get the medicines if I die? Rather than answer their questions, I would ask them what they thought and their answers were surprising. Most explained that the child would figure it out for themselves, “when they were at the stage of understanding things.” For example:

Maybe when she’s 10, that time when she has a little wisdom in her.
   - Mother of six year old Lisa

I cannot tell him… He will find out when he decides to go for an HIV test himself.
   - Mother of two year old Henry

He will hear it from friends, because they will see him going to the hospital.
   - Mother of 13 year old Felix

I will just tell him at a certain point: ‘My son, I passed you a virus and that’s why you are taking these medicines. You have to be taking care of yourself.’
   - Dorothy, mother of nine year old Jacob

None of the caregivers I spoke to had spoken directly to the child on treatment about their HIV status, although caregivers with older children felt that many already knew their status. Thus, in
practice, most children figured out they had HIV on their own, often years before any adult in their life had a direct conversation with them about their illness.

Interestingly, the approach taken by most caregivers is contrary to the recommendations by public health researchers who prefer to see a more formalized process in place. Researchers, however, characterise the lack of formal discussions between caregivers and children with HIV as a sign of guilt, fear of stigma, or because they are “ill-equipped to handle this process positively” (Lowenthal et al. 2014:8). However, these researchers have paid little attention to strategies that caregivers already have in place to facilitate age and child-appropriate information about HIV. Anthropologist Bluebond-Langer notes in her ethnography of children diagnosed with terminal cancer that researchers looking at illness disclosures too often assume that ideal disclosure practices are those where children learn from adults. She argues against the possibility of formalizing the disclosure process by highlighting how children are purposeful actors capable of interpreting the behaviour of others to come to their own conclusions (1978: 4-14; Bluebond-Langer and Korbin 2007). A child for example, learns that he is sick because his mother is crying or because when he behaves badly no one reprimands him. In Malawi, children also act on and interpret the world around them and come to their own conclusions about their HIV infection and their treatment. For example, they overhear conversations about HIV and HIV treatment between health care workers and fellow patients at the monthly ART clinic when they wait to pick up their medicines. Children on treatment were also always present during my interviews with their caregivers, who openly discussed how and when the child became HIV infected. While playing with their friends some children on treatment figured out that they were different when they found friends who did not have to take medicines everyday like they did. Others knew they had HIV because other people told them. For example, one drunk man shouted in front of the whole town about a five year old on treatment: “This one is [sic] HIV!”

Contrary to the assumption of some researchers that HIV disclosure is delayed out of “reluctance” or fear that their children will blame them for their own HIV infections, most understood HIV disclosure as a process that children facilitated themselves. Caregivers did not

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210 This was an interesting ethical quandary during my fieldwork that was never addressed during my ethics clearance. In practice, I always asked the caregiver I was speaking to whether they wanted the child present for the interview or not and they always opted to have the child stay and never seemed concerned that we would discuss the child’s HIV status in front of them. I was also always given permission to ask the child about how they felt about the medicines.
censor their conversations about HIV in front of infected children and felt that eventually the child would “figure out” that they were different from other children. A few had strategies in place to help facilitate this process. For example, a few children less than 10 years old came to the ART clinic on their own each month to collect their medicines. When I asked one mother why she encouraged this she replied:

“If I die, he needs to know how to be taking care of himself on his own.”

Perhaps what worries some researchers and policy makers is that without a formal process, children and adolescents are more likely to obtain false or misleading information about their treatment or their infection from others. Either way, transitioning into adolescence has been clearly identified as a period where children on ART may choose to stop or interrupt their treatment for a variety of poorly understood reasons.

“How long will he live?”: Therapeutic Disjunctures for Children Living with HIV

At Temwa, the therapeutic efficacy of ART was transmitted through adherence workshops, radio broadcasts, public health posters and clinical encounters. The message conveyed by health care workers at Temwa emphasized the short term benefits of treatment, such as symptom relief, with few or no references to a child’s long term chances. This cautious strategy was deployed partially because there was no scientific “fact” to draw on to make claims about the life expectancy of HIV positive children on treatment. Health care workers also felt that treatment efficacy was mediated through local biologies. As Mr. N, a doctor at a district hospital in the Northern region explained to me:

An American doctor volunteering here told me: ‘some children have lived for 22 years,’ but here this is a new program and some are orphans, just being cared for by very old people or by others, who maybe don’t have the resources to give the medicines every day. So when parents ask, ‘will this child live into adulthood?’ we are just encouraging them since we don’t know the answer to that question. I have one child in mind that I like to tell them about if they are worried that it is just a waste of time and resources. I tell them about this four year old who was so sick he was no longer walking, but after three months he was able to play with his friends and go to school.
Instilling hope within caregivers by drawing on specific examples was always tempered by strict precautions that emphasised how patient choices (such as finding good food or adhering to the treatment regimens) would increase their efficacy. The caregivers I spoke to, on the other hand, found this imagined future tantalizing, but pragmatically daunting. A vision of their child’s future, where their children might finish school and even get married and have children themselves one day, was tempered by the realities of their materially poor world. Mothers, who were the primary targets of pediatric HIV treatment programs, must manage the incongruities between what policy makers imagine ART can do and what they experience in their daily lives. While policymakers emphasize the ability of treatment to transform a deadly disease into a chronic one, caregivers emphasized that treatment outcomes are subservient to life’s twists and turns. In many ways the health outcomes of Temwa’s local biologies as shaped by precarity are unpredictable. While most children thrive on ART, some die, and it is this unpredictability that contributes to the perception by health care workers and caregivers that ART efficacy in the long term cannot be trusted.

With me, many health care workers also wondered out loud about the long term efficacy of treatment adherence for children; many were from rural communities like the ones surrounding Temwa and were not sure that treatment would be effective “beyond a few years.” Health planners in Lilongwe and beyond, on the other hand, were much more optimistic about the potential of ART and explained away poor retention rates and early mortality in terms of patient “denial” or “fatalism.” For them differential health outcomes were the result of delayed treatment initiation brought about by a lack of “awareness” about treatment availability for children or a fear of HIV-related stigma. When asked for her opinion about the reasons behind Malawi’s poor retention rates for example, one director of a prominent NGO explained, “there is just so much denial.” Unfortunately, current efforts to improve ART retention rates reflect these assumptions. Very little attention has been paid to the combined social, economic or environmental conditions that undermine therapeutic efficacy. These perspectives create blind spots preventing more innovative and effective treatment interventions that embrace the reality that health and healing are biosocial processes.
Conclusion

Global health discourse surrounding ART treatment for children presents a vision of infected children returning to normal life with more and more vertically infected children surviving into adolescence. TMGs trying to raise HIV positive children in Malawi long for that imagined future, but everyday challenges, such as finding food, negotiating help with relatives, developmental delays, the death of a loved one, migration for a job or the child’s own wishes to stop treatment all interfere with this imagined future. However, rather than locate the source of this reality within the patient or caregiver themselves by labelling them as “ignorant” or “non-compliant” we can take their concerns seriously. Lock (2001) has argued that rather than ignore biological difference, anthropologists need to reassert it and argue against a universal human body by drawing attention to how social and historical processes shape illnesses and treatments. I have extended this argument further to argue that the material and social realities of children’s lives in Malawi need to be taken more seriously. Disproportionate rates of HIV infection among children in Malawi, for example, cannot be explained by human biology or imagined genetic differences between Malawians and Canadians, for example. They are the direct result of poor living conditions, food insecurity and global health policies that limit the availability of ART to pregnant and breastfeeding mothers (see also Fassin 2007; Nguyen 2013). The concerns expressed by caregivers about the long term treatment of children with HIV reflected this reality. Rather than the “therapeutically illiterate” superstitious lot “in denial” about the severity of their symptoms or the efficacy of ART imagined by policymakers, most of the caregivers I spoke to raised serious questions about the limitations of pharmaceutical interventions to alter the material and social conditions of their everyday lives. ART, for example, could not solve household food insecurity problems, but it could unintentionally speed up the death of severely malnourished children on treatment. By drawing attention to how local biologies shape treatment outcomes for infected children I aim to highlight how these therapeutic disjunctures – or how treatments work in practice versus how they work on idealized universal bodies – undermine the success of pediatric ART programs in the long term.

An overemphasis on pharmaceutical intervention also focuses attention on pharmaceutical access, obfuscating the challenges with long term treatment adherence and safety for children on treatment. A lot of attention has been paid to how we can get medicines to
children faster and cheaper, and not enough attention has been paid to improving the quality of life for children on treatment. At the Temwa Rural Hospital this phenomenon is reflected in the ready availability of free ARVs for children, but the total absence of any financial, medical or social resources that are known to improve their therapeutic efficacy. For example, although the link between good nutrition and therapeutic efficacy is well known (Kalafonos 2010), children with HIV at Temwa are not provided any nutritional support or counselling. Considering that Malawi has one of the highest rates of child malnutrition in the world, with nearly half of all children chronically malnourished (NSO 2010), the lack of attention to known factors that seriously undermine treatment outcomes for children is unsettling. In my conclusion I explain why so many of the contextual factors surrounding ART roll-out have been elided by GHIs so far and offer some concrete solutions for improving ART programs for children in Malawi and throughout the region.
Conclusion

In August 2010, near the end of my fieldwork in Malawi, I attended the first annual meeting of the International HIV Social Science and Humanities Conference in Durban, South Africa. On my panel, titled “Children Infected and Affected by HIV/AIDS,” a social worker from Australia outlined very comprehensive national treatment guidelines for the care and support of children infected with HIV and on ART in Australia. These treatment guidelines included laws protecting the privacy of children’s health records; a strategic training for teachers at schools where HIV positive children were enrolled to prevent transmission, and workshops, as well as counselling services for children and their families to discuss disclosure options with schools, friends, neighbours and other family members. Miller (2010) provided examples of the kind of support offered to families when children disclosed their HIV status to friends while playing or the kinds of treatment regimens they offered when children developed co-infections or treatment related side effects. This programme was staffed by range of health experts: a social worker, nurses, psychologists and pediatricians who conducted regular health checks as children grew older. While listening to her presentation, I was struck by the deep level of inequality between Australia’s and Malawi’s national treatment programmes. Australia had a comprehensive and context sensitive pediatric HIV care and support policies designed to both mitigate long term problems and anticipate potential ones for the 100 children infected with HIV in the entire country. This programme stands in stark contrast to the barebones programme designed to support more than a quarter million children infected with HIV in Malawi alone.

Listening to the situation in Australia, it also struck me that the challenges raised by the caregivers I met in Malawi, such as disclosure at school, medicinal side effects (including hunger) and the transition into adolescence, had already been planned for and mitigated in other contexts where pediatric HIV treatment has been available for almost two decades (Hazra et al. 2011). Yet children in Malawi were still only offered the most basic of services: adult formulations of ART drug regimens that caregivers split into appropriate dosages themselves, which were dispensed by mostly undertrained and overworked health care workers. My findings discussed throughout this dissertation also show that most children never even access treatment, often dying a sad and painful death “around the time of walking,” or before the age of one. While global health interventions often refer to treatment programmes like Malawi’s as a “scale-up,”
they are in reality a massive “scale-down” of programmes offered in high-resource contexts. Malawi’s national treatment programme was in every way a skeletal version of Australia’s in expertise, testing technologies, treatment regimens, support and overall therapeutic effectiveness. But how do we reconcile these sharp disparities with the global health community’s supposed commitment to the health and happiness of children with HIV? Stated otherwise, why is it that children in Malawi with HIV are mostly left to die, while children in Australia with the same condition are offered extraordinary care and attention to ensure their life-long well-being?

Embodied Inequalities and Universal Access

Throughout this dissertation I have explored how global health policies converge at a Rural Hospital in Northern Malawi to provide medications (ART) for a health problem (pediatric HIV) mainly only found in the world’s poorest countries. While the stated aim of these interventions is to ensure “universal access” for those “in need,” I show throughout how new forms of embodied inequalities sprang up in tandem with new pharmaceutical regimens and biotechnologies. Not only were many children left to die with other equally treatable illnesses, such as asthma, malnutrition, diabetes, diarrhea, pneumonia, but certain kinds of HIV infected children were often underrepresented in treatment programmes. The design and implementation of Malawi’s national treatment programme favours educated (i.e. “empowered”) patients who seek out testing and families with higher volumes of total capital (social, economic, symbolic, cultural). Treatment disparities were not just divided along geographic (urban/rural) and economic fault-lines, but along socially valued gradations of “belonging.” Tenant farmers were both excluded from care at the Temwa Rural Hospital by health care workers and simultaneously avoided HIV testing and treatment initiation, preferring instead to initiate at “home” where the social and economic resources required to maintain long term treatment adherence were greatest. My findings raise questions about the context specific pathways to embodied inequalities in other settings, where standardized treatment guidelines formulated in Geneva are likely not sensitive enough to ensure equitable access. These disparities will become even more important as more HIV treatment programmes try to achieve “universal access” targets, but find that they cannot reach locally defined vulnerable populations. In particular, the ongoing treatment disparities between adults and children, and Malawi’s very low ART retention rates after five years, suggest
that more targeted approaches within and between countries will be necessary as time goes on. This perspective adds much needed insight into the reproduction of embodied health inequalities in Malawi and beyond since it helps explain why disparities exist not only between countries (such as rich ones and poor ones), but also within countries.

Of course, huge disparities in HIV infection rates and the quality of care and treatment programmes are also deeply rooted in decades of neglect inextricably linked to global political-economic processes (Farmer 2004). Anthropologists have used the concept of “structural violence” as a metaphor to examine these powerful, but “hidden” forces behind inequalities. While this concept helps expand our understanding the political and economic forces behind embodied inequalities it does not help us explain how these forces persist even after they are identified and described. As Kirmayer urges, it is not enough to point out that the system is unfair; we also “need to understand how the system builds and rebuilds itself, neutralizing opposition and reform” (2004: 321). Nor does structural violence help us explain why and how certain causes, like the provision of free ART for children with HIV in Malawi that I describe throughout this dissertation, suddenly became the focus of a major global health intervention, while many other causes were left behind. Southern Africa, for example, has the highest rates of esophageal and lung cancer in the world, often due to the occupational and environmental health risks of mining asbestos and uranium for North American and European markets (Hecht 2009, 2012). Yet, cancer treatment remains firmly outside the global health agenda (Livingston 2012). Health inequalities, therefore, are more than just structural, they are political (see also Fassin 2007; Tiktin 2008). By that I mean those designing global health interventions are deciding how and to whom global health resources should be distributed to (Fassin 2007: 509). In this case children with HIV are considered worth saving, while migrant labourers (and many others) are excluded from care.

To date, GHIs targeting children with HIV have also largely concentrated their economic and biomedical capital (through expertise, funding, NGOs) in urban enclaves, while leaving aside the abandoned hinterlands to generalized abjection (Ferguson 2006: 48). Anthropologists have been very effective at interrogating the rationale behind many global health interventions (Bornstein 2005; Closser 2008). While these studies have provided valuable insight into how global health interventions operate, not enough attention has been paid to social spaces where these interventions have a less tangible presence (see Piot 1999 for an exception; also Classen
2013 on rural youth in Malawi). This may be because the technologies often associated with GHIs are far less visible outside of these enclaves, extending our analysis “up” to the “global” seems more difficult. After all, there were no foreign doctors, no Land Rovers, no cutting edge technologies or foreign-funded NGOs operating at Temwa to make these connections explicit. Rather, research outside of these enclaves requires, almost by necessity, an examination of policy as an instrument of global health governance from afar. Policies are, by definition not discrete observable “things,” but an “assemblage” that changes as it enters into new relationships with actors, objects and institutions in different historical, social and political settings (Shore and Wright 2011: 20). By focusing on the roll-out of Malawi’s National Pediatric HIV treatment guidelines (mostly formulated in Geneva) at one very ordinary rural hospital in Malawi, I add to what Buroway has called the construction of “globalization… from below” (2000: 341). The anthropology of policy is a fruitful avenue for medical anthropologists trying to understand how inequalities are reproduced over time in specific contexts.

**Dangerous Imaginary Thinking: The Lure of the Technofix**

AIDS in Africa connotes certain values and images that circulate globally. These ideas are constituted among the public through the media and a range of institutions created to alleviate suffering, such as UN agencies, NGOs, public-private partnerships, research universities, philanthropic foundations, religious organizations, states, celebrities and other actors. It is, as Paula Treichler (1988) memorably termed, an “epidemic of signification,” and mass-mediated images of suffering have permeated public consciousness (Comaroff 2007; Mbembe and Nuttall 2004). Many of these images and campaigns were instrumental for grassroots movements trying to secure treatment programs in countries that were being denied treatment (Robbins 2004, 2006). A major shift in the global health landscape at the time was an unprecedented collaboration between pharmaceutical companies, government and civil society – or what are now termed “global public private partnerships” (Walt and Buse 2002). João Biehl argues that one result of these emerging partnerships is a tendency to focus on technical solutions to disease, or what he calls the “pharmaceuticalization of public health”; pharmaceuticalization signals a shift in the global health landscape from a model of public health understood as prevention and care to “access to pharmaceuticals” (Biehl 2006: 222-224; Bell and Figert 2012). While “pharmaceuticalization” draws attention to larger political and economic forces shaping
global health policy, it does not really explain why so many ordinary people find the lure of the technofix so seductive. After all, it is not just global institutions embracing pharmaceutical intervention, but more and more individuals are turning to pharmaceuticals to solve political and social problems in their own and/or other’s lives. For example, McKinney and Greenfield (2010) describe the underground trade in pharmaceuticals on a US campus to get better results on exams (see also Ecks and Basu 2008). Richey and Ponte (2008) also point to new modalities in aid circulating around HIV/AIDS treatment initiatives. They illustrate how Product Red, a brand created to raise awareness and money for the Global Fund, engages consumer-citizens in profitable “helping” for distant others, while simultaneously facilitating corporate agendas (see also Ecks 2010). The recent rise in what McGoe (2014) has described as “philanthrocapitalism” points to the need for more ethnographic studies examining how these dynamics influence specific global health interventions, the policy making process and the global health agenda.

In Malawi, the recent convergence of public and private interests resulted in Malawi’s national pediatric HIV treatment programme. These two forces brought about a specific kind of intervention for children with HIV: one that focuses on what historians have called the “Magic Bullet” approach to public health (Birn 2010). Global health has a long history of biotechnical interventions focused on specific, mostly infectious diseases, but with the exception of smallpox eradication, most of these programmes have been unsuccessful (Birn 2010; Greenough 1997). The most recent UNAIDS (2013) report on HIV/AIDS highlights how fully global health organisations have embraced biotechnical solutions to complex health problems. The report notes that while “the benefits of behavioural and structural approaches” have value, “biomedical prevention tools…” “…have never been more promising” (2013: 5). To that end they advocate for the “scale up” of technical solutions such as male circumcision, better HIV testing technologies for children, increased treatment access for pregnant women to prevent new vertical infections between mothers and infants and more research into formulating better drug formulations for children. There is little discussion of what “behavioural” or “structural” efforts might be effective, reflecting a general trend in development criticized by many to “render social suffering technical” (Li 2007: 123-151; Hunsmann 2014).

As I pointed out in my introduction, Calhoun argues it’s not that suffering has changed over time, but that how we imagine we should fix suffering has changed. While clearly corporate interests are at stake here, the wider public has also become emotionally, financially and
politically invested in the idea of AIDS as a manageable chronic condition, to the point that they are now able to buy Red shoes, IPods and t-shirts to show their commitment to make sure pharmaceuticals are “accessible”. The concept of the pharmaceutical imaginary I develop throughout this dissertation therefore implies an optimistic story of the many-possibilities of ART for children by evoking specific emotions, desires and political aspirations, which circulate widely (Lakoff 2011). Although some may wonder what the difference between “hegemonic” ideas and imaginaries are, the concept of the imaginary grew out of a frustration for Marxist and deterministic thinking. Imaginaries therefore evokes the affective and imaginative dimensions of new ideas and interventions.

Although technical solutions can be very efficacious at treating particular diseases, they also create new inequalities. For example, in Mozambique’s national ART programme, Kalafonos (2010: 375) demonstrates how the distribution of a limited supply of food supplements to a small number of HIV positive patients on treatment exacerbated social tensions and inequalities by allowing those who were equally food insecure, but HIV negative, to starve. Nowhere is this tragedy more obvious than the fact that while children now have access to free ART, the remedies that could have prevented their becoming infected in the first place (clean water, functioning health system, ART for their breastfeeding mothers) are still far too scarce (Lewis and Donovan 2009). Thus, while the pharmaceuticalization of pediatric HIV treatment allows donors to celebrate the individual lives they save, the very structures implicated in the epidemic remain untouched (see also Marsland and Prince 2012; Nguyen 2007).

An additional problem with imaginary thinking is that it makes the intervention or approach seem “natural” and even moral. A key feature of the pharmaceutical imaginary is that the range of acceptable responses to pediatric HIV is exceedingly narrow: drugs into bodies. It also sidelines alternative stories that might question the effectiveness or safety of treatment for children in the long term. In Malawi, I showed how the long term challenges of ensuring children stay on ART, including the death of their parents, hunger and toxic side effects, are rarely discussed in global health planning circles. Rather programs focus on the numbers of “lives saved” instead of considering the quality of life families hope their children will have after they are gone. In a similar vein, Callhoun argues that the emergency imaginary encourages individuals to focus on immediate responses to urgent need, rather than on long-term solutions for economic development, the promotion of democracy or advocacy for human rights (see also...
Malkki 1996; Ticktin 2006). Thus, anthropologists studying global health need to continue examining what is being foreclosed by a pharmaceutical approach to disease prevention and control and why. In particular, the rise of private-public initiatives in global health needs to be interrogated ethnographically from a number of different perspectives.

Another key feature of imaginaries is that they promote envisioning and acting in the world as it “should” be, rather than depicting an accurate description of how things actually are. For example, Delvecchio Good (2007) argues that overly optimistic narratives surrounding cancer treatments in North America obscure the toxic side effects and mostly experimental nature of many of these treatments. This is why patients on palliative treatments maintain hope for a cure despite being diagnosed with a terminal cancer (Stone, forthcoming). Calhoun (2008) also notes that even after more than 60 years, the displacement of Palestinians is still called an “emergency.” The problem for children with HIV is that imaginary thinking forecloses any discussion that could lead to meaningful change because it obscures social, political and economic factors that led to the problem in the first place. For example, while GHIs focus on “universal access”, poor treatment retention rates in Malawi remain poorly understood and rarely discussed. As Delvecchio Good notes, biomedical failures, such as organ trafficking or deaths from medical malpractices, are often subsumed within a larger “political economy of hope” which emphasizes the “many-possibility science of medicine” rather that its potential pitfalls (2001: 399). For example, ART medicines are often depicted as “life-saving miracle drugs”; yet, as I pointed out earlier, nearly half of the people who start treatment in Malawi have either died or stopped treatment just five years later (UNGASS 2010). The cancer epidemic emerging in Botswana as a partial result of ART roll-out also highlights the rarely discussed side effects of biomedical intervention (Livingston 2013). Thus, pharmaceutical imaginaries often exclude any discussion surrounding both the safety and efficacy of ART treatment in different contexts, while simultaneously pharmaceuticalizing the global response to HIV/AIDS.

Lastly, imaginaries help us explore the affective dimensions of new ideas and the specific interventions that spring from them, in a way that many other approaches cannot. For example, Wendland (2012) recently used the concept of medical imaginaries to explore how the subjectivities of medical students in Malawi are shaped by the medical imaginary depicted in their Western textbooks and in their conversations with foreign physicians, an imaginary which contrasts sharply with the improvisational nature of their daily lives and the scarcity of clinical
realities in Malawi, where necessities like gloves, soap, analgesics and running water remain luxuries. She argues that in this context many medical students use the medical imaginary to imagine themselves as better doctors than their foreign counterparts, since by necessity they can diagnose and treat without fancy diagnostic technologies (2012). In this way, the concept of the pharmaceutical imaginary encourages us to explore how the enthusiasm for or rejection of specific biotechnical technologies stems not just from their therapeutic efficacy, but also from their imagined potential (or lack thereof). Thus, I use the pharmaceutical imaginary to encourage anthropologists to go beyond the structural conditions that result in embodied inequalities for different categories of people, some who gain access to biomedical resources for their health conditions (i.e. HIV infected children) while others do not (i.e. tenants who have children with HIV). Exploring the disconnect between the global pharmaceutical imaginary and the day-to-day reality in Malawi (or in any other “abandoned hinterland”) narrows the gap between providers and recipients, laying bare programme weaknesses, gaps and assumptions.

Global Health Beyond Bare Life: Recommendations for Research and Practice

Ethnographic approaches to global health interventions also pay a critical role in helping programmes improve their interventions. Despite my criticisms of the pharmaceuticalized approach to pediatric HIV prevention and treatment, even adult dose ART regimens reduce mortality and improve the quality of life for children living with HIV. There is no doubt in my mind that without treatment nearly every child I worked with would have died over the course of my fieldwork; instead by the time I left 32 of the 35 children on treatment at Temwa were alive and (mostly) doing well. My findings indicate that the challenge for pediatric HIV treatment programmes in Malawi is twofold. First, intrarural inequalities will continue to undermine universal access targets and second, treatment programs in the long term will only be successful if they take into account the social and economic factors that influence treatment outcomes for HIV infected children on treatment. To that end my dissertation offers a number of practical policy oriented recommendations.

First, a major challenge with the design and implementation of Malawi’s pediatric HIV treatment programme is that it is poorly integrated into other health services, creating unnecessary bureaucratic delays and numerous lost opportunities for early diagnosis. International donors and the Ministry of Health need to consider practical (and ethical) ways to
integrate pediatric HIV testing into routine child vaccination schedules and other non-biomedical health care settings. On the whole vaccination coverage rates are fairly high in Malawi and it would be feasible to introduce a rapid test for all children at the 12month MMR vaccination followed by the immediate enrollment of the child into an HIV treatment programme. Involving community leaders (religious leaders, traditional healers and knowledgeable grandparents in specific communities), in community based solutions to the identification of children possibly infected with HIV would also ensure early uptake of treatment regimens for very vulnerable children under one year. As I noted earlier, many grandparents, religious leaders and traditional healers knew from a very young age that a child may have HIV, but social hierarchies often impeded early treatment initiation. I think asking them directly what strategy they think would work best would likely help therapy management groups negotiate these dynamics. For example, villages could elect (the same way they elect members of the Village Development Committees) a local elder to counsel and advise families with sick children. Of course, accommodations would have to also be made for tenant farmers who are excluded from these supportive community structures. Practitioners should proceed thoughtfully and with the full participation of the communities they work in. The solution for one village may not work in another, and there should be room for communities to develop locally relevant and flexible solutions to their health problems.

Second, treatment programs need to recognize that access to ART is not nearly enough. While many children with HIV may not die directly from AIDS, they will die from HIV complications, toxicities, side effects, treatment interruptions and, as children grow up and take over their treatment regimens, they may also choose to stop treatment to fulfill their own life projects (Mattes 2014). My findings indicate for example that many children on ART are doubly disadvantaged; not only is their overall health compromised by late treatment initiation and HIV-related morbidities before treatment initiation (i.e. deafness) but they often lack the social and economic means that will ensure success in life, including an education and access to land. The Ministry of Health needs to cooperate with the Ministry of Education to ensure that children who miss exams due to illness are not forced to repeat an entire school year. For children suffering from still poorly understood disabilities related to their HIV infection or ART toxicities, skills building training needs to be in place to ensure they can support themselves into adulthood.
Many children with HIV are likely to lose their parents to HIV before they reach adulthood; thus, ensuring that they are able to support themselves is crucial to their long term survival.

Third, cooperation and communication between different cadres of health care workers (clinical officers, health surveillance assistance and nurses) needs to be supported. HSAs for example are already in the homes and communities with children who have HIV; they are often aware of the social conditions surrounding these children’s lives, including the likelihood of infection (i.e. death of a parent from HIV-related symptoms) and the long term treatment challenges for families raising children with HIV (i.e. food security). Their knowledge could be used to contextualize the current standardized and “one size fits all” approach to pediatric HIV. While HSAs are crucial to Malawi’s health care system it is also critical that skilled medical professionals monitor children with HIV. While it may not be necessary for them to be monitored once a month, international donors and the Ministry of Health in Malawi need to find a way to incorporate checkups with a trained pediatric HIV specialist, at least once a year.

Lastly, there need to be targeted programs for vulnerable groups. While in Rumphi district tenant farmers were the most likely to be excluded from care, in different regions of Malawi (and throughout sub-Saharan Africa) the definition of a “marginalized group” is likely to vary. For example, in Nkhata Bay district, there are large fishing camps attracting migrant fisherman, but rather than travelling with their families, their wives and children stay behind in the home village to farm. Thus, the composition of the child’s TMG is completely different, but we have no idea if this impedes or facilitates treatment access, as it might in Rumphi. Or for example, there are large numbers of rural youth without access to farm land migrating to urban centres in Malawi or South Africa; are these youth able or willing to access HIV treatment programs once removed from their therapy management groups? Unfortunately we still know far too little about how therapeutic outcomes are distributed along these social and economic fault-lines. It is important for treatment programs to start gathering more specific information about the kinds of patients on treatment in their respective regions and then to move forward with plans to integrate locally defined marginalized populations into treatment programmes.
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