Encouraging Transformation in Mfuleni:
An NGO’s Influence on Health Citizenship

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by

Lynn E. Wagener

Dr. Erin E. Stiles/Thesis Advisor

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We recommend that the thesis prepared under our supervision by

LYNN E. WAGENER

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Erin E. Stiles, Ph.D., Advisor
Mikaela Rogozen-Soltar, Ph.D., Committee Member
Greta de Jong, Ph.D., Graduate School Representative
David W. Zeh, Ph.D., Dean, Graduate School

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ABSTRACT

Non-governmental organizations (NGOs) pride themselves in facilitating positive change within local communities across the globe. For anthropologists, they provide valuable sites for understanding community empowerment, societal change, and definitions of welfare and human rights. This ethnographic study examines how Community Care Workers at Afrika Tikkun, a child and youth development and primary health care NGO in South Africa, establish a sense of health citizenship for community members within the township of Mfuleni. By working predominantly with the primary health care employees of the NGO, observing and participating in their interactions, and conducting individual and group interviews, I explore how certain services provided by the NGO empower community members to become active participants within the community. Furthermore, this thesis reveals how health is situated in a grassroots, activist framework in order to influence democratic transformations in the “new” South Africa.
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral Therapy/Treatment</td>
</tr>
<tr>
<td>ARV</td>
<td>Antiretroviral</td>
</tr>
<tr>
<td>BFSS</td>
<td>Breast Feeding Support Specialists</td>
</tr>
<tr>
<td>CCW</td>
<td>Community Care Worker</td>
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<tr>
<td>CYDP</td>
<td>Child and Youth Development Program</td>
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<td>ECD</td>
<td>Early Childhood Development Program</td>
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<tr>
<td>FBO</td>
<td>Faith-Based Organization</td>
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<td>FSS</td>
<td>Family Support Services</td>
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<tr>
<td>GBV</td>
<td>Gender Based Violence Program</td>
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<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>HCBC</td>
<td>Home and Community Based Care</td>
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<tr>
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<td>Integrated Management of Childhood Illnesses</td>
</tr>
<tr>
<td>M &amp; E</td>
<td>Monitoring and Evaluation</td>
</tr>
<tr>
<td>MSF</td>
<td>Medecin Sans Frontieres (Doctors Without Borders)</td>
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<tr>
<td>NGO</td>
<td>Non-Governmental Organization</td>
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<td>PHCP</td>
<td>Primary Health Care Program</td>
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<td>PMA</td>
<td>Pharmaceutical Manufacturers Association</td>
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<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission</td>
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<td>Rotavirus Vaccine</td>
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<td>South African Social Security Agency</td>
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<td>Youth Skills Development and Placement</td>
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<td>Treatment Action Campaign</td>
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CHAPTER 1
INTRODUCTION:
RESEARCH SITE AND METHODOLOGICAL APPROACH

“Anthropologists narrate the stories of others, translate experience, acknowledge unrecognized or marginalized truths, and provide witness to people's struggles, hardships, and joys.”
- Catherine Besteman in Transforming Cape Town (2008:149)

In January of 2013, I visited South Africa for the first time and was immediately captivated by the country’s beauty and mystery. The people whom I have spoken to and who have also visited South Africa share in my fondness for the country, but after this first trip, I also felt an intense curiosity that other visitors did not necessarily express. As a budding anthropologist, I left with more questions than I had answers due to the enigma that was South Africa. It all began with that first descent into the Cape Town International Airport.

As the plane broke through the clouds, I was graced, first, by the beautiful soft sand beaches that hug the coast of the Western Cape. Then, almost as if it rose out of nowhere, I caught sight of the majestic Table Mountain. Embracing the southern border of Cape Town, the mountain gets its name from its plateaued top and the soft clouds that often curl over the top-most ridge creating the image of a table cloth spread out over a large table. As I observed the metropolitan area of Cape Town, lying at the foot of Table Mountain, my immediate “Western” expectations of a developing country were splintered. The city was vibrant and bustling. Several high-rise business buildings
stretched into the sky, the famous, bubblegum pink Mount Nelson Hotel was in plain
sight, the rainbow neighborhood of Bo Kaap lay nestled at the base of the Lion’s Head (a
smaller mountain formation west of Table Mountain), and the large glistening Ferris
Wheel was busy turning with tourists at the pristine V & A Waterfront. As the plane
continued on, slowly approaching touch down, the landscape changed both suddenly and
intensely. Table Mountain and Cape Town seemed like distant dreams in comparison to
the miles of informal settlements that now stretched before me. Directly below lay the
largest township in Cape Town, Khayelitsha. There were no high rises or glistening
tourist attractions. All I saw now was the extreme poverty that is so characteristic of
South African townships: aluminum shacks cramped into the most impossible spaces,
rivers and streams littered with discarded waste, and the webs of electrical wires that
seemed to dominate the surface of the landscape. I knew in those first few moments that
this trip would be unlike any other and indeed, this turned out to be the case. So much so
that when I began my graduate program in anthropology, I told my advisor without any
hesitation that I needed to go back to South Africa in order to begin to comprehend the
abundance of questions that I had left unanswered.

The inspiration for this thesis came, primarily, from the stark divides that I had
witnessed through my observations (as detailed above) as well as through the experiences
that I had had with the diversity of people whom I met during my three-month stay. I
wondered why this divide existed, how these realities affected the lives of the people, and
whether there was a desire to implement social change. After conducting some
preliminary research, I found the South African people’s want for change was extensive,
having one of the highest numbers of established NGOs and grassroots initiatives in the
world. An abundance of these organizations focus on aspects of health (especially in the context of HIV/AIDS), education, and community development. My subject interest in health activism led me to read an article in my local newspaper about the youth development and primary health care NGO, Afrika Tikkun, located throughout many townships in South Africa. Upon contacting the NGO and receiving a warm response, I knew that I had found my research site.

This thesis takes as its framework post-apartheid South Africa and takes as its primary focus the many transformations that have taken place and are still ongoing. I will argue that the supports and services that are provided to the township of Mfuleni through the Primary Health Care Program at Afrika Tikkun, establish a sense of “health citizenship” for community members; health citizenship is a concept introduced by Steven Robins and Bettina von Lieres in their work on HIV/AIDS activism in post-apartheid South Africa (2004, 2006). This form of citizenship empowers community members to become “responsibilized” for their own health and to become active participants in the development of the “new democracy” of South Africa. This concept corresponds to the way that the Treatment Action Campaign, a grassroots effort that pressurized the South African government to provide HIV treatment, provided an engagement with the community “in an attempt to disseminate the politics of rights and health citizenship into the institutional fabric of society” (Robins and von Lieres 2004: 88). As Robins and von Lieres maintain, “the aim is to transform practices in these institutions and to bring these institutions to the people” (Robins and von Lieres 2004: 88). I argue that Afrika Tikkun is an example of these institutions, which establishes a new sense of citizenship in respect to the health of formerly marginalized communities of
people. Furthermore, with the support of rich ethnographic examples, I will explore the relationship that the concept of health citizenship has to the notion of empowerment and disempowerment in a variety of health-related contexts.

*Research Site*

*Afrika Tikkun.* My research took place at Afrika Tikkun, a youth development and primary health care NGO in the rural community of Mfuleni near Cape Town, South Africa. There are a total of six South African branches of Afrika Tikkun with various offices located internationally. The international offices, located in the United Kingdom, the United States, and Australia, primarily perform administrative duties and disperse the monetary donations received either through Afrika Tikkun’s website or from the businesses and corporations who choose to invest in the NGO. The international offices also recruit volunteers to work at several of the South African branches. However, during my time at Afrika Tikkun, I was told that the volunteering aspect of the NGO was not popular because only a handful of volunteers have visited Afrika Tikkun since its establishment in Cape Town.

There are six branches of Afrika Tikkun in South Africa: four in the Johannesburg area and two in the Cape Town area. Each branch in South Africa consists of three Core Programs: Early Childhood Development Program (ECD), Child and Youth Development Program (CYDP), and Youth Skills Development and Placement Program (SED). These programs focus on “the specific developmental and age appropriate needs of children and youth” to facilitate a “Cradle to Career” model of operation (Afrika Tikkun: 2015). As the model implies, the NGO prides itself in providing aid and support from the time a child is born, through his or her secondary school years, and onward into
young adulthood when they are able to obtain a local or regional job. Each branch also includes a dimension of the following three Support Programs: Nutrition and Food Security Program, Primary Health Care Program (PHCP), and Family Support Services (FSS). Additionally, each branch incorporates a variation of two of the following three Outreach Programs: Gender Based Violence (GBV), Primary Health Care in the Western Cape, and the Empowerment Program for Children and Families Living with Disabilities. Afrika Tikkun takes into consideration that each community is unique in regards to the challenges that they face, and as a result, the NGO’s outreach programs focus on the needs of the community in addition to the services provided through the Core Programs, which focus on the individual. This encompasses the holistic approach that the NGO sets as its mission. The late Nelson Mandela visited one of Afrika Tikkun’s first locations in 1995 and was so impressed by the NGO that he declared himself the Patron-in-Chief for the organization.

Afrika Tikkun’s vision is to provide a “sustainable future for children in South African townships” with the hope of “continuing to empower communities in the development of new generations of productive citizens” (Afrika Tikkun 2015). The multitude of programs that exist at Afrika Tikkun provide valuable insight into the production of “new generations of citizens” at the local level. Moreover, because each program expresses discourses of aid, support, and change in the South African townships, the NGO serves as a foundation for the transformation of “new productive citizens” to develop in each of the communities that they serve. I chose to spend the majority of my time in the Primary Health Care Program (PHCP) in the Mfuleni branch of Afrika Tikkun
and focused on how the topic of health is negotiated by the employees at Afrika Tikkun to empower citizens in the Mfuleni community.

Figure 1.1: Map of Mfuleni in respect to Cape Town.

Figure 1.2: Map of Mfuleni in respect to the townships of Delft, Khayelitsha, and Mandalay located on the Cape Flats.
The Township of Mfuleni. Mfuleni is one of 29 townships located in the Cape Flats near Cape Town (see Figures 1.1, 1.2, and 1.3). The term township itself does not carry any racial connotations and is in fact a legal term referring to land titles. However, during the Apartheid Era, from 1948-1994, many spaces inside the city of Cape Town were designated as “white only” resulting in mass evictions of its “non-white” population: blacks, coloreds, and Indians. Official legislation applied by the apartheid government allowed for the forced removal of these populations, who were then placed into racially segregated “townships” around the periphery of the city. One of the most influential acts of legislature, the Group Areas Act of 1950, included the restriction of

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1 Also referred to as “suburbs” at the local level.
2 These townships were, at first, given the term Bantustans referring to the areas where speakers of the Bantu language group were settled. This included the native languages of Xhosa and Zulu.
land ownership and occupation to South Africa’s black population. Through this Act, therefore, the government appropriated formerly racially mixed areas of Cape Town for use by whites only. Additionally, policy makers in the 1950s used the term “slums” synonymously with townships, ultimately giving townships their racially pejorative connotation.

From the onset, these townships were not developed with the proper resources or infrastructure needed for the large populations of people that were moved there. For example, a Cape Town local who I had met on my previous trip to South Africa, told me that only a third of government housing units were built relative to the vast population occupying the townships. This resulted in the construction of informal settlements or “shacks” around the perimeter of each township by those who could not afford the government housing in the center. As the populations in the townships grew, so did the number of shacks. Consequently there was a serious shortage as far as sewage, water, and electricity were concerned. Electricity, for example, became so sparse that a group of shacks, as well as the established government houses, would illegally tap the one power box in any given area creating a complex web of wires across the surface area of a township (See Figures 1.4 and 1.5). This is still characteristic of the townships today and also remains one of the leading factors in frequent power outages and what are known locally as “shack fires.” Although the lack of resources is still apparent two decades after the end of apartheid, it is primarily the deficit of clean water and sanitation that has led to the most debilitating consequences for those groups living in the townships. In a study on development planning in Cape Town, John Williams (2005) finds that in 2003 “7.5 million South Africans lack access to running water and 21 million are without indoor
sanitation” (Williams 2005: 49; Sunday Times, 27 April 2003). Extreme poverty and inadequate educational facilities further add to the disparities between the populations in the metropolitan area of Cape Town and the surrounding Cape Flats.

Figure 1.4 The webs of electrical wires that span across Mfuleni.

Figure 1.5 An example of four homes that are connected to the same electrical box.

*The Community of Mfuleni.* Mfuleni is located south east of Cape Town, near the townships of Khayelitsha and Delft, which became famous for their riots during the imprisonment of the late Nelson Mandela in 1962. When I spoke to several Cape Townians about my research, they did not hesitate to warn me that Khayelitsha, specifically, is still known for its sporadic uprisings and has become known to locals as a
sort-of “no-man’s land” for white South Africans. I experienced this for myself on a few occasions when I needed to drive alternate routes to my research site in the mornings or when I was driving home in the evenings due to a riot that had erupted in a neighboring township. My driver, Ephraim⁴, would term these riots “doing toyi-toyi” or “making noise.” The characteristic black clouds of smoke spotted among the townships as a result of the burning of tires and other materials indicated such riots. Ephraim told me stories of friends he had in Khayelitsha or Langa (another township in the area) who would be restricted to their homes and could not go to work because of the riots taking place in the streets nearby. Ephraim shared with me that in one instance, a family of four, whom he knew by acquaintance, were killed because “there was too much toyi-toyi in front” of their home.

My collaborators, including Ephraim, informed me that Mfuleni was a “good township.” There was very little activity in regards to uprisings and the population was ethnically mixed. According to Freez (pseudonym), one of the employees at Afrika Tikkun who worked in Family Support Services, the “diversity is good…we can learn from each other…different religious beliefs and they all have different jobs and it just works better.” When I asked my collaborators what the name Mfuleni meant, only two could confidently tell me that it meant “small river.” Fittingly, a small river does flow along the eastern edge of the township. The nurses at Afrika Tikkun informed me that it was extremely toxic and parasitic and that the river contributes to the mortality of several

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³ Ephraim preferred I use his actual name.
⁴ I did not receive an exact definition of the term “toyi-toyi” from Ephraim, but the Complete and Unabridged Collins English Dictionary defines it as “a dance expressing defiance and protest” (2003).
Mfuleni children every year who acquire heavy diarrhea after playing in or near the water during the hot, humid summers.

The township does seem relatively peaceful on a superficial level. However, Mfuleni is still severely deficient of the resources required to meet the basic needs of its population. Most residents settled in Mfuleni in the late 1990s due to a series of fires and floods that occurred in neighboring townships and forced many to re-locate. According to the 2011 City of Cape Town census, more than 64 thousand people live in Mfuleni (City of Cape Town 2011). The majority of the population falls under the black racial category and speaks Xhosa, one of the 11 official languages of South Africa. Most of Afrika Tikkun’s employees, and some community members with whom I interacted, also spoke English. There are a few colored residents and no white residents in Mfuleni. The population faces high unemployment rates, increasing crime rates, and high rates of domestic violence and substance abuse. Indeed Afrika Tikkun views Mfuleni as an especially problematic area; the NGO literature states that “there are high incidences of teenage pregnancy and prostitution; and rising gangsterism amongst primary school children…The situation continues to become more difficult as community numbers swell without corresponding economic growth” (Afrika Tikkun 2015).

Many health issues exist in Mfuleni due to the lack of clean water, proper sanitation, and health education. Tuberculosis and diarrhea are among the health issues risking the lives of the Mfuleni community today. In 2014, HIV/AIDS moved up from its position as the sixth to the third leading cause of death in the Western Cape (Statistics South Africa 2013). The exact HIV/AIDS prevalence rates for Mfuleni are unknown due to the high rates at which residents move in and out of the township. However, a wide
range of data collected by UNAIDS and the South African National HIV Prevalence, Incidence and Behavior Survey presents an idea of the prevalence rate based on national statistics. This data concludes that the “estimated HIV prevalence was 17.3% among 15-49 year olds at the end of 2011…[and] implies that around 5.6 million South Africans were living with HIV at the end of 2011, including 460 thousand children under 15 years old” (Simbayi 2014: 37-44).

The literature produced by Afrika Tikkun outlines that in 2005, the NGO partnered with the City of Cape Town, the Department of Sports and Recreation, and the Mfuleni Community to develop a 350m² training and resource center that the City of Cape Town named Mfuleni Community Park (Afrika Tikkun: 2015). The center launched in 2012 and provides services to approximately 2,220 beneficiaries across all ages per annum (Afrika Tikkun: 2015). The center is home to the Early Childhood Development Program (ECD), the Child and Youth Development Program (CYDP) as well as the Primary Health Care Program (PHCP).

As I have mentioned, most of my work took place in The Primary Health Care Program, or PHCP. It is the only program within Afrika Tikkun that works directly with the South African government. The Western Cape Department of Health is responsible for the majority of the program’s funding and serves as a primary influence in many of the program’s community outreach services. The PHCP was developed as a response to the rising need for health care services in the most impoverished communities of Cape Town. The Afrika Tikkun literature details that “Mfuleni was recently accorded the dubious distinction of having the highest rate of HIV-infected children in South Africa, an indication of a hopelessly under-resourced children’s environment, [and] more than a
third of families live in informal shacks without water and electricity” (Afrika Tikkun: 2015). Due to the successes that Afrika Tikkun had through its development programs and the strong relationships that the NGO established in the community of Delft⁵, the Department of Health asked Afrika Tikkun to host the PHCP in Mfuleni as well.

Methodology

I conducted my research over the course of six weeks in June and July 2014. I worked at Afrika Tikkun Monday through Friday, beginning my workday at 8:30 a.m. each morning and leaving between 4:00 p.m. and 4:30 p.m. each afternoon. When I arrived in the mornings, I checked-in with Melrose (pseudonym), the receptionist for the Primary Health Care Program, and joined the Community Care Workers, or CCWs (who I will describe in detail in Chapter 3), in one of the boardrooms for the morning prayer.⁶ The remainder of my day was divided into two parts. From 9:00 a.m. to 1:00 p.m., I attended home visits in the community with two or three Community Care Workers. On a few occasions, one of the nurse coordinators would accompany us as well. Lunch was served at 1:00 p.m. in Afrika Tikkun’s kitchen. During the latter part of my day, from about 2:00 p.m. to 4:00 p.m., I would “hang out” with the nurse coordinators, lay coordinators, or the employees working in the Child and Youth Development Program (CYDP) of the NGO. Several days during this six-week period were inconsistent with the

⁵ Delft is a rural community located on the Cape Flats about 7.4 kilometers north of Mfuleni. Afrika Tikkun was established in Delft’s Mandela Peace Park 15 years prior to the NGO’s opening in Mfuleni.
⁶ The Primary Health Care Program Manager mentioned to me on my first day at Afrika Tikkun that Mfuleni’s primary religion was Christianity. In addition, a few community members practiced Islam. The morning prayers included a biblical verse chosen and spoken by a single individual and several songs sung in Xhosa by all of the Community Care Workers in attendance.
above schedule. Several special events, health education courses, and in-service trainings were conducted at the NGO, which I also made a point of attending. During weeks four and five of my stay, the primary schools in the community were closed due to winter holidays. Afrika Tikkun, therefore, opened their doors for the children from 9:00 a.m. to 5:00 p.m. each weekday, providing them with an abundance of activities and games in a safe learning environment. During a handful of these afternoons, I would take the opportunity to play with the children and establish a rapport with the CYDP facilitators who were chaperoning the children. This allowed me to explore other dimensions of the NGO as well.

**Participant Observation.** The majority of my research consisted of participant observation as well as unstructured and semi-structured interviews. During home visits, the Community Care Workers (CCWs) would introduce me, in either Xhosa or English, to the individual or family we were visiting and ask them if they felt comfortable with my attendance. After receiving verbal consent, I would sit with the CCWs and observe the interactions between them and their patients. If the conversations were primarily in Xhosa, the CCWs would stop every few minutes and translate for me in English. During most home visits, I did not take any notes until I was back in my office at Afrika Tikkun. At the end of each home visit, I took the opportunity to ask any questions that I had for the CCWs or the patients, again receiving translations by the CCWs when needed. I spent most lunch periods with the CCWs as well, taking these moments to “hang out” and participate in casual conversation with them.

I attended special events, health education courses, and in-service trainings with the CCWs and other personnel and participated in any activities that those in attendance
were required to participate in as well. During my conversations and observations with the nurse coordinators or lay coordinators, I was asked to perform minor tasks for them such as delivering paperwork to another office, making copies, or helping nurses pack their first-aid bags. The nurses would provide me with a copy of any materials that they handed out to the CCWs or members of the community. In addition, they accompanied me to the Dr. Ivan Toms Clinic (a local clinic which I will discuss in Chapter 4) and helped me track down the manager of the clinic in order to receive a copy of important supplemental materials, such as the Road to Health Card, which is usually only reserved for new mothers (I will describe the Road to Health Card in detail in Chapter 5). I was particularly interested in this document due to the value that was placed on it during home visits and the challenges it posed during many of these visits.

*Interviews.* The majority of conversations were unstructured in nature. I spoke to employees of Afrika Tikkun (from both the Primary Health Care Program and the Child and Youth Development Program) primarily in Mfuleni with a few interviews that took place in Delft. I also spoke to a few patients in the community and my driver, Ephraim. I spoke to a total of 60 people in the form of unstructured interviews. Conversation times ranged from a few minutes to two or three hours. When topics of interest would arise, I would ask any follow-up questions that I had on the subject.

I conducted 20 semi-structured interviews, during which I would schedule a time with each interviewee(s), in the setting of their choice, with a list of general questions to act as a guide (see below). Each interviewee of the semi-structured interviews was an employee of Afrika Tikkun. Seventeen of the 20 interviewees were employees in the Mfuleni branch and three were employees in the Delft branch. Some interviewees
preferred to be interviewed in a group of two to four people, whereas others preferred to be interviewed alone. Prior to each interview, I asked for the verbal consent to record the conversation with a voice-recorder. Fifteen people consented to the recording and five preferred to abstain. For those who provided consent, I would place the voice-recorder in complete visibility of all interviewees. After the interview, I offered to play back the recording and let the interviewee(s) decide whether they wanted to change or delete any part of the recording. Only one interviewee expressed the desire to hear the recording after the interview had ended and, then, decided to leave it as it was. My voice-recorder included the option to place a lock on each recording after it was completed, which did not allow for anyone to listen to the recording until it was uploaded to my computer. The semi-structured interviews consisted, loosely, of the following questions, which were used only as a guide throughout the conversation:

1) How did you become involved with Afrika Tikkun?

2) In your own opinion, what are some of the benefits and challenges that you have experienced while working at Afrika Tikkun?

3) How has your experience been working with other employees at Afrika Tikkun?

4) How would you consider your own role at Afrika Tikkun?

5) How would you consider my role at Afrika Tikkun?

6) In what ways could I give back to the NGO and the community?

Since the employees of Afrika Tikkun were eager to describe to me what they did, I felt questions one and two were appropriate starting points during the semi-structured interviews. Questions three and four were chosen in order to gain insight into the
thoughts, feelings, and concerns that the employees had working at Afrika Tikkun. Questions five and six were meant for my own reflections on the topics of positionality and further engagements in the community (I will touch on this again in Chapter 6).

Confidentiality. Whether or not I recorded an interviewee(s) or took field notes during observations, I consistently told my research collaborators of the value that I placed on the confidentiality and privacy of their thoughts, concerns, and opinions. As I mentioned in the above section, I allowed each interviewee to choose the setting in which they felt most comfortable for each interview. Often, this was their office, my office, or a common area of Afrika Tikkun, such as the boardroom. I would allow each interviewee the option to close the door to any of these areas if they preferred to do so. The lock that I placed on each recording after an interview protected the thoughts of each interviewee in the case that my voice-recorder would be lost or stolen. As I have mentioned, I could only gain access to these recordings by uploading them to my computer. My computer was also password protected and each fieldwork-related document required a unique password in order to gain access to it. My field notes were taken on a note pad and two separate journals, which I carried with me most of the time. When I was participating in certain events, I kept my field notes in my office and ensured that the door was locked. I would take notes on these events after I finished participating in them. The note pad was used to jot down quick notes as I observed, experienced, or heard topics of interest. One of the two journals was used to reflect more deeply on the occurrences of each day and the other was used primarily as a planner, including goals I wanted to accomplish each day of the week and my schedule for the semi-structured interviews.
As I became acquainted with the people with whom I worked, I would ask them individually and privately to choose a pseudonym for themselves. I expressed to them that this was meant to protect their identities if I were to write about what they did or said. Interestingly, some individuals took this very seriously and would think on it for a few days. They would then come back to me with what they thought to be their perfect alias. Some expressed to me that they would like me to use their original name.

Living and Transport. Prior to my trip, several individuals with whom I had become acquainted on my previous visit to South Africa, advised me to stay in a “backpackers,” or traveler’s hostel, due to safety reasons. Therefore, during my research, I stayed at Ashanti Backpackers near central Cape Town, an approximately twenty minute drive to Mfuleni. In hindsight, living in Cape Town, away from the Mfuleni community, did not allow me certain details of the NGO and its employees that I may have had access to had I chosen to reside in Mfuleni. However, since crime is a real-life, daily occurrence in the townships, I made the conscious decision not to take the extra risk.

Ephraim, my driver, became my primary source of transportation to and from Afrika Tikkun as well as around Cape Town in the evenings and on weekends. Ephraim had been hired by the traveler’s hostel where I stayed during my previous trip to South Africa as their official taxi driver, and so I knew I could rely on him. On almost every trip to and from the NGO, Ephraim updated me on the politics of the country and provided

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7 For example, when Aija (a pseudonym), one of the CYDP coordinators, was absent from the NGO for a few days, he expressed to me later that all four of his car tires had been stolen overnight and he had no other opportunities for transport to work. He told me that this had happened to him, as well as other friends and family members, on several other occasions as well.
me with answers to historical questions that I had. After receiving his consent, Ephraim, too, became an active collaborator in my research.

*Engagement and The Media.* One of the objectives of my research was to find out how I could take a participatory stance in the engagement that Afrika Tikkun provided for the community. I, therefore, made a conscious effort to ask the employees at Afrika Tikkun how I could give back to the community and how I could continue to stay engaged in the future. After collecting the opinions of the majority of the employees in the PHCP individually, I presented the ideas to the group of CCWs after one of the morning prayers. A unanimous vote was presented for the filming of a short interview, between myself and 11 CCWs, and was scheduled to be broadcasted on a local news station in my hometown of Reno, Nevada. I was asked by the nurse coordinators to lead the project. First, I received the consent of the program manager, the general manager, and the marketing directors of Afrika Tikkun’s Cape Town offices to go ahead with the project. Then, the marketing directors, Terry and Mooks (pseudonyms), aided me in writing a letter of request to the CEOs of Afrika Tikkun to be sent via e-mail to Johannesburg, South Africa and New York City, USA. The following week, we received permission from both offices to begin filming. We scheduled to film on July 16th 2014, two days before my last day at Afrika Tikkun. Terry brought the necessary equipment to Afrika Tikkun and 11 CCWs were chosen by the nurse coordinators to take part in the interview. The 11 CCWs who were chosen had volunteered to participate and were wearing their full uniform, including name badge.

During the lunch hour, after the 11 CCWs returned from their home visits, Terry set up the filming equipment in the office of the Family Support Specialists because it
was the quietest room of the building. The CCWs were divided into two groups at
random. One group consisted of five people and the other of six. Each group was seated
separately, opposite me. The camera was placed on my left side so that I would remain
off camera. I chose not to appear on camera since the object of the segment was to
highlight the work that the CCWs did at Afrika Tikkun. Each group was asked a series of
questions that a news reporter at the local news station in Reno had presented to me prior
to the day of filming. Since I elected not to appear on camera during the interviews, Terry
asked me to film a separate testimonial detailing my overall experience at Afrika Tikkun.
The testimonial is public and can be found on YouTube\(^8\).

The CCWs hoped to accomplish one simple objective through this project: for
Afrika Tikkun, an NGO specializing in youth development and primary health, to gain
more visibility around the world. It is important to reiterate, here, that I made it a point
during my fieldwork to commit to an engagement that I could follow up with in the future
and to facilitate a lifelong dialogue between the NGO, its employees, and myself. After
filming wrapped, however, the project did not reach completion. Terry finished editing
my testimonial a few weeks after my departure, but the video starring the CCWs has yet
to be completed. I have kept in regular contact with Terry, who expressed to me that
several of his team members in the administration offices of Afrika Tikkun in Cape Town
have since left and are no longer involved with its programs and projects. The key to
committing to an active engagement in cultural anthropology and ethnographic fieldwork
is to be both a researcher and an activist. It involves continuously taking an activist stance
in an organization’s outreach within the community that they serve and to keep current on

\(^8\) http://www.youtube.com/watch?v=NIOHxxmd5BY&feature=youtu.be
community members’ needs. Although the video project did not come to fruition, I remain in constant contact with several CCWs, one of the nurse coordinators, and the program manager.

Social media outlets such as Facebook and Whatsapp also took an interesting role throughout my fieldwork and still remain the primary source of communication between the CCWs and myself. Originally, and as established by the Institutional Review Board (the ethics board at the University of Nevada, Reno), I am unable to publish any photography containing the faces of the people with whom I worked in order to preserve their privacy and identity. However, “posting” photographs to social media became a topic of negotiation throughout my time at Afrika Tikkun. Several CCWs, as well as other employees, began “adding” me to their social media profiles and “posting” photographs of me posing with other CCWs while we conducted home visits in the community. As is the nature of establishing rapport, I allowed them to “post” these photographs. In return, I asked the CCWs who “posted” the photographs with me in them if they would allow me to “post” those same photographs to my own social media profiles. I not only received the consent of most members of the NGO, but many asked me to “post” a photograph on certain sites first in order for them to be able to show it to their families and friends. Those who I had “added” to these sites would also leave comments and “tag” their friends in these pictures. Social media quickly became a space for communication and for the sharing of photographs, memories, and experiences. Through social media, therefore, the line between what should and should not remain private in respect to an individual’s identity within ethnographic fieldwork is severely blurred. Anthropologists have always been committed to the protection of their
collaborators and although social media continues to play a large role in my own
engagement with Afrika Tikkun, I urge anthropologists to ask new questions regarding
the topic of ethics in the age of the Internet and the rapid spread of social media.

In the next chapter, I will provide an analysis of the literature on the anthropology
of citizenship. Several essential forms of citizenship present themselves in relation to
health citizenship as discussed by Robins and von Lieres (2004, 2006) in the context of
South Africa. *Cultural citizenship* as argued by Renato Rosaldo (1994) and Aiwha Ong
(1996), is a type of citizenship in which culturally constructed rights to belonging are
discusses an *agrarian citizenship*, which provides insight into the ways that the power of
citizenship is transferred between citizens through land and property ownership.

*Biological citizenship*, as discussed by Adriana Petryna (2003, 2004), speaks to the way a
citizen’s body and bodily harm is used to gain a sense of citizenship in the form of
monetary compensation from a governmental system that failed to provide its citizens
with a right to health. In this thesis, I will focus primarily on the notion of *health
citizenship*, which Steven Robins and Bettina von Lieres (2004, 2006) propose as the way
impoverished South African citizens have gained a sense of empowerment through the
participation in the Treatment Action Campaign (TAC) and the subsequent governmental
distribution of antiretroviral treatments for HIV/AIDS. Health citizenship remains unique
to South Africa’s history and the democratic transformation that the country experienced
in the early 1990s. Furthermore, the notion of a “responsibilized citizen” plays a vital role
in the definition of health citizenship by empowering a community to take responsibility
for their individual and their family’s health.
In Chapter 3, I will provide details on the inner workings of the Primary Health Care Program (PHCP) at Afrika Tikkun in Mfuleni. The PHCP consists of many employees who all carry specific duties and goals that aid in establishing a sense of health citizenship to the Mfuleni community. Chapter 4 elaborates on a group of employees known as the Breast Feeding Support Specialists (BFSS). This group of women establishes a sense a health citizenship within the community through their health talks, which educate new mothers on the practice of “exclusive breastfeeding” and encourage HIV-positive mothers to commit to antiretroviral therapy, lessening the chance of HIV transmission from mother to infant. In Chapter 5, I will explore a specific program within the PHCP that monitors the many health issues that children face in Mfuleni. The program is known as the Integrated Management of Childhood Illnesses, or IMCI, and presents both benefits and challenges for the Community Care Workers as well as the community members involved in the program due to the contents of a measurement tool known as the Road to Health Card. In Chapter 6, I will explore my own positionality to better explain why certain ideas and concepts may have been inaccessible to me throughout my fieldwork.
CHAPTER 2
LITERATURE REVIEW AND THEORETICAL ORIENTATION

The Anthropology of Citizenship

What it means to be a “citizen” in any given society has been contested, negotiated, and re-defined with each historical, political, and social change that society has experienced. Within the last twenty years, as anthropologists have chosen to include activism and human rights work as supplemental to their ethnographic research, definitions of citizenship have become especially salient in understanding how citizens negotiate who they are and how they are defined within a community to construct new discourses of culture change and social aid. Collectively, anthropologists have agreed that citizenship is an innately social phenomenon and includes the notions of belonging and participation as its two most prominent characteristics (Rosaldo 1994, Ong 1996, Holston 1999, Petryna 2003, Petryna 2004, Robins and von Lieres 2004, Siu 2005, Schiller 2005, Robins and von Lieres 2006, Robins 2006, Anzaldua 2007, Wittman 2009, and Levinson 2011). Hannah Wittman goes a step further by adding that “a broadened conception of citizenship goes beyond a passive and hierarchical relationship between individual; persons and the state, in which the state mediates the awarding rights discriminately according to particular terms and subjectivities” (Wittman 2009: 160). Thus, citizenship includes more than a sense of political belonging to a nation-state, entailing the rights and
duties detailed in state policies and legislation. It “includes and also goes beyond the
dichotomous categories of legal documents, which one either has or does not have…”
(Rosaldo 1994: 75) such as birth certificates or passports. Citizenship expands upon the
historical, political, and economic parameters most commonly attributed to the concept
and provides for its citizens, a sense of identity, power, and “subjecthood.” Furthermore,
Renato Rosaldo writes, “citizenship can be a matter of degree” (Rosaldo 1994: 75) in the
sense that distinctions exist in how individuals and communities define a “sense of
belonging, entitlement, and influence” (Rosaldo 1994: 75) within various contexts.

In order to understand the changes in the definition of citizenship in South Africa,
and through the services provided at Afrika Tikkun, I will first address how other
anthropologists have studied citizenship in a number of different contexts. This is
important because as communities around the world continue to seek out and engage with
their rights as citizens, often challenging or redefining earlier forms of citizenship,
anthropologists continue to gain an understanding of how new discourses and
participatory spaces are formed.

Anthropologists have traditionally focused on the topic of citizenship in
communities where notions of belonging and participation have shifted due to global and
local processes. Although anthropologists have provided a number of different ways for
citizenship to be described and defined in a variety of contexts, there are three prominent
forms of citizenship that I will discuss here due to their relevance and connection to the
way citizenship is interpreted at the local level in my research with Afrika Tikkun. These
three forms, coined and elaborated on by each of the following authors, are: cultural
citizenship (Rosaldo 1994, Ong 1996), agrarian citizenship (Wittman 2009), and biological citizenship (Petryna 2003, Petryna 2004).

Cultural Citizenship. Rosaldo defines cultural citizenship as “the right to be different (in terms of race, ethnicity, or native language) with respect to the norms of the dominant national community, without compromising one’s right to belong, in the sense of participating in the nation-state’s democratic process” (Rosaldo 1994: 75). Rosaldo uses this definition to inform his research on Latino identity and notions of belonging in the United States. He argues that citizenship is often denied to marginalized groups, usually of a minority ethnic group, because of a “struggle to achieve full enfranchisement” in part through the constitutionally “defined number of exclusions that formed the basis for social movements over the last two centuries” in the United States (Rosaldo 1994: 77). These exclusions combined with “rightist national politics…the United States has witnessed a return of citizenship as a site of political struggle” (Rosaldo 1994: 77). Rosaldo demonstrates, in the following example, how this sense of collective struggle within Latino communities in the United States, in fact, challenges the terms of citizenship rooted in pre-established American political ideologies.

Latinos in the United States have legitimized their struggle for enfranchisement through a number of demands ranging, for example, from “legal, political, and economic issues to matters of human dignity, well-being and respect” (Rosaldo 1994: 75). For instance, one of Rosaldo’s interviews with a Chicana activist demonstrates that a paternal member of the family instructs his children on the notion of respeto (respect) through a list of actions that “underlines that different individuals are capable of experiencing the world in very different ways and that being respectful has to do with finding out what
another individual sees and feels” (Rosaldo 1994: 76). A portion of Rosaldo’s interview with the Chicana activist, voicing her father’s advice, reads: “first…you must listen…Second, don’t tell them that they don’t feel something just because you don’t…” (Rosaldo 1994: 76). As Rosaldo explains, evidence from interviews such as this “confirms that respeto is a key term in how Chicanos/Mexicanos understand human dignity, both as conveying a sense of full citizenship and as a potential area of violation” (Rosaldo 1994: 76). The Latino notion of respect, in other words, provides the possibility for a sense of entitlement. Cultural citizenship, thus, is one way of claiming and expanding on the rights referenced through legal definitions of citizenship and is re-negotiated and re-imagined in an increasingly ethnically, racially, and otherwise diverse context.

Aihwa Ong also writes on the topic of cultural citizenship as it can be “applied to various global contexts,” but adds to it the “cultural process of ‘subjectification’ in the Foucauldian sense of self-making and being-made by power relations” (Ong 1996: 79; Foucault 1989, 1991). For Ong, cultural citizenship refers to:

The cultural practices and beliefs produced out of negotiating the often ambivalent and contested relations with the state and its hegemonic forms that establish the criteria of belonging within a national population and territory…Becoming a citizen depends on how one is constituted as a subject who exercises or submits to power relations… (Ong 1996: 80).

Ong’s definition of cultural citizenship does not reference the attention to disadvantaged populations in the sense that Rosaldo’s (1994) definition does. Ong resolves that Latino immigrants can create their own definitions of entitlement and legitimization and thereby “escape the cultural inscription of state power and other forms of regulation that define
the different modalities of belonging” (Ong 1996: 80). In Ong’s view, cultural citizenship must take into account the dialectical relationship between the state and its subjects. She argues that race and citizenship are often intermingled topics within the “Western consciousness” due to past colonial encounters (Ong 1996: 81). Influenced by the work of Memmi (1967), Fanon (1967) Alatas (1977), Said (1978), Nandy (1983), Gilman (1985), and Stoler (1995), Ong argues that these encounters created the view that “white-black hierarchies are homologous with levels of civilization [resulting in] a racist hegemony” that still exists within discourse of citizenship in the United States (Ong 1996: 81). Specifically, values of “individualism, progress, and the celebration of freedom…has become synonymous with being American…Western civilization more broadly,” and by extension, “whiteness” (Ong 1996: 81). Consequently, subjects assuming these normative standards are considered ideologically “good citizens” (Ong 1996: 81) and thus gain access to the cultural citizenship of the United States.

Ong’s research with various immigrants of Asian descent in the United States serves as an example of how, “whatever their origin or race, they were ideologically positioned within the hegemonic bipolar white-black model of American society” and are thereby assessed by non-immigrant Americans on the certain cultural practices that fit into the already established ideologies constituting “good citizens” (Ong 1996: 83). Cambodians, for example, were positioned into an ideologically black Asian category due to their acquisition of the image as “welfare dependent immigrants” whereas Vietnamese “who are celebrated for their ‘Confucian values’ and family businesses…the general perception of them is as possessed as ‘can do’ attitudes closer to the white ideal standards of American citizenship” (Ong 1996: 83). Ong continues that it is, therefore,
“not surprising that Cambodians are almost always referred to as ‘refugees’ whereas Vietnamese refugees are viewed as immigrants” (Ong 1996: 83-84). The term “refugee” already serves as an indication of the lack of citizenship status in global standards, but even more so by positioning Vietnamese immigrants “above” Cambodian immigrants, “inscribing them as citizens of differential worth” (Ong 1996: 82) due to the hegemonic ideologies in place in the United States.

Thus, Ong views cultural citizenship in terms of “the ideological entanglements of race and culture” (Ong 1996: 90) in a dialectical relationship between colonial histories and the State, which is then set into the “Western consciousness.” Citizenship, in this way, produces “subjectivities” by prescribing citizenship to those who “fit-in” to hegemonic ideologies. Furthermore, as Ong concludes, this “dynamic othering…but shapes attitudes [and identities] and encodes discourses directed at immigrants from the rest of the world that are associated with racial and cultural inferiority” (Ong 1996: 90).

**Agrarian Citizenship.** Within anthropology, citizenship has also been used to discuss participation in land resources, land cultivation, and land ownership. Hannah Wittman (2009) defines this agrarian citizenship in terms of citizens’ lived experiences in rural versus urban contexts, specifically as discussed in her research in Brazil. She states that

The concept of agrarian citizenship…is modeled not solely on the geographic location of rurality but rather on understanding the changing political basis for agrarian social action, which includes differential practices of production and political participation conducted within and beyond rural space (Wittman 2009: 150).
Wittman considers this form of citizenship to understand the ways “rural actors and spaces…have historically been marginalized…to the periphery of political articulation” (Wittman 2009: 149) due to the immense political weight carried in a citizen’s right to land access. This access “has structured control over labor and material resources even when the ownership and occupation of land are separated, with urban landowners exerting political influence over rural people and the land they work” (Wittman 2009: 149). In terms of defining citizenship, then, Wittman writes that “members of rural polities often find themselves in a situation in which they have the technical rights of citizenship, but lack the substantive rights to participation, or the power to govern the development of land resources” (Wittman 2009: 149).

Wittman examines the framework of agrarian citizenship in relation to her ethnographic fieldwork in Brazil. She proposes that due to Brazil’s colonial history, land grants became “a sign of social prestige to the elite who maintained ties to the Crown” (Wittman 2009: 151). The “possession of property guaranteed [them] political voice and substantive citizenship rights…making land possession the basis of power and a clear territorial mechanism ensuring [a discrepancy] in citizenship by limiting access to political participation” (Wittman 2009: 151). She writes that this excluded rural groups from important participatory attributes of citizenship, such as land ownership and voting rights (Wittman 2009: 151).

Wittman claims that through grassroots initiatives that took place in the decades prior to her research, however, the possession of land no longer equated to citizenship directly, but “associated the struggle for land with the struggle for social incorporation…[in the sense that] it situated land-holding in a complex and changing set
of social relations, rights, and responsibilities that are (re)produced through democratizing access to land…” (Wittman 2009: 151,158). An example from Wittman’s research shows how a group of activists working in the Antonio Conselheiro Settlement in Matto Grosso use this “struggle” to formulate a “movement” that centers around educating settlers on “how to negotiate bureaucracy through collective action to obtain agricultural supports (land, credit, technical assistance) to which they have rights as rural producers” (Wittman 2009: 153-154). Moreover, the movement “situates their particular agricultural problems as small producers within the larger historical context of global political economy…” (Wittman 2009: 154). One activist, and one of Wittman’s informants, expresses the importance of this education in order for settlers to understand their rights to land as rurally positioned citizens: “First they come to understand the theory, right, about what is an encampment, what is the movement in theory, to later participate in practice…politically who is the enemy and who isn’t, to understand the political process of the whole society…they learn before and then they go” (Wittman 2009: 154). This educational movement stresses “new ideas and new discourses” in order to “connect the individual struggle for survival to a collective agrarian situation beyond local boundaries…” (Wittman 2009: 154). Through this grassroots movement, activists are able to draw attention to the importance of a political education as well as to the recognition that the agricultural and social challenges that these communities face result in much more than an accomplishment of material intentions. These challenges and “struggles” become the foundation of citizenship (Wittman 2009: 154).

As Wittman demonstrates through her work in Brazil, activists were able to establish a “new discourse” in defining the participatory rights of rural communities in
relation to agrarian politics. Through the establishment of a movement educating Antonio Conselheiro settlers on the political processes of land ownership, the resulting personal and social transformations authenticates the development of a “collective consciousness,” regardless of political difference (Wittman 2009: 157). More importantly, membership in the movement facilitated a process, as one activist mentions, “of the people conquering a space of their own, with their own force…that is the key in the new reformulation of agrarian citizenship” (Wittman 2009: 154,157). The creation of this participatory space produced the outcome of a “collective rural consciousness…in order for the small farmer to become a subject of his/her own history,” thus, reframing the concept of an agrarian citizenship (Wittman 2009: 157).

*Biological Citizenship.* Adriana Petryna defines biological citizenship as “a demand for, but limited access to, a form of social welfare based on medical, scientific, and legal criteria that recognize injury and compensate for it” (Petryna 2004: 142). She argues that this form of citizenship becomes especially pertinent in contexts where “the very context of citizenship is charged with the super-added burden of survival… [and where] the injured biology of a population has become the basis for social membership and for staking claims to citizenship” (Petryna 2003: 7, Petryna 2004:142). The body has, in this definition, taken the form of a multidimensional biopolitical power: a “versatile material through which the state and new populations can be made to appear” (Petryna 2004: 145). An example is that of the Chernobyl incident of 1986 in Soviet-Ukraine, which Petryna uses as a case study in order to reveal the ways in which citizens have come to rely on accessible forms of technology and legal procedures that may grant a
citizen political recognition and the inclusion in some form of welfare (Petryna 2004: 143): a biological citizenship.

The explosion of the Chernobyl nuclear reactor caused a variety of devastating damages to the population exposed as well as to the surrounding environment. Moreover, the disaster continued well beyond the time of the immediate explosion as “plant workers were recruited to work at the disaster site…handling polluted soil, reactor core – radioactive graphite…and other radioactive debris” (Petryna 2004: 140) without receiving the knowledge of potential health effects and risk factors from the Soviet state who “claimed the biomedical aspects of Chernobyl were under control” (Petryna 2004: 140). These workers became known as “bio-robots” and as Petryna describes, “their biologies were exploited ‘and then thrown out’” (Petryna 2004: 140).

When Ukraine gained independence in 1991, the government announced a series of hopeful safety standards that addressed the issue of Chernobyl. However, “exposed” populations still felt excluded due to the absence of protection after the Chernobyl incident that seemed “a natural and legal right protected as a matter of birthright” (Petryna 2004: 142). Petryna explains that these populations, therefore, negotiated a discourse of “economic and social inclusion…using the constituent matters of life” in activist and bio-medical arenas within Ukraine’s new political economy (Petryna 2004: 142). “Exposed” citizens were…aware that they had fewer chances for finding employment and health in the new market economy [and so] accounted for the elements in their lives (measures, numbers, symptoms) that could be linked to the state, scientific, and bureaucratic history of mismanagement and risk. The tighter the connection that could be drawn, the
greater the chance for securing economic and social entitlement (Petryna 2004: 143).

Petryna gives the example of a nine-year-old boy who showed a multitude of symptoms pointing toward mental retardation. Neuropsychiatrists, together with the boy’s family, reconstructed his disorder as “having a radiation origin…due to his mother’s occupation-related exposure during pregnancy” (Petryna 2004: 143). Earlier tests showed that the boy’s radiation dosage was actually quite low and pediatric doctors explained that a different form of birth trauma could very probably have caused the disorder. However, due to the social attention the Chernobyl incident produced in terms of compensation and biological protection from the new Ukrainian government, “radiation-related disease became a central source for local scientific research… [in effect] researchers constructed a human research cohort” related to the Chernobyl radiation (Petryna 2004: 143). In doing so, “they were also constructing a destiny for newly designated human research subjects…precisely the destiny the parents were intent on offering the child – a biological citizenship” (Petryna 2004: 144). Ukrainians, therefore, “tried to put their suffering in perspective vis-à-vis the representative model of science and state” in order to use biology as a form of social and “market” compensation (Petryna 2004: 144-145). The result was a group of citizens who gained citizenship due to the power that their biologies had in relation to the Ukrainian state.

*Toward a New Citizenship.* Anthropologists have come to understand the concept of citizenship as an essentially cultural process and it will, therefore, continue to be a dominant discussion in the anthropological literature. Citizenship can be contested, negotiated and re-negotiated in order to legitimatize, authorize, and create a sense of
belonging for individuals and groups who share or desire the rights and duties bestowed upon them.

The concepts of cultural citizenship (Rosaldo 1994, Ong 1996), agrarian citizenship (Wittman 2009), and biological citizenship (Petryna 2003, Petryna 2004) illustrate that the anthropology of citizenship extends across an array of channels that can all provide a sense of belonging and participation for citizens. Rosaldo (1994) and Ong (1996) express cultural citizenship in terms of how the ideological climate of a given state can either provide or deny entitlement to its immigrant populations. A cultural citizenship focuses on topics of difference, whether that be ethnic, ideological, or cultural, that is negotiated between the State and its population to produce new modes of consciousness or to perpetuate old ones. Wittman (2009) discusses agrarian citizenship through the power relationships that exist in the ownership of rural versus urban land. A sense of belonging and power, characteristic of urban centers, is brought to the geographical and social position of rural citizens through the active participation with rural land and education movements supporting the rights to land ownership. Petryna (2003, 2004) initiates discussion of biological citizenship describing the notion that a citizen’s biology can carry a great deal of political power. Biological citizenship addresses aspects of belonging to certain biological cohorts, using biology to gain compensatory access in market economies, and challenging a State’s protection of citizens’ biologies to produce new ways of accessing social entitlement.

There are, of course, many other forms that citizenship can take, such as educational citizenship (Levinson 2011), transborder citizenship (Schiller 2005, Anzaldua 2007), insurgent citizenship (Holston 1999) and diasporic citizenship (Siu 2005), but I
have chosen to focus on the three forms expressed above due to the parallels that can be
drawn in relation to my own findings in South Africa. Cultural, agrarian, and biological
forms of citizenship all attend to the creation of participatory spaces through the activist
stance that the people, in each of the above contexts, take in order to establish a sense of
belonging, entitlement, or empowerment. Moreover, these notions fit neatly into the
notion of health citizenship in South Africa. In the following section, I will outline the
concept of “health citizenship” and the subsequent notion of a “responsibilized citizen” in
the context of South Africa’s history with HIV/AIDS (as well as other health issues) in
relation to the political history unique to the “rainbow nation.”

Defining Citizenship in South Africa

The beginning of South Africa’s democratic government, in 1994, was also the
beginning of several of South Africa’s major milestones on the road to social
transformation. The stage was set for activist groups and social movements to challenge
former ideologies and definitions of citizenship and to become active participants in the
reconfiguration of South Africa’s new democracy. South Africa’s democratic politics
became “notable for the way in which its liberal framework has been challenged by the
consequences of widespread political and economic marginalization” (Robins and von
Lieres 2004) and as a result, established a breeding ground for activist groups and social
movements. Moreover, as Robins and von Lieres argue, “participatory spaces are more
often shaped by poor people themselves than offered by outside actors” (2004: 576). The

9 The “rainbow nation” is a term coined by Archbishop Desmond Tutu and elaborated by
President Nelson Mandela to describe post-apartheid South Africa. It both symbolizes
and embraces the unity of South Africa’s multi-cultural and multi-national population,
especially after having been under strict divisions during apartheid.
opening of this participatory space in the climate of a new democracy meant that marginalized populations could finally speak to their injustices and become participatory citizens, especially since their citizenship had been restricted until the abolition of apartheid. Together with the focal concept to strive toward a “new South Africa,” activist groups emerged as participants from marginalized groups who challenged everything from gender violence to education to health care. These groups both supported and questioned the new government in influential ways and became vital aids for the transformation into a democracy, often providing a new sense of citizenship to its most marginalized groups.

I argue that the three forms of citizenship I discussed in the previous section all serve as the basis for a new category of citizenship that appears in the context of South Africa: health citizenship (Robins and von Lieres 2004, Robins 2006). Health citizenship takes into account the influences and ideologies of the state in relation to the differing ethnicities of its population, as cultural citizenship does. It includes aspects of power between urban and rural communities based on issues tied to land ownership, as agrarian citizenship assumes. And the body becomes a vehicle of power in the context of demanding the rights to one’s own health, as discussed through the notion of biological citizenship. Health citizenship, however, involves a new understanding of citizenship as a kind of empowerment through the “responsibilization” of health (Robins and von Lieres 2004, Robins 2006).

The term “responsibilization” has most commonly been discussed in the social sciences, public policy, and public health as a feature of Michel Foucault’s description of neoliberal governmentality (Löwenheim 2007: 204-05, Burchell 1996, Garland 1996).
Governmentality is defined as a “from of political power that consists of various technologies, mentalities, and rationalities of governing others and oneself” (Löwenheim 2007: 204, Foucault 1991). In a neoliberal context, governmentality facilitates a form of “self-governing” in which a “state encourages or even impels people and communities to acknowledge…and assume…a responsibility of…self-management” (Löwenheim 2007: 204, Burchell 1996: 29). It is important to note that “responsibilization” does not equate to “self-help,” but instead emphasizes the “duties of the prudent and rational citizen” (Löwenheim 2007: 204, O’Malley 1996: 200, Kemshall 2002: 42). Within public health and the field of medical anthropology, specifically, “responsibilization” has been widely criticized as an inefficient way for a state to provide a sense of empowerment or autonomy for its citizens (Strong 1986, Navarro 2008, Trnka 2013).

For example, medical anthropologist Susanna Trnka (2013) discusses her work with asthma patients in New Zealand and in the Czech Republic in which the neoliberal health care systems expect patients to manage the use of medications and to track symptoms on their own. In severe cases and in cases of asthmatic children, specialized services are provided. However, while the responsibility of looking after oneself is meant to empower patients, “for many of the patients or parents of asthmatic children…it can feel onerous, confusing and difficult, especially initially when one is struggling with how to cope with a potentially life-threatening condition” (Trnka 2013: 182-83). Through her research, Trnka explains that a number of the patients with whom she worked, “turn ‘self-management’ into ‘self-blame,’ assuming that there is something morally wrong with respect to their capacities to manage themselves if their asthma is not under control” (Trnka 2013: 183). Trnka writes that it is due to the continuous strain “between neoliberal
logics of ‘responsibilized patients’ and post-socialist ethics of the state’s duty of care to its citizenry” that has evolved through an “economic restructuring of…health services, the adoption of world-wide guidelines…and the global economic crisis, [that] there is also a pressure to devolve services onto patients” and emphasize this neoliberal rationale of “responsibilization” (Trnka 2013: 183).

Similarities can be drawn from the work by Marian Burchardt (2012) in which he discusses the responsibility of sexual openness in relation to HIV disclosure within a faith-based organization (FBO). He begins by discussing that “the idea of openness was developed in relation to the willingness to assist HIV-positive people in their plight” (Burchardt 2012: S499), and he continues by stating that “such assistance would depend on people declaring themselves to be HIV-positive, and therefore on acts of disclosure” (Burchardt 2012: S499). In the context of the Christian FBO in which she worked, disclosure and, as Burchardt terms, “the language of sex” (Burchardt 2012: S503) became a site of contention. Throughout his research, Burchardt continuously discusses that this form of “responsibilization” is problematic due to the stigma and “judgmentalism” that is tied to the epidemic as well as the “prevailing cultural assumption that infection resulted from transgressive sexuality” (Burchardt 2012: S500).

However, Burchardt speaks of “responsibilization” in a more positive manner as well. The FBO in which he worked strategically focused on HIV-positive children as “innocent victims…reflecting more general Christian cultural tropes about children as pre-sexual beings…beings that exist outside the binary of sin/virtuousness” (Burchardt 2012: S500). He describes that this method allowed parents to “break the silence” surrounding the epidemic and led to the parents’ own disclosure of their diagnoses as
well (Burchardt 2012: S500). It is precisely this more positive idea of “responsibilization” that is discussed by Robins and von Lieres (2004, 2006) and is most relevant to my own research and to the remainder of this thesis.

In this section, I will address how health citizenship remains one of the most influential and original forms of citizenship in South Africa today. I will establish how the Treatment Action Campaign (TAC) provided an opportune platform for marginalized groups in desperate need of health care, especially in the context of HIV/AIDS, to gain the social and political leverage needed to assume the role of citizen, which was denied to them during apartheid. Moreover, I will discuss how these groups cleverly avoided “going into battle” with the political opposition because of the sense of entitlement and empowerment, which they gained through the internalization of the idea of a “responsibilized citizen.”

According to Robins and von Lieres, health citizenship is a notion particular to South Africa due to the specific political climate present at the start of the new democracy as well as the struggle involved in gaining access to treatment for people living with HIV/AIDS (Robins and von Lieres 2004, Robins 2006). First, I must stress that it is due to South Africa’s unique history of apartheid and the transformation into a democracy that allowed for the “unmaking of marginalization and the remaking of citizenship” (Robins and von Lieres 2004). By “involving forms of participation aimed at creating new interfaces between marginalized people and the institutions that affect their lives, particularly those of the state,” (Robins and von Lieres 2004; Cornwall 2002: 20) these marginalized groups experienced a shift in what it meant to be a South African citizen. The pre-apartheid black individual was restricted to segregated areas, whose
primary source of identity in the face of the apartheid government was a paper
identification card with a designated number. The post-apartheid black individual was a
participant and an actor with a voice, whose identity was open for reinterpretation.
Second, a redefinition of citizenship was made available due to the gravity of the
consequences that resulted from apartheid by denying citizenship to those groups forced
into racially segregated townships.

Third, the most momentous human right denied to these groups was that of health.
Not only was health an issue in the townships due to the extreme poverty, lack of
sanitation and clean water, but also by 1993, 322 thousand people were infected with
HIV/AIDS (Avert 2015). Moreover, at the start of the democracy, HIV/AIDS was still
subject to a series of denialist leaders and dissident science, providing no clarity or aid for
the exponentially growing infected population. For example, “in 2000, President Mbeki
convened a Presidential Advisory Panel on AIDS that included two internationally
renowned ‘dissident’ scientists…[who] did much to perpetuate the views that HIV did
not cause AIDS, that HIV tests were inaccurate and that anti-retrovirals were lethal
poisons” (Leclerc-Madlala 2005: 849). This demonstrates one of the many denialist
perspectives that soared through mainstream South African AIDS policy deliberations
and media outlets in the early 2000s.

Finally, in all of this complexity, it was the “perfect timing” of the Treatment
Action Campaign (TAC) and its activist stance in the HIV/AIDS epidemic that, in many
ways, became the “life-line” that these marginalized groups needed to guide them into the
role of citizen and subsequently, to open up a participatory space for the redefinition of
citizenship. Thus, the concept of health citizenship was born (Robins and von Lieres 2004).

Robins (2006) refers to health citizenship as ways in which pain, illness, and suffering mold an individual and society’s sense of belonging to a citizenry within politically charged experiences of disease in communities lacking political power. He describes how health citizenship in South Africa revolves around its most prominent diseases, including HIV/AIDS, tuberculosis, heart disease, and meningitis, due to their high mortality rate and chronic nature (Robins 2006: 315). Importantly, the notion of health citizenship directly relates to the idea of “responsibilized citizens”: that citizens should take responsibility for their own health as advocated by activist groups such as the Treatment Action Campaign, TAC (Robins 2006: 312-13, 321). For a patient being treated for HIV, the notion of health citizenship takes into consideration that the “experience of pain and suffering is fundamentally social” (Robins 2006:313). The body, thus, takes center stage in South African political debates, contributing to the growing number of activist groups who, as Hannah Arendt (1958) notes, become “increasingly concerned with [the] biological existence and management of ‘life processes’” (Robins 2006: 313). TAC is one of those activist groups and has subsequently become the largest and most effective national activist organization in post-apartheid South Africa by “demanding greater governmental involvement in the HIV/AIDS struggle” (Leclerc-Madlala 2005:850). By “politicizing the right to health care [and] empowering citizens…TAC’s organizational structure and support networks crossed race, class, ethnic, occupational, and educational lines” (Robins 2004: 663, 669). TAC, therefore, led the way for a newly “responsibilized citizenry” to continue creating participatory spaces
in which the shared struggles of rights to health care could be further contested in the face of the “new democracy” of South Africa.

_The Treatment Action Campaign (TAC)._ On December 10, 1998 (International Human Rights Day), Zackie Achmat, TAC’s founder, living with HIV, along with fifteen protestors took to the steps of St. George’s Cathedral in Cape Town “to demand medical treatment for people living with HIV/AIDS” in a climate that “assumed that anti-AIDS drugs were beyond reach for all developing countries” (Robins and von Lieres 2004: 577). After collecting over one thousand signatures, the government was called upon to organize a treatment plan for all those living with the disease and so the Treatment Action Campaign, TAC, was born.

As Robins and von Lieres describe, “the majority of TAC volunteers were working-class township youth and unemployed African women…of which many were HIV-positive [and] desperate to access life-saving drugs for themselves and their children” (Robins and von Lieres 2004: 580). Furthermore, as a result of the stigma the disease still carried due to its “early associations with homosexuals, bisexuals, blacks, sex workers and drug users,” these women “experienced hostility and rejection from their communities, friends and family” (Robins 2004: 662, Robins and von Lieres 2004: 580). Although it may seem that the power of stigma would deem TAC unsuccessful it actually became the most important reason for its successes in “grassroots mobilization…[because] of its capacity to provide these poor unemployed HIV-positive mothers with hope and support” (Robins and von Lieres 2004: 580), which also reflected the image of hope that President Mandela presented for the “new South Africa.”
Equally impressive was TAC’s ability to “draw on the anti-apartheid movement’s highly effective use of the courts to challenge racist politics” (Robins and von Lieres 2004: 580). For example, soon after their establishment, “TAC, together with the South African government, became embroiled in a lengthy legal battle with international pharmaceutical companies over AIDS drug patents and the importation of generics to treat millions of HIV-positive poor people in developing countries” (Robins and von Lieres 2004: 577). Due to their extensive and “highly successful global and national media campaigns,” TAC was able to gain immense support from international public opinion and the Pharmaceutical Manufacturers Association (PMA). These reactions resulted in an argument for affordable HIV treatment drugs that was judged as “undeniably right and just” (Robins and von Lieres 2004: 577). A national survey conducted in South African antenatal clinics by Avert, an international HIV/AIDS charity based in the UK, estimated that 24.8% of pregnant women, aged 15-49, were living with HIV in 2001. These numbers, along with similar reports presented by UNAIDS and the Constitutional Court Case: *Government of the Republic of South Africa and others v. Grootboom and others*\(^\text{10}\), sparked TAC to take the state to the High Court of South Africa. Their argument was that “the State had a positive obligation, according to section 27(2) of the Constitution, to promote access to health care and that this constitutionally bound obligation could be extended to AIDS drug treatments” (Robins and von Lieres

\(^{10}\) *Government of the Republic of South Africa and others versus Grootboom and others* is a landmark case in international jurisprudence, heard in 2000, “marking the first time in any nation that a constitutional court enforced the constitutionality of a socio-economic right”, giving legitimacy to the “second-generation” (post-apartheid) of citizen rights (see Williams 2005). The focal argument was to establish clean water, housing, health care, and a clean environment as basic human rights.
Robins and von Lieres argue that although the “thrust of TAC’s argument…focused on socioeconomic rights, specifically on citizens’ rights to health care…TAC lawyers raised broader issues relating to questions of scientific authority and expertise” (2004: 579). These monumental proceedings led to the obligation for the South African government to “address the ongoing contestation over the scientific ‘truth’ on AIDS” (Robins and von Lieres 2004: 579). In fact, President Nelson Mandela “publicly stated his regret over the fact that his government did not do as much as it should have to combat the growing threat of HIV/AIDS” and apologized, again, for his denial when his own son died of AIDS in 2005 (Leclerc-Madlala 2005).

Not only did TAC’s grassroots initiatives and interventions in the state promote a growth in their support base and membership, “helping it turn into a multiclass and multiracial movement,” but “by drawing attention to…threats to independent medical science, TAC was also simultaneously creating the political and discursive space for the emergence of new claims and expressions of health citizenship” (Robins and von Lieres 2004: 578). TAC, therefore, completely opened the doors for other activist groups to establish themselves and continue the “democratic discourse of health citizenship” (Robins and von Lieres 2004: 580). These groups based themselves in local communities, keeping on the path that TAC paved, and provided AIDS awareness and prevention, “as well as treatment literacy campaigns, in schools, factories, community centres, churches, shebeens (drinking places), and through door-to-door visits in the black townships of major urban centres” (Robins and von Lieres 2004: 579). I argue that Afrika Tikkun is one of these groups, continuing TAC’s goals to empower its citizens through a consciousness of health. Furthermore, as Robins and von Lieres describe in terms of
establishing a sense of health citizenship, I argue that Afrika Tikkun “helps give previously powerless people political agency and encourage [citizens] to assert control over their own lives and bodies” (Robins and von Lieres 2004: 580).

As I have mentioned above, the definition of health citizenship incorporates the notion of a “responsibilized citizen” who becomes empowered to take responsibility for their own health. Activist groups such as Afrika Tikkun, as well as public health experts, have continued working toward providing health education to the communities they serve and in so doing, produce a “highly motivated, ‘responsibilised’, and knowledgeable client” (Robins and von Lieres 2004: 584). Drawing on the successes of TAC’s treatment literacy campaigns, activist groups empower citizens by placing them in a position in which they are able to voice their biological and social experiences living with HIV and other health issues. Moreover, by providing citizens the health education that was denied to them through the South African government’s acknowledgment of dissident science, it “created an empowered citizenry with high levels of understanding of AIDS issues reinforced by community advocacy and mobilization processes that promote the rights of people living with HIV/AIDS” (Robins and von Lieres 2004: 584). Consider the following treatment testimony as an example of a “responsibilized citizen:”

I’m Sipho from Cape Town…I was diagnosed in 2001, three days after my birthday. I was very sick. When you get sick you just ignore it. You say, ‘Oh it’s just the flu.’ You’re in the denial stage. You say your neighbor is a witch…We thought this disease belonged to other people elsewhere in Africa. From my point of view, HIV is real, it’s here. I never thought I would be here today. I couldn’t stand, I was sick. My CD4 count was 110 and my viral load was 710,000. Then I started ARVs with MSF in Khayelitsha. Now I’m strong…I’m committed to my AIDS
work. AIDS is in my blood (Robins 2006: 317; testimony given at Durban TAC Congress 2003).

Sipho encompasses what it means to be a “responsibilized citizen” by acknowledging that he has been diagnosed with HIV and is committed to working with TAC to not only receive treatment but to serve as an activist for others. Furthermore, Robins argues that Sipho’s proclamation that “AIDS is in my blood…signifies both a scientific statement about HIV/AIDS infections as well as a metaphorical statement about ‘who I am and what my purpose is’” (2006: 317). Scientifically, Sipho’s statement evidences the education he may have received on the basis that the physical location of HIV/AIDS is “in your blood,” a new concept to the previously trusted “AIDS myths” that the disease was a result of witchcraft. The same statement also carries what Robins refers to as “symbolically charged language” that captures the notion of health citizenship by serving to provide “extraordinary agency and a sense of purpose that Sipho and many other activists living with HIV/AIDS seem to share” (Robins 2006: 317). Testimonies such as Sipho’s are concerned with “both rights-based struggles and creating collectively shared meanings of the extreme experiences of illness and stigmatization of individual AIDS sufferers” (Robins 2006: 320). TAC and other activist groups, therefore, continued to expose and encourage the “participation of spaces created by marginalized groups” (Robins and von Lieres 2004: 585) in which citizenship was appropriately and continuously placed within discourses of health to provide empowerment and a sense of identity in the most marginalized areas of South Africa.

The notion of “responsibilized citizen” in the context of health citizenship is an ongoing project. As activist groups such as Afrika Tikkun continue their grassroots
involvement in the communities that need the most help and “articulate new forms of citizenship from below,” there is no knowing to what extent these new citizenships can “transform entrenched inequalities and marginalization inherited from the apartheid era” (Robins and von Lieres 2004: 585). What remains clear is that health citizenship is one of the most powerful means of participation in political and social life in South Africa and has provided a rope with which marginalized groups can pull themselves up with to become active and vocal citizens in the “new South Africa.” In the following chapter, I will discuss the Primary Health Care Program, PHCP, at Afrika Tikkun and how the programs that are conducted within the PHCP continue the legacy of a “bottom-up” approach to activism that TAC had set forth for activist groups in order to establish a sense of health citizenship for impoverished communities such as Mfuleni.
CHAPTER 3

THE PRIMARY HEALTH CARE PROGRAM: A LOCAL PERSPECTIVE ON PUBLIC HEALTH

In this chapter, I propose that a sense of health citizenship is established in a number of ways for both the patients and the employees of Afrika Tikkun through the services provided by the Primary Health Care Program. Most of these services revolve around the related idea of a “responsibilized citizen” and contribute to a sense of empowerment within the community. However, before I discuss several cases that demonstrate the concept of health citizenship, I will first dive into what the Primary Health Care Program is and how it functions in the community. I will also provide a description of all the personnel involved in the program. These descriptions will provide an understanding of the services that two of PHCP’s outreach programs: the Breast Feeding Support Specialists and the Integrated Management of Childhood Illnesses (which I will discuss in detail in Chapters 4 and 5, respectfully) implement in the Mfuleni community and how they function to establish a sense of health citizenship.

The Primary Health Care Program

The Primary Health Care Program is one of six programs within Afrika Tikkun and is the largest and most prominent program in Mfuleni. The Western Cape Department of Health established the Primary Health Care Program (PHCP) in order to
provide a community support system “geared towards health promotion and prevention of risk factors for health conditions with a complimentary capacity for curative, rehabilitative and palliative care” (Western Cape Government 2014: 2). The Western Cape Department of Health used Afrika Tikkun’s idea of “person-centered care,” already a highlight of Afrika Tikkun’s other programs, and created a system known as Home and Community Based Care (HCBC). HCBC recognizes that most people are eager to find help when it comes to their health issues and “involves a range of context-sensitive interventions” that provide ways for citizens to empower themselves in terms of their health. These interventions include coping strategies, health education, and positive habit formation (Western Cape Government 2014: 2).

The PHCP communicates regularly with the other five programs at Afrika Tikkun. The programs with which they work most closely, however, are the Nutrition and Food Security Program and the Family Support Services Program (FSS). Both of these programs existed at Afrika Tikkun before the PHCP was established. However, they are now of vital importance in perpetuating the health education that the NGO provides for its beneficiaries. The Nutrition and Food Security Program, for example, involves a group of employees and cooks who have planted a fully functioning annual garden on Afrika Tikkun’s property in Mfuleni. The garden includes cabbage, sweet potato, green beans, and a variety of other vegetables and legumes. These are used to cook the daily meals for Afrika Tikkun employees, the children in the Early Childhood Development Program, and the students in the Child and Youth Development and Job Readiness and Entrepreneurial Development Programs in order to encourage healthy, balanced diets.
The Family Support Services Program is a group of four employees who conduct daily visits to the community to search for the most in-need families that would benefit from extra support provided by Afrika Tikkun. These supports take the form of both temporary and long-term projects. For example, a temporary project includes “shack builds.” If the FSS find a family living in a shack that is leaking or falling apart or if they come across a family that does not have a home at all, motions are set in place in order to fix or construct a new shack for those families. The process from start to finish takes a few weeks’ time. I was unable to witness each stage of the process, however, near the beginning of my fieldwork, I did meet a family who requested a new shack while I accompanied the FSS employees on a visit. I met this family again, on my last day at Afrika Tikkun (coincidentally also Mandela Day) and watched as a few strong men, who had been recruited from the community, raised up the tin walls of the family’s new home (see Figure 2.1 and 2.2). Long-term projects for the FSS consisted primarily of recruiting children at preschool age to join the Early Childhood Development Program. These children were then guaranteed a spot in the subsequent programs of the NGO. This included passing through the Child and Youth Development Program as well as the Job Readiness and Entrepreneurial Development Program. Supporting community members throughout these stages of their life facilitated the NGO’s overall goal of providing aid and support for the community from “cradle to career.” The Nutrition and Food Security Program and the FSS Program, therefore, provide added support for the PHCP and remain important functions in the success of the PHCP in terms of preventative health care.
The driving forces of the PHCP are the Community Care Workers, or CCWs. These workers engage with the Home and Community Based Care (HCBC) model by visiting households in Mfuleni and providing services for whole families. This includes checking in on any children residing in the household through a program called Integrated Management of Childhood Illnesses (IMCI) and includes “TB case finding, sexual and reproductive health advice, and safety and hygiene education” for adults (Western Cape Government 2014: 3). Through the HCBC model, CCWs also look for any elderly individuals within the household in order to provide extra care regarding general hygiene issues and adherence to medication.

In order to understand what the CCWs do and the role that they play in the community, I must first begin with a description of the hierarchy of employees in the PHCP, starting with the role of the program manager. This will provide further insight into the importance of the CCWs in establishing a sense of health citizenship at the local level.
The Program Manager and Administration

The Primary Health Care Program (PHCP) is host to several teams of employees. At the top of the hierarchy is the Program Manager (I will call her Delilah) who oversees all employees and outreach projects within the program. Delilah is the Program Manager for the PHCP in both the Mfuleni and Delft branches of Afrika Tikkun. Her main office, however, was located in Delft and she spent most of her time there. The majority of her visits to the Mfuleni branch were solely for the purpose of dropping off documents and equipment for the nurses, attending meetings with the general manager, and relaying quick updates to the CCWs after the morning prayer. My contact with her was, therefore, infrequent, and any time I was able to speak to her, our conversations were kept brief.

Several administrators worked directly under Delilah. For instance, the Data Capturer, Lucia (a pseudonym), is in charge of inputting information received from patient files into a computer program developed by the Western Cape Department of Health in order to track the progress of the PHCP. This included spreadsheets following morbidity rates of HIV/AIDS, fluctuations in the overall population of Mfuleni, the numbers of infants born in the informal settlements of Mfuleni, and mortality rates. Lucia told me that these numbers would be analyzed by the Department of Health and used to evaluate the amount of funding that the PHCP would receive.

Another group of administrators were known as the Lay Coordinators. The Lay Coordinators are a group of three women who coordinated with a multitude of outreach projects that were occurring throughout the Cape Town area and with which Afrika Tikkun wanted to involve themselves. One of the largest outreach projects to occur while I was at Afrika Tikkun was a mobile dental clinic for children who ranged in age from
four to twelve. Afrika Tikkun hosted this project in their gymnasium in Mfuleni, and recruited several CCWs to help supervise in the clinic. I volunteered three days of my time as well, helping to supervise children in the designated waiting areas, filling “goody-bags” with toothbrushes, toothpaste, and small toys, and speaking to several of the dentists and other volunteers who had traveled from all over the world to donate their time to the project.

The Nurse Coordinators

There are three certified registered nurses on staff who carry the title of nurse coordinator, although I will refer to them as the nurses. One of the nurses, Sheikha (a pseudonym), is primarily a Training Coordinator & Quality Assurance Coordinator. This means that she organizes the certificate-based training workshops and specialty courses for new and existing CCWs. Certificate-based workshops include trainings on condom use, cancer treatments, and sexually transmitted infections, or STIs, during pregnancy (all of which I attended while at Afrika Tikkun, among several others). Sheikha also instructs two annual six-month long courses for new CCWs. Each course is broken up into two parts: three months are spent in a classroom setting and three months are spent doing practicals\textsuperscript{11} in a nearby clinic or day-hospital\textsuperscript{12}. After students complete and pass the exit-exam for this course, they become fully-fledged CCWs and are placed under the

\textsuperscript{11} A term taken from “Western” medical- or nursing-school settings in which students must demonstrate their practical abilities and skills as part of an exam or series of exams in order to complete their specific programs of study.

\textsuperscript{12} The day-hospitals provide secondary and tertiary levels of care and are often shared between two or more townships. The term derives from the fact that many are only open during regular business hours and close in the late evening. Patients requiring overnight stays are moved to the larger hospitals in Cape Town.
supervision of one of the other two nurses. The other nurses, Lily and Misty (also pseudonyms), supervise about 30 CCWs each.

The tasks of Lily and Misty at Afrika Tikkun are nothing short of extensive. First and above all, they have the most comprehensive medical training at the NGO, which means that the 60+ CCWs depend on their expertise. That said, they are also the only professionals certified to take care of patients beyond the level of “basic care”: basic hygiene, basic health education, and adherence support for patients taking medication. For example, a few of the responsibilities that only the nurses can perform include dressing open wounds, HIV, STI, and TB testing, and analyzing the medications which the doctors have prescribed for their patients.

Lily and Misty work closely with the Dr. Ivan Toms Clinic in Mfuleni, the day-hospital in the neighboring township of Bellville, as well as with a social worker who works primarily with the Delft branch of Afrika Tikkun. Through these three resources, patients are referred to Lily and Misty because the doctors and other nurses agree that their patients would benefit from the PHCP at Afrika Tikkun. The nurses then divide up these patients between each of the 60+ CCWs, allocating between four and eight patients to each CCW. The nurses set up files for each patient, separate from their medical files at the clinic or hospital, which they use to track the progress of each patient. The files also include each patient’s personal information: HIV status, family medical history, and additionally for women, the number of pregnancies. For each new patient, the nurses conduct what are known as M & Es, Monitoring and Evaluations. This includes visiting the patient’s home, asking patients to sign a consent form in order for Afrika Tikkun to work with them, and asking a series of questions designed to aid the nurses in filling out a
Home Based Care Assessment Form (see Appendix A 1.1 and 1.2). This information helps the nurses classify each patient as a Category 1, a Category 2, or a Category 3.

During an interview with Lily, she defined each category as follows:

…we'll have to categorize the patient because they have the category 1 patient. That person is on medication, but they are able to take their own medication. And then you get the category 2. They need some assistance. That is now minimal assistance regarding their health issues. And then you get the 3, the third category, which is now they are totally dependent on home based care…maybe they are bed-ridden, they need to have full baths, bed washes, they need to be educated, personal hygiene, environmental hygiene...we'll include the families in health talks and all that.

As described by Lily, the categories mark in ascending order, the severity of a patient’s needs. I was fortunate to accompany both Lily and Misty on several M & E visits during my time at Afrika Tikkun and to meet the people behind each of these categories. On each M & E visit, Misty and Lily take additional notes in their personal journals, which include information on the patient’s health status, on any updates in medication usage, and on the overall environment of the home, such as the number of people living in the household and cleanliness of the home. On my first M & E visit with Misty, she asked me to also take notes in my field journal as I sat listening to the conversations with her patients. At the start, I was hesitant to take out my journal because my first priority was to establish a strong rapport with my research collaborators. As time progressed, however, it became routine for me to take notes at the same time as the nurses and the CCWs. Also, the more frequently I accompanied the nurses and the CCWs on their visits out to the community, the more people viewed me as being affiliated with the PHCP at Afrika Tikkun and so carrying a notebook around was not perceived as an
unusual or threatening phenomenon. The following are examples taken from my field notes of a few M & E visits that will provide a glimpse into what the patient categorizations look like for the nurses.

*Category 1:* This patient was a young female, possibly in her thirties, who was diagnosed with tuberculosis a few weeks prior to our visit. She was very knowledgeable about her illness, her prescription medication, and the time of her next doctor’s appointment. She knew to keep the windows and doors open throughout the day and to keep a few windows open at night in order to keep the air circulating throughout her home and prevent the spread of TB to her children. When the nurse asked to see all of the patient’s medications, she provided them without hesitation. The nurse showed me how she counts all of the tablets remaining in each container and subtracts that number from the number of days since the patient was prescribed the medication to prove the patient’s adherence. Also, the patient provided us with her birth control pills and again, the nurse showed me that the patient was regularly taking her birth control and that the pills left in the package were up to date with the day we were visiting. Furthermore, the patient showed us her calendar with each doctor’s appointment clearly marked, including the time and location. The nurse told me that this patient could be classified as a category 1 because she can be trusted to continue her adherence to the medication plan and shows responsibility through her knowledge of TB and the times and dates of her next doctor’s appointments.

*Category 2:* This patient was an adult female, age unknown. One of the carers who was assigned to this patient informed me that the patient had been involved in a car accident in her youth, but had not experienced any immediate health effects. However,
twelve years after the accident occurred, the patient began developing problems in her lower back and had trouble walking. Due to her lack of financial resources and lack of support from her family, she was unable to acquire medical attention and became completely bedridden as her health deteriorated and she lost the ability to walk. When she was referred to the PHCP at Afrika Tikkun, she was given a wheelchair and is now able to feed and wash herself as well as do simple housework. She was not taking any medications when the nurses and I visited her and so we were unable to record the regularity of her adherence, but overall, she was functioning well. Neighbors would help her by getting her groceries or supplies for her house and the CCWs would help her with transportation to and from clinic visits. The nurses, therefore, labeled her as a category 2.

Category 3: This patient was an elderly female, about 75 years old, who had suffered a stroke seven years ago and presently experienced hypertension. This patient provided the nurses with her medications and was knowledgeable on the days and times that she needed to take each one. However, when the nurses counted each tablet, the numbers did not always add up correctly and many of the medications had expired. The nurses told me that this makes tracking the patient’s adherence to the medications very difficult. Also, when the nurses checked her “clinic card” (a small business-card that a doctor provides after a check-up indicating the next appointment’s date and time), the date was scheduled for the day on which we were visiting. The patient had forgotten to check the date and therefore, the nurses advised her that she visit the clinic the following day. The nurses told me that due to the patient’s age and her history of stroke, she often misses her appointments and also forgets to “wash.” “Washing”, as the nurses and CCWs used it in this setting, includes bathing oneself, brushing one’s teeth, and cleaning oneself
after use of the toilet. Fortunately, the patient’s daughter lives with her and helps her maintain generally good hygiene, but the patient cannot take care of herself on her own and requires the extra care. These characteristics classify this patient as a category 3.

The above categorizations allow the nurses to analyze how much care and support their patients will need and help inform the work done by the CCWs when the nurses designate these patients to them. Additionally, after a new patient goes through the initial M & E visit, the nurses conduct further M & Es, on a weekly or monthly basis, depending on the scope of the patient’s health and wellbeing. The CCWs, together with the nurses, continue updating their patient’s health status in the patient files and relay this information to the Data Capturer who submits it to Western Cape Department of Health.

The nurses are adamant about keeping up to date with the M & E visits because they also serve as a way of double- and triple-checking the work done by the CCWs. For example, Misty often mentioned to me that the CCWs were not always thorough with what they wrote in the patient files; this would not only cause issues for the NGO, but would reflect negatively on its employees and the families whom they were serving. On one such occasion, I overheard Misty fuming and venting her anger to a couple of CCWs upon returning from a home visit. Rather than asking her what had occurred immediately, I waited until I conducted my semi-structured interview with her a few weeks later when she disclosed the following story:

…one morning I came on duty and a carer came to me and said ’Please come and assess, there's a patient, an unconscious patient that we must go wash in the community.’ Now unconscious is a red flag, you have to jump up immediately, whatever you had planned...because it is your first priority to get that sorted and well anyway, to make a long story short...I went there and I assessed the
patient, took them straight to the health facility and looked up the folder...the carer changed my category 3 to 2. The patient was hospitalized in the end, about three days after that she died. So the carers don't have the know-how, don't have the experience to... distinguish between a very sick patient, an almost dying person, and someone who needs a wash...They are dishonest, some of them are very dishonest. You cannot trust them. You cannot... and I don't want to be like a policeman, I'm a nurse not a policeman, and that upsets me very much.

Misty’s story serves as a perfect example of the vast amount of responsibility that the nurses must carry due to their medical expertise. They are not only obliged to assess the patients brought to the PHCP, but they must also supervise and coordinate with the CCWs and make sure that the patients are receiving the care that they need. During the same interview, Misty also shared with me how overwhelmed she feels when she is made aware of the dishonesty of some of the CCWs: “So now you can see, if you sit with 30 carers, each of them having eight clients, how vast, how enormous are our responsibilities. That is how I feel.”

The Community Care Workers

The Community Care Workers (referred to as CCWs or Carers) are a group of about 60 women\textsuperscript{13} who conduct home visits to serve each of their four to eight patients. As I have mentioned above, the nurses assign these patients to the CCWs after their initial M & Es. This allows the nurses to designate certain categories of patients to certain CCWs. For example, the fewer patients a CCW has, the higher the likelihood that those patients will be a category 3 patient since they demand more care. A CCW having the maximum of eight patients, therefore, will have one or two category 3 patients and the

\textsuperscript{13} This description relates to the Mfuleni branch of Afrika Tikkun only. The Delft branch, for instance, had their own group of 60+ CCWs and included one male worker.
rest will be either category 1s or 2s. This presents a sense of fairness in the amount of responsibility and work that each CCW is assigned.

Each category number also corresponds with the number of days per month that each CCW will visit that patient. Category 3 patients will be visited three times a month, category 2 patients will be visited twice and category 1 patients, only once every month. Some patients need to be visited more often or less often depending on their specific needs. For example, I accompanied a CCW on a home visit to one of her category 3 patients who was severely abusing alcohol and who had been stealing money from his mother. He was visited by the CCWs once a week, and sometimes even more frequently, to provide food parcels\textsuperscript{14} for his mother and to continue encouraging him to go to the clinic and seek rehabilitative care. On the day that I accompanied the CCW to this patient’s home, I learned that he had also been battling AIDS for 16 years because he had neglected to take his antiretroviral medication (ARVs) consistently. His mother told us that due to his diagnosis and his recent breakup with a girlfriend, he suffered emotionally, which in his case undoubtedly contributed to his alcoholism as well. His mother also stressed that she no longer knew how to help her son and that even the nurses at the clinic had told her to “leave him alone and let him die.” Due to the gravity of both the mother’s and her son’s emotions and the patient’s health concerns, the CCWs visited this category 3 patient much more frequently than the designated three times a month.

\textsuperscript{14} A food parcel is a small plastic container filled with one serving of the daily meal cooked at Afrika Tikkun. Patients could only request food parcels if they did not already receive social welfare grants from the South African government (known as SASSA: South African Social Security Agency). The food parcels would either be delivered directly to the patients or could be picked up at any Afrika Tikkun facility.
The CCWs, as I have stated before, are the foundation of the PHCP. The work that they accomplish in their daily four-hour shifts provides the community of Mfuleni with the grassroots support that is so influential in the concept of health citizenship (I will develop this idea further in the following chapters). They begin their days at 8:00 a.m. with a morning prayer followed by updates from the nurses or the program manager. An hour later, they split off into groups of two or three for safety reasons, grab their patient files, and head into the community for their home visits. They are required to walk from house to house in order to serve as a model for the healthy lifestyle that Afrika Tikkun encourages. However, on a few occasions, the CCWs hop into a “mini-bus” or taxi when they grow tired of walking. From 9:00 a.m. to about 1:00 p.m. they visit the patients scheduled for that day. During these visits, the CCWs sit with their patients and ask them a series of questions that help them update the patient’s file. This includes asking if the patient’s health has improved since the last time that the CCW visited and if they are taking their medications regularly. If the patient has grown more ill or shows the need for support in another aspect of their lives, the CCWs take note of this and report it to the nurses. Also, depending on the severity of the health issue that their patients face, the CCWs take the time to help them bathe, prepare a meal, or make doctor’s appointments at the nearest clinic. Each home visit is concluded with what is known as a health talk or health education talk. The health talks include topics on child safety (especially during the winter months in which I did fieldwork), proper storage techniques for the paraffin liquid used in heaters, and the fruits and vegetables that are in season during the winter months in South Africa. The health talks are usually conducted in a somewhat casual manner. Usually, the CCWs are sitting with their patients inside their homes and
communication is fluid and conversational. Patients also ask questions of the CCWs, which the CWWs are happy to answer. The CCWs are also eager to provide advice, especially since they have become familiar with the needs and wants of most of their patients. When all of the home visits are completed for each CCW, they return to Afrika Tikkun for the lunch meal. After lunch, some return to their own homes, others pick up their children from school, and still some others catch a mini-bus to a second job in Cape Town.

Each CCW has gone through the certification courses provided by Sheikha and have gained the knowledge needed to provide basic health care services to the community of Mfuleni. After the completion of their courses, each CCW receives the top portion of their uniform, adorned with Afrika Tikkun’s logo (see Figure 2.3). The tops of the uniform are available in navy blue, royal blue, black, or white and the CCWs are able to choose which color that they prefer. The CCWs are guaranteed three styles of tops, including a button-up polo t-shirt, a cotton long sleeve shirt, and a windbreaker style jacket. The Afrika Tikkun logo is consistently embroidered on the left breast pocket (see Figures 2.4 and 2.5). The CCWs are required to purchase their own pants, skirts, and shoes for the uniform, which must all be black in color. If the CCWs need to wear extra layers in order to keep warm, these clothing items do not need to show the Afrika Tikkun logo, but do need to match the color scheme detailed above.
Each CCW working for Afrika Tikkun lives in and is familiar with the community that she serves. According to the Guide for Home and Community Based Care Workers, distributed by the Western Cape Department of Health July 1st 2014, CCWs are hired directly from their respective townships in order to “foster stable, long-term, personal relationships with households which builds understanding, empathy, and trust…pivotal to continuity of person centered care” (Western Cape Government 2014: 2). I argue that the CCWs do much more. It is through their work with the PHCP and Afrika Tikkun that the concept of health citizenship is both created and perpetuated. I will focus the next two chapters on two programs that involve the CCWs and demonstrate how their roles provide a health citizenship for both themselves as well as their patients in Mfuleni. Chapter 4 gives a detailed account of a program within the PHCP that is comprised of a group of women known as the Breast Feeding Support Specialists (BFSS). In this chapter, I will discuss how the BFSS successfully establish a sense of health citizenship for their patients through their health education talks. In Chapter 5, I will discuss the outreach program Integrated Management of Childhood Illnesses (IMCI), which shows how a sense of health citizenship can be established for some community members, but limited for others due to a measurement tool known as the Road to Health Card.
CHAPTER 4

THE BREAST FEEDING SUPPORT SPECIALISTS: ESTABLISHING A SENSE OF HEALTH CITIZENSHIP FOR WOMEN THROUGH BREASTFEEDING EDUCATION AND ANTIRETROVIRAL THERAPY

The Breast Feeding Support Specialists (BFSS) are key contributors in providing the Mfuleni community with a strong sense of health citizenship, especially for new mothers. The work that this team of women accomplishes not only connects the local community with global processes, but also empowers new and existing mothers in such a way that the impact of the BFSS is felt in many other dimensions of these mothers’ lives as well. Furthermore, the BFSS are well known for their work and knowledge on breastfeeding in the community, which also establishes a health citizenship for the support specialists themselves. The two most prominent approaches that the BFSS encourage in order to provide their patients with health citizenship are “exclusive breastfeeding” and antiretroviral therapy (ART). Before I delve into each of these approaches, I will detail who the BFSS are and how they received their title. Furthermore, I will illustrate how the grassroots nature of the BFSS is connected to larger, global processes, such as the human rights guidelines established by the United
Nations, that help support the South African government in its ability to perpetuate the notion of health citizenship as well.

*The Breast Feeding Support Specialists*

The Breast Feeding Support Specialists (BFSS) are a team of CCWs who have been chosen by the nurses at Afrika Tikkun to specialize in antenatal care and support in Mfuleni based on their personal interests in the subject. Ophe, one of the BFSS, expressed to me on multiple occasions how much she enjoyed her job. During one particular car ride on our return to the Afrika Tikkun offices after a visit to the Dr. Ivan Toms Clinic, Ophe told me the following in reference to all the BFSS: “We love the job. We love what we are doing. Without money...yes there is no money\(^{15}\), but we love because we are in our community.” Ophe was one of the six BFSS\(^{16}\) with whom I worked. Ophe and the other BFSS, Tandie, Agie, Deneo, Kockie, and Zara (all pseudonyms), are all women between the ages of 27 and 50, and all have children, and some have grandchildren, of their own.

I worked most closely with Ophe and Tandie during my time with the BFSS. The passion and knowledge that they each had for a multitude of health-related topics was reflected in the way in which they spoke to their patients. Ophe specifically enjoyed educating members of her community on the different forms that cancer can take within the body. On one occasion, I observed her giving a health talk on cancer in the waiting room of the clinic. Her overall demeanor when presenting the information was both

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\(^{15}\) During one unstructured interview, Tandie told me that the CCWs’ income is set at 1400R (116.67 USD in 2015) per month, which ranks below the minimum wage for health care workers employed in the rural areas of South Africa, which is set at 2900R (241.68 USD in 2015).

\(^{16}\) A few months after I left, I learned that the BFSS had grown to include ten women.
enthusiastic and authoritative, and her knowledge on the subject greatly affected the patients with whom she spoke. They willingly participated in her discussion by asking her detailed questions and commenting on their own curiosities of what cancer entailed.

On another occasion, I observed a lecture that she gave to a group of incoming CCWs who were enrolled in Sheikha’s certification course. Again, her passion for the subject and the enjoyment that she felt when educating others in her community shone through. One of the students in this course told Ophe that she was living in fear because the only knowledge that she had acquired on cancer was that it could be fatal, but she did not know what cancer was exactly and how it could be prevented or treated. She thanked Ophe for visiting their class and expressed that due to Ophe’s comprehensive lecture, she no longer felt fearful, but instead felt empowered to share this new information with her family and friends.

Tandie was equally passionate in her role as educator, especially on the topic of breastfeeding. She tended to lead the conversations on breastfeeding support during clinic and home visits. During one of our visits to the clinic, Tandie was the first to sit down with a new mother, who was struggling to attach her baby to her breast, and guided her through the steps of successful breastfeeding. Tandie would also present her patients with examples of her own breastfeeding experiences with her two children, which allowed her patients to relate to her and trust her as a knowledgeable specialist in the community.

The BFSS’s schedule differs from the other CCWs at Afrika Tikkun in that the majority of their week is spent in either of two clinics (Dr. Ivan Toms Clinic and Drifsands Mobile Clinic) in Mfuleni with the added task of performing home visits. Their rounds in the clinics consist primarily of visiting the pre-natal and pediatric wards where
pregnant women and new mothers have come for check-ups, immunizations, and other medical services. Here the BFSS give health talks tailored to labor and delivery, breastfeeding, and caring for new infants. The BFSS also provide health talks to audiences of patients in waiting areas on the subjects of cancer, diabetes, and eating vitamin-rich foods, but I will only be focusing on their specialty of providing support in antenatal settings.

The BFSS, as a specialized team within the PHCP (Primary Health Care Program), was created to provide antenatal care as one of the primary services that the Western Cape Department of Health set as an objective for the Mfuleni community, which was limited in these services prior to the establishment of the PHCP. Furthermore, in accordance with the United Nations’ International Guidelines of HIV/AIDS and Human Rights (updated in 2006), the BFSS were assembled in order to meet the criteria of Guideline Eight, which asserts:

States, in collaboration with and through the community, should promote a supportive and enabling environment for women, children and other vulnerable groups by addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups (UNAIDS 2006: 19).

As I have detailed before, the PHCP is the only program in the NGO that is federally funded. Therefore, the inclusion of the BFSS within the PHCP is a way for the South African state to demonstrate that it is working to meet the guidelines set forth by the United Nations and to provide health support services for the communities that are most in need of it. Furthermore, the establishment of the BFSS maintains the sense that the government is actively contributing to the “new democracy” on both a local and a global
scale. As described in Chapter 2, one of the defining characteristics in the “new democracy” was the creation of a space where its citizens could become active participants in larger political processes and give voice to their past injustices. I will therefore, situate the BFSS, and the PHCP more broadly, within Robins’s and von Lieres’s notion of health citizenship in order to show how the concept fits into the ways that the BFSS empower their patients to become participatory, “responsibilized citizens.” I will show how a sense of health citizenship is established by the BFSS through the health education, breastfeeding support, and antenatal care that they provide in the clinics and homes of Mfuleni. Moreover, two methods, which I will describe below, allow community members to spread the notion of “responsibilized citizens” to others; this illustrates the idea that the production of a health citizenship is most effective through grassroots support. I will also provide examples of the ways in which the BFSS establish this sense of citizenship to their patients.

“Exclusive breastfeeding” and Antiretroviral Therapy (ART) are two methods used by the BFSS that suit the notion of establishing a sense of health citizenship to new and existing mothers within the community of Mfuleni. Each method also reflects the notion of “responsibilized citizen” to create a participatory space between the BFSS and their patients, as well as with Afrika Tikkun. As a general rule of thumb, once a patient was assigned to the BFSS, the support specialists followed them throughout the remainder of their pregnancies and until their infant turned six months of age. Since patients were only provided support from the BFSS for a maximum of 15 months, it allowed the BFSS to take on many more patients each month than the other CCWs in the PHCP. The patients whom the BFSS work with are, in most cases, category 1 patients.
Many of them are HIV-positive and are taking antiretroviral medications (ARVs) consistently. A few patients whom I met or about whom the BFSS told me have other health issues as well, such as TB or meningitis. Overall, most patients are able to care for themselves without additional support from Afrika Tikkun and their adherence to medications is fairly consistent. I never found out the HIV “status” of the BFSS themselves and do not know whether they suffered from any other health issues. Because I worked with them for a relatively limited period of time and because their primary focus was on their patients, I felt it inappropriate to delve too deeply into their personal lives. From the start of my fieldwork, they were eager to allow me access into their lives as BFSS and to show me around their community, introducing me to their patients. Therefore, I felt that the trust built through my own interests in their work and my experiences with them (and their patients) would be compromised had I turned the focus elsewhere. Furthermore, a few of the BFSS did approach me toward the end of my fieldwork to express some of their personal struggles and concerns and although I will not speak to these concerns in this thesis, they still remain valuable in that they strengthened the relationship I had with the BFSS. Had I pushed for this information earlier, I would not have been met with the same openness that I had otherwise. In the following section, I will describe the practice of “exclusive breastfeeding,” how the BFSS strategically navigate between “the old” and “the new” in terms of infant feeding methods, and how the benefits of “exclusive breastfeeding” grant mothers a sense of health citizenship.
“Exclusive Breastfeeding”

As their title implies, the focus of the BFSS’s work is to provide breastfeeding education and support for pregnant women and new mothers. One of the most important aspects taught by the BFSS is known as “exclusive breastfeeding.” Its importance stems from the high infant mortality rate, which is a direct result of compromised immune systems (usually due to HIV) or diarrhea caused, in large part, by the lack of sanitation in many South African townships. “Exclusive breastfeeding” encourages breastfeeding as the sole form of infant feeding and “should be continued until the baby is six months of age” (Western Cape Department of Health 2014: 26). Throughout these six months, mothers should refrain from any “mixed-feeding,” which includes any combination of two or more methods of infant feeding. The Western Cape Department of Health advises that, “no other foods or fluids should be given (not even water) unless recommended by a qualified health worker” (Western Cape Department of Health 2014: 26). Throughout much of the world, “exclusive breastfeeding” remains the recommended infant feeding method from birth to six months if a mother is able to breastfeed or uses a wet-nurse, but it is especially encouraged in developing countries as the only method of infant feeding due to restricted access to clean water, sanitation and health services (Unicef 2005). Not only is breastfeeding (and breast milk specifically) sanitary and sterile, but it also provides all the necessary nutrients that infants need in order to assure proper development and good health during the vital first year after birth. Furthermore, the “first milk,” colostrum, produced after a mother has given birth coats the infant’s gastrointestinal tract to provide a barrier to foreign substances and naturally strengthens the infant’s immune system.
Bottle-feeding and “mixed feeding” increase the risk of diarrhea and other ailments due to the lack of proper sanitation in townships such as Mfuleni. I was told by the BFSS that these methods of feeding were still an issue in Mfuleni because the generations that preceded them were taught to use formula bottles and other feeding methods due to the fear of transmitting HIV/AIDS to their children if they were to breastfeed. One of the patients with whom I was able to speak during a routine home visit told me that her mother had taught her to bottle-feed instead of breastfeed and that her baby (who was about two years of age at the time of my visit) was very sick for the first year of her life and that she feared for the life of her daughter. She said that she felt ashamed for having practiced bottle-feeding her mother’s way. Since the visit by the BFSS, she understands that “exclusive breastfeeding” is much more beneficial. She told me that even when she goes to the clinic, she sees how healthy and “big” other mothers’

17 “Big” was a term that many community members used as a defining characteristic of a healthy infant, and in some cases a healthy adult as well. Many of the people with whom I worked told me that to be “bigger,” in terms of body size and weight, was regarded as more appealing and more attractive. Although I consider myself to have a healthy build in proportion to my height and weight based on American standards, the BFSS, as well as others occasionally commented on my “small” stature and that I needed to eat more in order to be “big.” One day, for example, I stood outside of the PHCP building of Afrika Tikkun waiting for the BFSS to retrieve their patient files and when they walked outside to meet me, a few of them immediately asked me if I was pregnant. I looked down at my stomach, while declaring “No!,” and realized I had eaten a rather large meal the evening before and was slightly bloated. Although I felt insulted at first, it became a comical conversation as we walked through the community that day and the BFSS asked me about the details of “my baby” and told me that I should be careful because the “bigger” I got, the more men would be attracted to me. In terms of the infants, “big” was not considered overweight, but comparably, a “big” infant in Mfuleni was about the average size and weight, relative to their age, of healthy infants in America (this was evidenced through the Road to Health Cards discussed in Chapter 5). The women in Mfuleni referred to this term as being healthy because of its correlation with attractiveness as well as with the infant’s increased chances of survival in relation to malnourished, “small” infants.
babies are in cases where the mother chose to practice “exclusive breastfeeding.” She concluded that she would breastfeed exclusively if she were to have another child. The nurses and BFSS told me that, ultimately, bottle-feeding and “mixed feeding” have resulted in higher infant illness and mortality rates because mothers do not have the resources necessary to make certain that bottles and other feeding containers are completely sterile. Research produced by the United Nations Children’s Fund, or Unicef, reflects the nurses’ and BFSS’ claims by stating that “mixed feeding and bottle-feeding poses the risk of contamination and diarrhea as artificial feeding and diminishes the chances of survival” (Unicef 2005). Additionally, in terms of “mixed feeding” specifically, the nurses mentioned to me that new mothers sometimes prepare porridges and other soft foods which lack the proper nutrients for their infants. This type of feeding leaves many children in Mfuleni malnourished and prone to other health concerns (also discussed by Unicef 2005).

The confusion permeating South Africa during the late 1990s and early 2000s on the topic of HIV/AIDS contributed to the introduction of bottle-feeding as the preferred method (as detailed in Chapter 2). The BFSS told me that the South African government released reports during this time which encouraged their mothers’ generation to practice bottle-feeding, but because their mothers did not trust the South African government due to the acknowledgement of denialist perspectives and dissident science, they also partook in using traditional healers\textsuperscript{18} to cure their own and their children’s ailments, which contributed to the practice of “mixed feeding.” When the PHCP was established in 2012, the BFSS had to find a way to bridge the gap between “the old days” (a term used by

\textsuperscript{18} The term that the BFSS and other CCWs used when describing the healers to me.
Tandie to refer to her mother’s generation) and the Western Cape Department of Health’s recommendation of “exclusive breastfeeding” for current generations. I argue that due to their status as Afrika Tikkun personnel in the PHCP and their relation with the community’s history and beliefs, the BFSS very successfully navigated between “the old” and “the new” to encourage women to practice “exclusive breastfeeding.” The BFSS are able to establish a sense of health citizenship through the sharing of scientific and medical knowledge with groups of new and existing mothers who had been denied this information prior to the establishment of the BFSS. As a result, the BFSS’s patients assumed the role of “responsibilized citizens” and incorporated “exclusive breastfeeding” into their lived experiences as mothers in Mfuleni, which exemplifies the qualities that mothers feel as “health citizens.” In addition to giving a sense of empowerment to women through this “new” knowledge, “exclusive breastfeeding” also revitalized intimacy and connectedness between mother and child. On a larger scale, “exclusive breastfeeding” has increased the survival rate and lowered the mother-to-child transmission rate of HIV (which will be detailed in the following section) to newborn infants in South Africa as well as in other developing countries; the practice thus adds an additional dimension of empowerment for new mothers living in the townships. This is evidenced by Unicef, who asserts that “the overall risk of mother-to-child transmission of HIV is reduced from 35%, in non breastfeeding populations, to less than 5% in breastfeeding populations” (Unicef 2005; WHO Rapid Advice on PMTCT Version 2 2010).

The following example is the BFSS’s perspective on how they deliver the message of “exclusive breastfeeding” to the community and establish a sense of health
citizenship to new mothers who choose to practice this method of infant feeding. The first time I accompanied the BFSS on their home visits in the community, I noticed that many of their patients were concerned about an infant ailment that they referred to as “wind.” The BFSS would tell them that in order to prevent “wind,” their patients needed to practice “exclusive breastfeeding.” The BFSS use this “old” ailment in order to encourage the “new” method of “exclusive breastfeeding” and in so doing, establish a sense of health citizenship for the now “responsibilized citizens.”

The following is an excerpt of an interview between Ophe, Deneo, Tandie and myself that explains what “wind” is, how it is treated, and the role that “exclusive breastfeeding” plays in curing it.

LW: …you say between zero and six months...you advise the mothers to exclusively breastfeed, but after that, they are allowed to do their traditional medicines. So, I'm wondering, what are those traditional medicines?

Ophe: As I see it...that we believe there is a thing, we call it a wind...then, that wind, it depends...some of them, they believe in those traditional medicines. Those traditional medicines you get from the trees, from the roots, you know...that is the medication I am talking about. So now after six months...you can give your child the medication, like for the colic and wind. Some of them, they go to the chemist for it. Some of them, they go to the traditional healers...to get that medication for the wind and colics.

LW: And what did you say that was called...that medication?

Deneo: It doesn't have a name.

Tandie: It doesn't have a name because it's a mixture of current medicines...most of the time they go to shop at Pick-n-Pay...those are the mixture of the small bottles

19 Pick-n-Pay is one of the supermarket chains that exist in South Africa.
they mix together, and then they say that mixture is good for the baby, will stop the baby crying. It doesn't have a specific name. It's just a mixture.

Ophe: Some they get from the bushes. Herbs! That is the name...the herbs.

Deneo: How do you see if that child has got that wind? Maybe that baby will have a big stomach. Whether he or she is hungry or not, and he will have a terrible rash on the body.

LW: And then they give them these herbs or mixtures?

Ophe: We don't have the right to say your thing is not right. Only what we do...we say to them exclusive breastfeeding until six months....we say whatever you do, you can do it after six months. Some of them, they believe in...old things, like...herbs we're talking about. Then we don't have the right to say 'No you cannot use it, this is wrong, this is right.' No.

Tandie: Like for example...also to add what is that, you see all the babies when they get the soft (pointing to top of head)...all the babies have got that soft fontanel and the baby, it's normal to cry for first, for first four months or...it depends for each individual...we black people, especially Xhosas and Zutus, we believe those babies are crying because of that wind and that soft fontanel is because of the wind also, so according to us, we give them medications, those mixtures...mixtures and herbs. It can cure with that, which is not true. It's just a belief.

LW: Okay...so do you also believe in those medications...for the wind?

Tandie: Yes, before I get this information that I spread now, I did it because I use those medications to my kids, to both kids, I did use it. But I won't say it work. It did not because the baby, mine, was crying until she feel to stop crying and I didn't take that...I was supposed to give that medication from zero to ten years...I give just two bottles and then I stop.
Ophe: Like also, the term I was getting at first...my mother was there...there is a thing called Mtuboti. That thing is also a traditional medicine. That is what they say when the child has got a rash. Then you make...you rub it to the stone and then put a little bit of water and then you apply it to the rash of the child. That was the time of my mother...but my mother believe on that. I don't know if it help or what, because the rash it just get off when my child was six months...but my second born was also having the same thing, but now my mother was not around that time. I take my child to the clinic and the clinic, they said it was eczema.

Tandie: ...so all in one, what we trying to say, we've been told by our mothers and grandmothers that we must practice what they did to us. We don't know the truth of what, but that is what we've been told by our grandmothers and mothers. Then we did it.

The above conversation carries an abundance of information that makes up the notion of health citizenship. I will begin with the topic of “wind” to illustrate how this ailment serves as a starting point in the discussion of health citizenship and as a reality that the BFSS can easily negotiate with, both due to its cultural and temporal dimensions. Through the descriptions provided by the BFSS, it is difficult to deduce exactly what “wind” is in “Western” terms, but this is not of importance here. What remains meaningful is that according to the BFSS, the ailment is a lived experience in the Mfuleni community and it negatively affects the health and wellbeing of new infants. Tandie describes the cultural dimension of “wind” in the context of South Africa by explaining: “We black people, especially Xhosas and Zutus, we believe those babies are crying because of that wind and that soft fontanel is because of the wind also.” Xhosa is one of

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20 I only heard Tandie refer to “Zutu” as an ethnic or language group. It may have a possible relation to Zulu or Sotho (another Bantu language spoke in South Africa), but I am not certain because I am unable to find the term elsewhere.
the official language groups in South Africa and is spoken primarily by black South Africans. Furthermore, Tandie’s statement provides a description as to when “wind” presents itself in an infant. As she points out, “wind” causes the infant to cry while the “soft spot,” or fontanel, is present on an infant between birth and six months of age. This corresponds to the time frame when the BFSS encourage “exclusive breastfeeding” to take place. In terms of timing, the BFSS can neatly “fit-in” this “new” notion of infant breastfeeding to explain a way to prevent infants from contracting “wind.”

The “traditional medicines,” as part of a South African cultural practice, also serve as a component in establishing a sense of health citizenship for patients through the BFSS’s consideration and support of its uses. It is clear that the BFSS in no way advise women to halt the use of these “traditional medicines” as they are a part of daily life in Mfuleni. In fact, I met two traditional healers in the community during several routine home visits with other CCWs. Through the way the CCWs and other community members spoke of them, I sensed that the healers carried a great deal of respect and prestige within the community and they are visited often by community members. Their defining characteristics are the white beads that they wear around their neck as well as on each wrist. The first healer I met was an elderly woman who had provided help to a family of six children in which the youngest, a girl of two years, had fallen ill. When I was visiting the healer, who was also a patient of one of the CCWs, the young girl whom she had treated was running and playing around the house wearing blue beads around her neck and wrists. When I asked what the beads meant, the CCW whom I accompanied explained to me that she wore blue beads because the healer had treated her. Furthermore, the healer had asked her family to sacrifice a goat in order for their daughter to return to
health. The healers are not only called on for aid in health matters, but also to serve as leaders in ritual ceremonies pertaining to birth, death, and marriage. The other healer whom I met was an adult male and was also wearing the same white beads. During our conversation, he mentioned what he enjoyed most was partaking in marriage ceremonies. Because the healers serve as such active members in the community, the BFSS, therefore, continue to incorporate the role of “traditional healers” within their health talks on “exclusive breastfeeding.” As Ophe stated: “We don't have the right to say your thing is not right…Then we don't have the right to say ‘No you cannot use it, this is wrong, this is right.’” She emphasizes that the BFSS only advise new mothers to practice “exclusive breastfeeding,” without the use of medications, until the infant is six months of age. After that, she says, the patients have the freedom to choose how they would like to feed and use medications with their children.

The uses of “traditional medicines” as well as the cultural and temporal dimensions of “wind” are discussed by the BFSS as components of the ailment that they can neatly map “exclusive breastfeeding” onto. What remains critical in the discussion of health citizenship, however, is the way the BFSS discuss their own knowledge of health in relation to previous generations. How do new mothers trust and integrate the method of “exclusive breastfeeding” in a community that has received a confused assortment of information in the past, especially information passed down through their mothers’ and grandmothers’ generations? As the BFSS mention, their own “mothers and grandmothers” practiced “mixed feeding” and used various “herbs and mixtures” from the healers to help cure their children of ailments, such as “wind.” Tandie explained that their own generation did what their mothers and grandmothers had done, because, as new
mothers, they “don't know the truth.” In a later conversation within the same interview detailed above, I asked the BFSS what exactly had caused the changes in perspective between their mothers and themselves. Their answer partially represents the influences that Afrika Tikkun has had on the BFSS, but more significantly it provides insight into the way that the notion of “responsibilized citizen” has influenced the encouragement of “exclusive breastfeeding” within the community.

Ophe: Oh! It's a lot changed because now we know eczema is eczema...we know now, if you mix feed, your child is going to get sick...not like before, you don't even know like if your child has the stomach cramps, why your child is like that, but now at least our mind it's open. We know why the child has got the stomach cramps...

LW: Okay, so you also got the health education that explained...what was going on?

Ophe: But for me, I didn't get the health education from the clinic.

LW: Oh, you didn't?

Ophe and Tandie: No.

LW: So where...

Ophe: I go to school here at Tikkun for that, but as more I go to school, I just know 'oh, that is diarrhea'.

This conversation shows that for the BFSS, changes in their own perspectives began when they received a health education from Afrika Tikkun, which closely reflects the notion of a “responsibilized citizen.” By providing the South African poor with the “truths,” in this case scientific and medical knowledge, a new sense of participation develops (Robins and von Lieres 2004: 580). As seen in the above excerpt, Ophe repeats several times the idea that “now she knows,” as opposed to Tandie’s description of her
mothers’ and grandmothers’ generations “not knowing.” As I explained in Chapter 2, due to the denialist perspectives and dissident science that permeated through South Africa in the late 1990s and early 2000s, the South African poor were left with a sense of confusion and mistrust toward the South African government in terms of their right to health. In essence, they were denied the knowledge needed to not only tackle health issues, but also to understand them and situate them within their own realities. Furthermore, due to the government’s own denials of this knowledge, health citizenship set into motion a “bottom-up” system of power that allowed the South African poor to influence their own government from the grassroots level. By making scientific and medical knowledge accessible to a group such as the BFSS, the specialists are, therefore, establishing a sense of health citizenship for their patients. First, the BFSS become “responsibilized citizens,” themselves through their own acquisition of this knowledge by taking the required courses at Afrika Tikkun; then they are granted the responsibility and the motivation to share their “new” knowledge with the community, in this case the practice of “exclusive breastfeeding.” In turn, this creates a participatory space between them and the community (as well as with Afrika Tikkun). Through the participation with the community and sharing this “new” knowledge with their patients, the BFSS also create “responsibilized citizens” in their patients. For example, the story of the woman whose daughter had fallen ill during her first year of life demonstrates how being presented with this “new” knowledge is a way to motivate mothers to take “responsibility” for what has occurred and change their methods of feeding for their future children now that they “do know.”
Another intriguing example of this concept unfolded as follows. During a home visit with Khokie and Zara (two other BFSS), we walked into a home where one of Khokie’s patients was living with her newborn infant as well as both of her parents. When we arrived, the mother of the patient told us that the patient was not home because she had an appointment at the clinic to get the incision wounds from her cesarean section checked. Both her mother and father told the BFSS that their daughter had been breastfeeding exclusively and enjoyed it very much. The mother mentioned to the BFSS that she had offered to make porridge for her daughter’s baby, but that her daughter refused and told her mother that the BFSS had educated her not to because her baby could get sick and catch “wind” if she practiced “mixed feeding.” The patient’s mother continued to say that a great deal has changed since the “traditional” practices she took part in, but that she was proud of her daughter for remaining consistent and raising a “big,” healthy baby. After this moment, I distinctly remember that Khokie turned to me and whispered that she would transcribe this in her daily journal and present it to the other BFSS as one of her success stories. It is clear that Khokie’s patient feels empowered through breastfeeding by turning away her mother’s porridge, remaining consistent with her practice of “exclusive breastfeeding,” and that her baby is “big.” This patient has gained a health citizenship that motivates her to continue participating in and being responsible for her own health by going to her doctor’s appointment for example, as well as continuing to breastfeed exclusively. Additionally, through Khokie’s comment to me, she demonstrates that by having been the provider for her patient’s sense of health citizenship, she also feels rewarded for being a “responsibilized citizen” and has a success story to show for it.
As shown in the examples above, the notion of “exclusive breastfeeding” has the potential to grant mothers in the Mfuleni community—along with the BFS—a strong sense of health citizenship. Practicing this method of feeding not only fits well within the already established reality of the ailment known as “wind” in order to interrupt the use of bottle-feeding and other “mixed” methods of infant feeding, but “exclusive breastfeeding” also takes into account the practices and beliefs in “traditional medicines” that are still used readily within the community today. Furthermore, by bringing scientific and medical knowledge to a community that had been denied it before, the notion of “responsibilized citizen” is created and perpetuated. Because the transfer of knowledge includes Afrika Tikkun, the BFSS, and the BFSS’s patients, a participatory space is created between them and their roles as “responsibilized citizens” are strengthened further.

What remains one of the most empowering dimensions of health citizenship and the practice of “exclusive breastfeeding” is that new mothers are not only raising healthier children, but the survival rate of these new infants has most likely increased. The World Health Organization has stated that, in general, “compared with the use of breast-milk substitutes, breastfeeding has been consistently shown to reduce infant morbidity and mortality associated with infectious diseases in both resource-rich and resource-poor settings, particularly in the first months of life” (Doherty 2010). Coupled with “exclusive breastfeeding,” the potential rise in infant survival also lies in the use of antiretroviral therapy, or ARTs, which I will discuss in the following section. In a community that has an array of health issues, as demonstrated in previous chapters, it is HIV/AIDS specifically that is still one of the most predominant concerns within many
South African townships. The notions of health citizenship and “responsibilized citizen” are especially salient in this context.

Antiretroviral Therapy

Antiretrovirals, or ARVs, are a collection of drugs used worldwide to treat patients who have been diagnosed with specific viral diseases, including HIV, the herpes virus, as well as certain hepatitis types. Henceforth, I will use the term only in the context of HIV/AIDS. Antiretrovirals are only administered to patients with HIV and are no longer beneficial if a patient has acquired AIDS. ARVs do not cure HIV, but inhibit the further development and progression of the virus. If taken consistently, particularly during the early stages of HIV, ARVs allow patients to control and even decrease their viral load (a term used to measure the manifestation of the virus in the body), which prolongs their overall life expectancy and decreases the risk of transmitting the virus to others, especially in terms of breastfeeding, as I will discuss in detail in this section.

As a result of South Africa’s denialist perspectives, ARVs were not made accessible to South Africa’s most vulnerable, impoverished populations and the HIV/AIDS epidemic skyrocketed. Between 2000 and 2005, HIV/AIDS and AIDS-related illnesses claimed the lives of more than 1.5 million South Africans. According to Avert, an international HIV/AIDS organization, South Africa was put on the map as having “the biggest and most high profile HIV epidemic in the world” (Avert 2015). During this time period, the ARVs that existed carried high price tags and only elite South Africans could access them. Zackie Achmat, the founder of TAC, led several more grassroots initiatives in order to obtain generic, affordable ARVs. He gained the attention of the international community, for example, by refusing to take ARVs himself “until they were freely
available in public health facilities,” and by illegally importing generic ARVs into South
Africa from Thailand (Robins and von Lieres 2004: 579, Robins and von Lieres 2004:
85). Furthermore, he was involved in one of the defining moments of TAC’s history: the
Christopher Moraka Defiance Campaign of July 2000. In short, the campaign began after
the death of Christopher Moraka, an HIV-positive TAC volunteer, who was denied the
drug fluconazole\(^ {21} \). Had the drug been made affordable, it could have eased his pain and
prolonged his life (Robins and von Lieres 2004: 579). Constitutional court cases, such as
the Government of the Republic of South Africa and others v. Grootboom and others in
2001, as referenced in Chapter 2, also contributed to the small victories needed to lead
the way for access to ARVs for all South Africans (Leclerc-Mdlalala 2005: 849).

In September of 2003 the South African government finally agreed to construct a
comprehensive roll-out plan: the “HIV/AIDS Operational Plan,\(^ {22} \) which they presented
to the public in November of 2003 (Leclerc-Mdlalala 2005: 850). Today ARVs are readily
available for community members in Mfuleni. They are not only free of cost, but are kept
in full supply in every clinic and hospital in the area. Community members have ample
opportunities to get tested for HIV as well, and various ARV pick-up points are set up

\(^ {21} \) Fluconazole is a prescription drug that prevents and treats certain fungal infections, and
is commonly used for oral fungal infections such as the infection of the mouth and
esophagus known as thrush. Christopher Moraka suffered from a severe case of thrush
due his body’s lack in immune response as a result of AIDS (Robins and von Lieres
2004: 85).

\(^ {22} \) The HIV/AIDS Operational Plan “estimated that 500,000 people needed treatment
immediately and set a goal of treating 53,000 people with ARVs by March 2005”
(Leclerc-Mdlalala 2005: 850). When Leclerc-Mdlalala published her research in 2005, she
states that in reality, the roll-out program “had been uneven with government having
fallen short of its stated goal. A total of 23,000 people were currently receiving ARVs in
the public sector” (2005: 850).
around the community, including at Afrika Tikkun, which designates certain hours on weekday mornings for anyone in the community who expresses the need for ARVs.

The availability of antiretroviral drugs in South Africa led to several important breakthroughs in the way ARVs were administered to patients in order to lower the HIV prevalence rate, especially in children. According to estimates made by TAC in 2001, “over 130 thousand children will contract HIV from their parents each year, and by 2010, two million South African children will have become orphaned because their parents would have died of AIDS-related illnesses” (Robins and von Lieres 2004: 85). In order to prevent these alarming statistics, the government initiated its Prevention of Mother-to-Child Transmission Program (PMTCT) in each of the nine provinces in June of 2001 (Leclerc-Madlala 2005: 849-50). In many ways, this was viewed by the South African people as “the first step toward a site-sponsored antiretroviral treatment plan…to set civil society on a course of action aimed at forcing government to expand its treatment program” (Leclerc-Madlala 2005: 849). It is the PMTCT Program that is especially influential for the BFSS at Afrika Tikkun and the reason that the BFSS are able to add another dimension of health citizenship for HIV-positive mothers in Mfuleni.

With the establishment of the PMTCT Program, came the introduction of Antiretroviral Therapy, or ART. ART consisted of combining three different ARV drugs that, if taken simultaneously and consistently, could drastically decrease an HIV-positive individual’s viral load. According to Avert, by 2009, “the average life expectancy in South Africa had increased by five years” due to the continued use of ART (Avert 2015). In order to prevent mother-to-child transmission of HIV, ART was primarily marketed toward HIV-positive women who chose to breastfeed their newborn infants. ART
required that mothers take these three\textsuperscript{23} ARVs consistently throughout the duration of their pregnancy as well as once they gave birth. If mothers continued ART while they breastfed as well, the chances of their baby contracting HIV through their breast milk is drastically reduced. Furthermore, the BFSS as well as the nurses in the PHCP mentioned to me that infants themselves were given ART from the time of birth to about six-months of age, and in some cases up to two years of age. ART has since led to an increasing amount of instances of HIV-free infants. Avert and the World Health Organization claim that, “without treatment, the likelihood of HIV passing from mother-to-child is 15-45\%.

However, antiretroviral therapy (ART) and other effective interventions for the prevention of mother-to-child transmission (PMTCT) can reduce this risk to below 5 percent” (Avert 2015; WHO 2014). The BFSS encourage the use of ART with their patients and, as a result, ART has created an incomparable “responsibilized citizenry” of new mothers who are raising a generation of HIV-free children.

The following example emerges from one of my visits to the Dr. Ivan Toms Clinic in Mfuleni with several of the BFSS. The clinic is about a half-mile walk from Afrika Tikkun and is where the BFSS spend the majority of their time speaking to and educating mothers on the benefits of breastfeeding and the role ART plays. As I walked into the clinic on this day, I was accompanied by one BFSS and met by three others who had arrived at the clinic beforehand. Ahead of me stretched a long hallway, lined, on the right side, with a wooden bench, and on the left, several doors leading to examination rooms. On the bench sat about 30 women at every stage of pregnancy; some had just

\textsuperscript{23} During a routine home visit with a few CCWs, separate from the BFSS, they mentioned to me that ART had recently been changed from three separate pills to one pill that contained the three necessary drugs.
received news that they were expecting and others had their six-month old baby tucked snuggly inside blankets and towels that were tied behind their backs in traditional South African fashion. For all of them, it was their first child.

The BFSS quieted the women and Tandie introduced me as a student from America doing research on health in Mfuleni. Immediately their interest was piqued as they all responded to the BFSS with a resounding “Ooh?” A few women declared, in Xhosa, that I could ask them anything and Tandie translated for me. This opened up a discussion within the group as to whom would tell me their story first. Since I had just met these women, I was caught slightly off guard that they immediately wanted to open up to me. The first question that I asked them was how they had benefitted from the support provided by the BFSS. One by one they spoke about their appreciation of the BFSS. One woman explained to me that she feared labor and delivery and that now, in her third trimester, she felt ready and prepared to give birth. Another mentioned that she would not have known how to breastfeed or how to hold her infant correctly. She said that she would have probably given up and bottle-fed her infant had it not been for the BFSS’s help. These examples reflect the health citizenship that was established for them in the same way that “exclusive breastfeeding” had in the examples discussed before. Through the health education talks provided by the BFSS’s on breastfeeding, the mothers now felt a new sense of empowerment due to the acquiring of that knowledge and the new responsibility for the health of their infant. The mothers were confident that they would continue these practices after their infants were born as well.

The most engaging examples in the context of ART, however, were the stories of four women who sat next to each other and who told me that they were HIV-positive and
that they had been suffering the repercussions of the virus ever since their diagnoses, prior to their pregnancies. One of the women took the primary speaker role for the others and explained to me, in Xhosa, that when they were diagnosed with HIV, they were convinced that their lives were over (again, Tandie served as my translator). Furthermore, when they received the news that they were pregnant (the exact stages of their pregnancies was never made known to me), they feared that their children would also contract the virus. Their antenatal nurse at the clinic referred them to Afrika Tikkun to speak to the BFSS at the start of each of their pregnancies. The BFSS, then, visited each of their homes individually and explained to them how ART worked and that the chances of bringing down their viral loads and prolonging their lives was very high. Even more appealing to these mothers was the assurance that a negative status for their newborns would also be very high if they were to adhere to ART throughout their pregnancies and while they breastfed. They each agreed to begin ART and told me that since they had begun ART, they have already started to feel healthier and are more excited about their pregnancies and their healthy babies.

The above example sheds light on the development of a health citizenship for HIV-positive mothers. In a community that still experiences the stigmatization of HIV, an HIV-positive diagnosis for a mother is an already difficult situation to cope with. To add an HIV-positive diagnosis to a newborn infant only escalates the negative reactions that the mother would receive from the community. Introducing ART to these mothers not only provides them with a “new life” in the sense that they regain their right to health, a dimension of their citizenship that they thought they had lost due to their positive diagnosis, but they are able to continue to lead long, healthy lives. Furthermore, they are
granted the ability to pass a health citizenship on to their children with the assurance that their newborn infants will not contract HIV. This results in “responsibilized” mothers who not only adhere to ART, but who spread the knowledge to other community members, continuously empowering new mothers who may be HIV-positive. This leads me to my next example. One of the follow-up questions that I asked the women in the clinic was whether they shared the knowledge they learned with others. I was met with an overwhelming yes, especially from the four HIV-positive mothers who told me that they shared everything they knew with their friends and sisters. Fortunately, I met them again in the following context.

During one of the home-visit rotations through the community, accompanied by Tandie, Ophe, Agie, and Deneo, Tandie told me that instead of visiting each of their patients separately that day, she would get a head start and ask all the mothers to congregate in the home of the first patient so that I would be able to speak to all of them at once. When the other BFSS and I arrived at the designated house, the four women whom I had met at the clinic were there, as well as half a dozen other mothers. Two of these mothers brought their babies with them and one of them immediately gave me her newborn son to hold. She told me that this would probably be the only time in her son’s life that he would be in the presence of an uMlungu, meaning “white person” in Xhosa. During this visit, the BFSS first spoke in Xhosa and then repeated everything in English. They reminded the mothers of ways that the mothers can keep their homes safe for their infants, especially during the winter months when the only heating source was the use of
paraffin heaters\textsuperscript{24}. The BFSS also demonstrated proper infant holding techniques for successful breastfeeding. When the BFSS gave me permission to ask questions, I looked toward the four mothers whom I had met in the clinic, hoping that they would be as open now as they had been previously. I told the group as a whole that they did not need to tell me about their “status,” but that I was interested in any information that they had on ART and how they or family or friends have felt about it. The BFSS translated what I had said into Xhosa, and to my surprise, again, one of the four mothers from our previous encounter told me, in English, that she was excited to breastfeed her baby when it arrived because she knew it would be healthy. The mother whose son I was holding chimed in and told me to “look at this,” and proceeded to breastfeed her son while walking me through each step of the process, as the BFSS had, and then told me “my status is positive and I can breastfeed my baby and his status will be negative…he is healthy.” The mother who spoke beforehand turned toward me and said “that, what sissy\textsuperscript{25} is saying, that is true. That is what I want and what I can have too.” Again, it is made apparent that ART is vital in establishing a sense of health citizenship to mothers in the Mfuleni community. The mothers within this group clearly show their excitement and the empowerment that they feel in the ability to breastfeed safely as well as the fact that their infants are unlikely to contract HIV through their breast milk. Furthermore, they become “responsibilized

\textsuperscript{24} Both the nurses and the BFSS told me that paraffin heaters were dangerous for infants and young children because they could easily burn themselves if left unattended. Furthermore, many people store paraffin fluid in old Coca-Cola bottles and other food containers, which has resulted in the hospitalization and death of small children because they mistake the fluid for soda pop and ingest it.

\textsuperscript{25} “Sissy” is a term of endearment that women call each other within the community.
citizens” by sharing the practice of breastfeeding and the benefits of ART with others in the community, including with me, which perpetuates the notion further.

A BFSS that I met in the Delft branch of Afrika Tikkun, Rochell (a pseudonym), told me the following during an interview. It is very similar to the reactions that I received from the BFSS in Mfuleni; the only difference being that I was able to audio record Rochell’s statement26. Her words add to the way that the BFSS perceive the effect that ART has had on their patients and how it has transformed them, giving them a strong sense of health citizenship.

Rochell: So that work I do in the community, I was so proud because when I got in the home and done my home assessments...I help so many people...now I deal with the families...and clients who were infected of HIV/AIDS and then, lucky enough, because our NGO took us to a training of HIV...we know exactly how to work and how to help people who are suffering with HIV. So now there I was working and really, people they transformed...they transformed their life because once you are there giving them health education and encourage them to take their pills and explain what the pills are doing in their bodies and why they have to take their pills every day of their life and...give their talks about adherence and compliance...I'm seeing...they are transformed.

Robins states, “South Africa now has an ARV program as well as national HIV/AIDS social movement, which offers the prospect of a more optimistic script, in which HIV-positive people are able to access life-enhancing drugs that can return the

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26 I was only able to spend two days in Delft. On one of those days, I met Rochell. I asked her if I could record our conversation since I would only see her that day and she agreed that I should record her now because I would probably not have the opportunity to see or speak to her again. I spent many days with the BFSS in Mfuleni so I only recorded when we were seated together at the Afrika Tikkun offices. Our conversations in the clinic and during home visits were more casual and I did not feel it appropriate to take out my voice recorder in these moments.
patient to health and the possibility of reintegration into the social world” (Robins 2006: 312). The ARV program, which he is describing here, is antiretroviral therapy, ART. As I have illustrated in the above examples, ART has produced a positive transformation within the community of Mfuleni and specifically, with the HIV-positive mothers with whom I was able to meet. These “life-enhancing drugs” not only established a sense of health citizenship for these mothers and a new right to life, but they are empowered to become the “responsibilized citizens” needed to continue the use of ART and to exclusively breastfeed their new infants. This is especially true in the context of South Africa and illustrates why health citizenship is both unique to the country as well as how it has successfully produced a “responsibilized citizenry” for what is likely generations to come.

Despite the positive reactions that are evidenced in the examples above, the following chapter will address some of the challenges that the CCWs face regarding the stigma that is attached to HIV/AIDS in the Mfuleni community. I will discuss the outreach program known as IMCI, Integrated Management of Childhood Illnesses, in comparison to the BFSS and how each has certain similarities and differences in the ways a sense of health citizenship is established for the community members involved in each program.
The Community Care Workers, CCWs, in the PHCP are involved in several outreach programs that provide additional health services and supports described by the Home and Community Based Care (HCBC) model, as referenced in Chapter 3. The Integrated Management of Childhood Illnesses program, or IMCI, is one of these outreach programs and is the one with which I had the most involvement while conducting fieldwork in Mfuleni. IMCI was originally included in the PHCP by the Western Cape Department of Health in order to manage the health records of children, ranging in age from infancy to early adolescence, in each community. It was a program designed to inform the government on prevalent illnesses among children and to aid in developing further prevention and treatment plans meant to keep children healthy in the townships.

Like the BFSS, the IMCI program is another contributor to the notion of health citizenship within Mfuleni. However, it differs from the BFSS (detailed in the previous chapter), in significant ways. The BFSS are a specific team of CCWs who provide specialized services to a very specific population and are involved in the community on a daily basis. IMCI provides many services and works with a large array of community
members during a limited number of days. Both are of great importance to the PHCP at Afrika Tikkun and many employees at the NGO have described both to me as being successful. On the one hand, the BFSS “drop” their specific services and supports into the “pool” of the Mfuleni community causing a ripple effect of health citizenship and “responsibilized citizenry” that spreads throughout the community. The IMCI program, on the other hand, allows insight into how the “ripples” caused by the PHCP’s more specialized services affect the community more broadly and how the notion of health citizenship continues on without the immediate involvement of the PHCP at Afrika Tikkun. I will describe the IMCI program in the context of Mfuleni and provide several examples to show the program’s role in producing a health citizenship in the community. I will illustrate how IMCI measures the health of young children with a tool known as a “Road to Health Card,” and show how this tool encourages the notion of a “responsibilized citizen” in the community. The “Road to Health Card,” however, also presents many challenges to the CCWs as well as to the community members who are required to make use of it. I will speak to these challenges and explore how the role of stigma, in regards to HIV/AIDS, contributes to these challenges.

*Integrated Management of Childhood Illnesses*

The Integrated Management of Childhood Illnesses, IMCI, is a program that operates similarly than the way the usual home visits are conducted by the CCWs in Mfuleni. However, the IMCI program is only implemented on Fridays and instead of visiting only their patients in the community, the CCWs break into groups that correspond to the various neighborhoods of Mfuleni and attempt to visit each person in that neighborhood. Usually, the CCWs choose to join those groups that are visiting the
neighborhood in which they also live. For example, the three CCWs who live in the neighborhood of Burundi in Mfuleni, consistently group themselves together and do their IMCI visits there: CCWs from other neighborhoods group themselves similarly. Therefore, the CCWs are familiar with the area in which they do their IMCI visits and are able to cover much more ground. Furthermore, prior to Friday’s IMCI visits, the nurses collaborate with one another to designate which streets that the CCWs should visit on that particular Friday. The CCWs are required to visit each home located on those streets. IMCI visits, therefore, include many more homes than just the homes of patients or community members affiliated with Afrika Tikkun. Theoretically, throughout the course of a few months, each home in Mfuleni should have been visited by a CCW and should have received the health education talks (as described in Chapter 3) that the CCWs perform during their visits. Many CCWs expressed to me that IMCI was their least favorite task within the PHCP because of the many challenges that it encompasses. Before I discuss these challenges, I will first take a look at the benefits that IMCI provides for the community. The following examples provide another look into how the notion of “responsibilized citizen” is manifested by the CCWs in the Mfuleni community during their IMCI visits.

The first example involves a young girl of about eight years old with severe cerebral palsy. On this IMCI visit, I accompanied two CCWs: Priska and Joselyn (pseudonyms). They are both empathetic, humble women who care a great deal for their patients. They also have children of their own and use many examples from their own trials and tribulations when they recite their health education talks to members of the community. As we approached the house where the young girl lived with her parents and
maternal grandmother, Joselyn whispered to me that I should not feel alarmed when we walked into the home because the young girl, whom the CCWs had visited once before, was not “normal” due to her condition, but was still a very happy child. I reassured them that I knew what cerebral palsy entailed and that I was interested in observing how the condition was perceived in the context of Mfuleni. They told me “okay” and we proceeded to knock on the door and vocalize the usual greeting “xho xho” to alert anyone inside the home that we were present. The CCWs told me, toward the beginning of my fieldwork, that this greeting needed to be spoken each time they approached a house, especially during IMCI visits since the individuals living in most of these homes do not know the CCWs or their affiliation with Afrika Tikkun. If the inhabitant repeated the greeting or if they responded with the greeting “Molo Sissy,” it signaled to the CCWs the permission to enter the house. “Molo” is the word for “Hello” in Xhosa, in its singular form. If more than one CCW entered the home, the plural, “Molweni,” was used. At this particular home, the young girl’s mother replied with “xho xho” and we entered the home. I saw that the young girl was seated on her mother’s lap, smiling. The CCWs reintroduced themselves and explained their connection to Afrika Tikkun. They also introduced me as a student from America who was studying health in Mfuleni. After the mother acknowledged the CCWs and welcomed me to South Africa, Joselyn approached her daughter and began massaging her hands. Joselyn explained to me that she needed to

\[ \text{\footnotesize 27 I perceived “xho xho” to be similar to the American version of the term “knock knock,” which is also used to alert someone of one’s presence at their door, whether that be of their home, office, or otherwise. The “xh” in “xho xho” is actually pronounced as the aspirated alveolar lateral click (IPA symbol: [kʰ]) in Xhosa. The letter combination “xh” is used when writing Xhosa in the Latin alphabet system to represent that click. The letters “c” and “q” are also representative of the plain central alveolar click [k] and the plain postalveolar click [kʰ] respectively.} \]
massage various parts of the girl’s body (her hands, feet, arms, and legs) and slowly bend her joints in order to keep her muscles flexible and “soft.” She told me that if she, and the girl’s parents, failed to do so, her muscles and joints would become stiff due to the inability for the girl to move these parts of her body on her own.

Both Joselyn and Priska spoke to the mother in Xhosa, and translated for me in English every few minutes. They asked the mother whether she was taking her daughter out of bed often, massaging her consistently, and allowing her to mingle with the family in the living spaces inside the home as well as outside. The mother told the CCWs that she had let her daughter sit outside with her as she spoke to her neighbor a few days prior and that her neighbor, as well as several other community members who had passed by her home during that time, were proud of the mother for bringing her daughter outside and allowing her to be seen in the community. She continued to say that now she also felt proud that she took her daughter outside. I took a moment to ask her what exactly made her feel proud, to which she responded (I received the translation from Joselyn) that when her daughter was born and for the first few years of her life, she felt ashamed to have a child with severe cerebral palsy because it was not a condition that was openly seen in the community. She told me that as time progressed and she told her friends that her daughter had this condition, they would tell her that she was a good mother for taking care of her daughter and giving her a good life. Priska added that she had done home visits in the past with children who have cerebral palsy and met parents who do not take care of their children like this mother does. She said that other parents have also felt ashamed and left the child in bed, hidden away, but that she is now also seeing changes in the community. Priska mentioned that she was one of the passersby of this mother’s home on the day that
her daughter was sitting outside with her. She told the mother that she, too, was happy to see the mother sitting in the sun with her daughter and socializing with others in the community.

This IMCI visit is one of many examples that show how the notion of health citizenship and a “responsibilized citizen” is manifested in a context other than those detailed in the previous chapter. Cerebral palsy is a condition that, according to the CCWs, is not common in Mfuleni and is said to have appeared relatively recently. The condition, therefore, serves as a valuable example of an issue that the IMCI program is set-up to evaluate because of its objective in obtaining updated information on the health issues that children face within the community. Due to representation of cerebral palsy as one of these issues, the Western Cape Department of Health can implement treatment options in the community to better serve those families who live with the condition. Furthermore, by acknowledging that this relatively “new” health concern is relevant in the community and that it now carries an explanation for treatment, the IMCI program helps to establish a sense of health citizenship within the community members affected. As the mother describes above, she felt proud after being told by other community members that she was a good mother for allowing her daughter to sit outside, as many community members often do as a form of social interaction. By placing her daughter in this social setting, her daughter’s condition becomes acknowledged and accepted by the

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28 I do not know definite incidence rates of cerebral palsy in Mfuleni. I speculate that cerebral palsy, the condition, may have existed prior to the time suggested by the CCWs and other community members, but that it may have been perceived differently. Through the increased number of medical facilities in the townships and medical professionals moving into the townships to work at a higher rate in recent years, the term “cerebral palsy” to categorize this condition may cause the condition to seem more novel.
community, which in turn, empowers the mother to become a “responsibilized citizen.” She is no longer ashamed of her daughter’s condition and does what she can to continue to provide her daughter with a good life in terms of her health.

As evidenced in the previous chapter, health citizenship is multidirectional. Not only is a sense of health citizenship established for the mother whom I have described here through the notion of “responsibilized citizen,” but her “responsibilized” actions also influence the community. As described by Priska, the perspective on cerebral palsy is changing in comparison to past viewpoints of the condition in the community. These changes include the acknowledgement of cerebral palsy as a relevant health concern as well as shedding light on the available treatments for the condition, which perpetuates the sense of health citizenship for mothers whose children may face this health concern. The IMCI program provides insight into the ways health citizenship and a “responsibilized citizenry” are manifested in the community even if Afrika Tikkun is not as involved in the community as they are in the case of the BFSS, for example. Another example that demonstrates how health citizenship can be seen through the role IMCI plays in Mfuleni lies in the government issued distribution of a “Road to Health Card,” which I will discuss in the following section. These “cards” carry significant benefits to the community and establish a strong sense of health citizenship for many community members. However, I did experience several cases in which the “cards” fell short of the empowerment created through health citizenship and instead, led to many challenges that frustrated and disempowered both community members as well as the CCWs.
The Road to Health Card

The Road to Health Card is, first and foremost, not a card. Community members, CCWs, nurses, and other employees at Afrika Tikkun refer to it as such because, just as the clinic cards that are given to patients after a clinic or hospital visit, Road to Health Cards are given to new mothers to take home with them free of charge (See Appendix B 1.1). The Road to Health Card is in fact a booklet distributed by the Western Cape Department of Health that acts as a medical file tracking a child’s health from the time of birth until the child is about 12 years of age. Every mother in Mfuleni is issued a Road to Health Card, irrespective of delivery method or setting29, at the time of the child’s birth or at the child’s first doctor’s appointment. A blue-green booklet is issued to the mother if her infant is male and a pink booklet is issued to the mother if her infant is female. The first two pages (indicated as pages two and three in the booklet, see Appendix B 1.2) include a chart that identifies the age (pre-recorded), growth since last visit, HIV status, TB status, and infant feeding method. The boxes below each of these categories (with the exclusion of age) are completed by a health professional at each visit to the clinic or day-hospital. The boxes containing the growth, HIV, and TB categories also contain the term “IMCI,” in parentheses, which indicates that CCWs who are conducting IMCI visits may complete these sections during their visits in the community, if they have not been filled in previously. These pages also include a chart that requires a health professional to “tick” or tally if the health records have been completed on subsequent pages for each

29 The nurses at Afrika Tikkun informed me that most births take place in hospital settings.
age that an infant is required to visit a health professional. The last column includes the
date of the next visit to the clinic or day-hospital.

The next two pages (indicated as pages four and five, see appendix B 1.3) include
details of the child and of his or her family: the child’s name, identification number, date
of birth, address of residence, the mother’s and father’s names, whom the child lives
with, the mother’s date of birth, the number of pregnancies that the mother has had, and if
the child is in need of special care. I asked a nurse at the Dr. Ivan Toms Clinic during one
of my visits with the BFSS why only the mother’s date of birth is asked in the Road to
Health Card. She explained that many women in Mfuleni have children with several
different partners throughout their lifetime, most of which do not provide care or support
for those children. She added that even if a woman is married, divorce and multiple
partners, both during and outside of marriage, are very common occurrences in Mfuleni.
She stated, therefore, that the father’s date of birth is not necessary as he is often nowhere
to be found. These pages also include the immunization records of the child, which is one
of the most important pages to the CCWs during IMCI visits. The immunization page is
examined at every home where there are children present and any inconsistencies are
taken very seriously by the CCWs who advocate for mothers to keep up-to-date on their
child’s vaccinations. I will provide an example of the importance of this page in reference
to health citizenship later on.

The following four pages are also crucial in understanding how the Road to
Health Card establishes the notion of a “responsibilized citizen” in the mothers who carry
these cards. I will focus primarily on pages seven and eight (see appendix B 1.4 and 1.5),
however, because the information that is meant to be collected on these pages present the
benefits and the challenges that mothers as well as the CCWs face during IMCI visits.

Page seven is labeled “PMTCT/HIV INFORMATION.” As I have referenced in Chapter 4, PMTCT stands for Prevention of Mother-to-Child Transmission in regards to HIV.

Page seven identifies whether the mother has had her latest HIV test and whether the outcome was positive, negative, or if she has yet to be tested. Furthermore, this page asks when the mother took the HIV test, whether or not she is taking ARVs, and if so, for how long she has been taking these medications. Page eight details the infant’s HIV status. If the infant is HIV-positive, a doctor or a nurse completes this page during the appointment that is scheduled when the infant reaches six-weeks of age. Page eight primarily identifies the various ARVs that the infant may be prescribed and includes the dates and results of future HIV tests.

Before I provide examples of the importance of pages five, seven, and eight (immunizations, HIV status of the mother, and HIV status of the infant, respectfully), I will provide a short outline of the remaining pages in the Road to Health Card for reference. Pages 10 through 13 are merely informational and include pictures along with descriptions of how to breastfeed an infant, how to play and communicate with a child, and how to pre-screen for potential development issues during certain stages of a child’s life. The remaining pages in the Road to Health Card include weight-for-age, length-for-age, and weight-for-length growth charts, hospital admission records, and whether a child has had any oral health examinations.

*IMCI Visits*

In this section, I will provide several comprehensive examples of IMCI visits that not only include aspects of pages five, seven, and eight in the Road to Health Card, but I
will also explore the benefits and the challenges that arise due to the information
presented on these pages in terms of establishing a sense of health citizenship for
community members. I will describe how the CCWs feel about the Road to Health Card
as well as how it causes discrepancies in the work that the CCWs provide community
members during IMCI visits, specifically in regards to HIV/AIDS. The following
examples all take place on the same IMCI day on which I accompanied two CCWs,
Priska and Leti, to a neighborhood known as Extension Five.

Priska, as I described her earlier, is a very caring, humble woman. She found a
great deal of joy in showing me around Mfuleni and in politely answering any questions
that I had during home visits as we walked through the community. She was also very
curious to know about America and would quietly ask me about the school that I attended
when we were out of earshot of other CCWs (I believe that she wanted to keep this
information somewhat confidential due to her interest in furthering her education, but
knowing that she had very little opportunity in the township of Mfuleni to do so). Leti, on
the other hand, was more outgoing than many of the CCWs. She enjoyed gossiping and
laughing with her colleagues, her patients, and other community members with whom she
crossed paths. In her mid-twenties, she was also one of the youngest CCWs employed at
Afrika Tikkun. Due to our similarities in age, we immediately became friends. We spent
a significant amount of time together and she habitually called me “girl” when she spoke
to me, which, I noticed, was a name only those CCWs who were close friends called one
another.

On this particular IMCI day, Priska, Leti and I began with a home that seemed to
be full of people. There was a great deal of commotion coming from inside the house and
there were several men and women gathered outside, listening intently in the direction of the open front door. About a dozen children ranging in ages from three to about eight or nine were running in and out of the home, chasing each other or playing with discarded material found throughout the township: old tire parts, branches and twigs, plastic bottles and containers, and a plethora of other miscellaneous objects. As we approached, we voiced the usual “xho xho” to five women who seemed to be arguing inside the doorway. One of the women motioned us inside while telling the other women something in Xhosa, to which most responded by throwing their arms up in the air and turning away. They all proceeded to walk out of the house and continued down the street. I never found out exactly what had happened between these women. Leti closed the front door and introduced herself, Priska, and me. Priska, then, asked the woman, in Xhosa, if there were any children who resided in the home. Leti stood next to me, whispering her translations into my ear. The woman gave us a nod and so Priska asked if she could check her Road to Health Card. The woman walked away for a moment, toward a room that I assumed to be her bedroom, and returned carrying two blue-green booklets. Priska carefully opened each booklet, first to the page that identified the child’s name and age and then to page five, the immunization record. The date of administration and the doctor’s signature were clearly marked next to each immunization that was required respective of each child’s age. Leti, whispering in my ear again, told me that this woman was up-to-date with each of her child’s immunizations. She mentioned to me, and the woman with whom we were speaking (first in Xhosa and then in English), that she was glad to see that the mother seemed responsible toward her children and that this made her job very easy. The CCWs thanked the mother and proceeded to give their standard health talk, which included
information on child safety in the home, proper storage techniques for the paraffin liquid used in heaters, and an update on the fruits and vegetables that are in season during the winter months in South Africa. This woman listened to Priska attentively and nodded her head in acknowledgement as Priska spoke. During this health talk, a second woman appeared from a different room in the home, breastfeeding her baby. The woman to whom we were originally speaking introduced the woman as her sister. As is custom during IMCI visits, Priska interrupted her health talk to ask this woman whether she lived in the home as well and if she could view her Road to Health Card. She acknowledged that she lived in the house with her sister, but did not have her Road to Health Card. Leti immediately responded by asking her what had happened to her Road to Health Card. The mother looked away and told the CCWs that she had lost it. As Priska finished her health talk, this time directing her dialogue to both women, Leti tapped me on the shoulder and then proceeded to whisper into my ear again, telling me that this second woman was lying to her about her card. I asked her how she knew this and she told me that it was common during IMCI visits that women say they do not have their Road to Health Cards when, in actuality, they do. She told me that some of the pages indicate the HIV “status” of the mother and her baby and by stating that she does not have the booklet, she does not have to show or admit to her HIV “status.” Leti helped Priska finish the health talk by participating in the usual closing suggestions on healthy eating habits and then thanked the women for allowing us into their home. We said our goodbyes and headed toward the next house.

This example provides great insight into the perception of the Road to Health Card in the community, as well as some of the challenges that the CCWs face during
IMCI visits in respect to the card. Moreover, it provides an additional perspective on the notion of a “responsibilized citizenry” by discussing the way that health citizenship is established in a household that has not been directly involved with Afrika Tikkun. As illustrated above, the first woman we spoke to did not hesitate to show us her Road to Health Cards. Priska analyzed the immunization record of each child and the records seemed to be current relative to their ages. Through this IMCI visit, it is apparent that this mother has been influenced by the notion of a “responsibilized citizen” because she shows that she took responsibility for her children’s health by assuring that they receive all the required vaccinations at each age specified in the Road to Health Card. Furthermore, Leti acknowledged this during our visit as well.

The “responsibilization” created by keeping current with a child’s immunization records stems from the history of accessible vaccines within the townships. When I accompanied Lily, one of the nurses in the PHCP, on one of her M & E assessments, I asked her how accessible vaccinations were to community members in the townships. She informed me, first, on the known health benefits of vaccinations and that vaccinations for health issues such as tuberculosis, tetanus, measles, hepatitis, and polio have been available to community members in Mfuleni, as well as other South African townships, for decades. Furthermore, vaccinations come at little or no cost to community members. During this conversation, Lily also described to me that the one vaccine that is especially important is labeled in the Road to Health Card as “RV” (with the corresponding numbers 1 or 2, depending on which dose a child receives). The nurses encourage the CCWs to check for the “RV” immunization first during IMCI visits due to the severity of the virus. “RV” stands for rotavirus and while it is not necessarily fatal,
Lily told me that she has encountered several infants with symptoms of the virus in Mfuleni because they have not received the vaccination. Rotavirus is transmitted through fecal matter and leads to severe diarrhea, dehydration, fever, and in some cases vomiting in infants and young children. Due to the frequent lack of proper sanitation and poor hygiene as a result of the severe poverty present in townships such as Mfuleni, children’s toys and food containers become contaminated with fecal matter. Children, then, ingest the virus by coming into contact with these objects or eating out of these containers. Lily mentioned that RV vaccination was not available in South Africa until 2009 and that many infants died from the virus before its distribution. All of the nurses, therefore, encourage CCWs to make community members especially aware of the importance of this vaccine due to the virus’s devastating history in the context of Mfuleni. The first woman, with whom we spoke in the example above, clearly shows that she has taken the proper precautions for her children’s health as demonstrated by her prompt presentation of her Road to Health Cards. She, therefore, becomes “responsibilized” in her care for her children. Because Priska focused on the immunization page of her Road to Health Card and acknowledged that it was complete, she reaffirms a sense of health citizenship for the mother. Furthermore, Leti’s comment on the ease of her job due to the mother’s actions has a similar affect through the acknowledgement that she is considered “responsibilized” by the CCWs.

The second mother with whom we spoke during the IMCI visit described above does not fall under the definition of a “responsibilized citizen.” She is an example of a

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30 Adults can contract rotavirus as well, but it is most prevalent in infants and young children.
community member who does not feel the sense of empowerment incorporated within the notion of health citizenship. Based on this one visit, she does not seem to be as active a participant in her child’s health in the same regard as others involved with the PHCP at Afrika Tikkun. As Leti described to me, this was not the first occurrence where a mother did not want to provide her Road to Health Card to the CCWs. During a later interview with Leti, I asked her whether she had experienced this refusal due to potential health issues other than HIV or whether mothers did not want to show the booklet to CCWs with the fear that the CCWs would notice that they were not current with their child’s immunizations. Leti told me that mothers who have inconsistencies or missing information in their Road to Health Cards with regards to their child’s immunization record or growth charts still show their booklet to the CCWs. Leti informed me that in these cases, the CCWs make these mothers aware of the inconsistency and encourage them to make a doctor’s appointment or visit the clinic in order to take care of the concern. She told me that patients do comply in most cases, which has led her to assume that when they “do not have their Road to Health Card,” then they are specifically hiding the fact that they are HIV-positive. With the stigma that HIV carries in the Mfuleni community, especially regarding the “status” of an infant, it is easy to infer the same assumption that Leti describes. Pages seven and eight in the Road to Health Cards provide information on the “status” of the mother and her child and may be a likely cause of a mother’s refusal to present the booklet to the CWWs. Furthermore, in the example above, due to the mother’s reluctant demeanor after Leti asked her what had happened to her Road to Health Card and due to the assumption that her infant was under six months
of age since she was breastfeeding, I would argue that the mother does not represent the health citizenship that her sister and other Mfuleni mothers have embodied.

I argue that there exists an added dimension of disempowerment for mothers such as this due to the reputation that the CCWs carry in the community, especially in the context of HIV/AIDS. The CCWs are well respected, as I have mentioned before, and many community members know of Afrika Tikkun and the services that the NGO offers because they see the uniformed CCWs walking through the community and providing health support for their patients on a daily basis. While I conducted the usual home visits with the CCWs, for example, some community members would approach the CCWs and ask them for whom they worked, what kind of work that they did, and whether the NGO was hiring. Others would tell the CCWs that they had heard of the work that they did and would describe an instance in which a relative or a friend had been helped or had regained health because of the NGO’s involvement. Still other community members would listen in on health talks given by the CCWs from outside of a home that the CCWs were visiting and approach them as they were leaving in order to ask a health-related question or if the CCWs could visit their home as well. Therefore, the CCWs are viewed as carers for the community and the chances are relatively high that individuals living in a visited household have heard of Afrika Tikkun or the work that the CCWs do. Furthermore, through specialized groups of CCWs, such as the BFSS, and specialized services in the PHCP, such as HIV testing and ARV distributions, the NGO is intrinsically affiliated with HIV/AIDS, which remains one of its most important and prominent focuses. These qualities follow the CCWs throughout the community and have an effect on community members in a fashion other than the more positive examples I
have provided thus far. I argue that this is the case with the mother who did not want to show her Road to Health Card. This mother, as well as others who may have similar hesitations, could feel disempowered if she tells a CCW that she is HIV-positive or that her infant is also HIV-positive, first of all, because of the stigma that is associated with the illness. Second, because the CCWs are such popular providers of support in the community, these mothers may feel disempowered by the fact that the CCWs are speaking to many other community members who may find out their “status.” Finally, because the CCWs partake in an immense amount of work in relation to HIV, it could act as a deterrent to some community members who fear that the CCWs will “disclose” them. I will expand on these latter two arguments in the following section.

The setting in which HIV is spoken about also changes the dynamics of how the CCWs establish a sense of health citizenship for the community. For example, in comparison to the four women whom I met at the Dr. Ivan Toms Clinic with the BFSS, and who had no hesitation in telling me their HIV “status” outright, I propose that because IMCI visits do not encompass the same intimacy and trust between the CCWs and their patients as the BFSS do, it is much more difficult to establish a “responsibilized citizenry” with these community members. Even though the CCWs are doing their part to provide health education to their community members, which has shown to establish a sense of health citizenship with new mothers who are taught “exclusive breastfeeding,” there are several other processes acting on community members during IMCI visits. The positions and reputations of the CCWs as well as the differences in the extent of their involvement in the community, cause discrepancies in the ability to build a health
citizenship and to empower community members to become “responsibilized” through IMCI.

Priska, Leti, and I experienced similar ups and downs throughout the remainder of the IMCI day detailed above. We attempted to visit between 12 and 15 homes that day, but concluded early because Priska and Leti felt frustrated and lost the motivation to continue their work due to the obstacles that we encountered (I will touch on these again later). Several of these homes did not present us with any challenges, however. These families allowed us into their homes, some prepared tea for us, and those families who had children willingly showed their Road to Health Cards to the CCWs. In these instances, most were up-to-date with their child’s or children’s immunization records, and if they were not, the CCWs advised them on the steps to assure that they completed their records. The CCWs also checked the first few pages of the Road to Health Cards, which included the charts indicating “IMCI” and completed these sections when necessary. In the next example, however, I will focus on the instances that presented challenges to the CCWs in order to illustrate how the notion of health citizenship cannot always be provided to an individual or a family through IMCI. Furthermore, as I have stated before, health citizenship and the empowerment that people demonstrate through the participatory space that is created between members of the community and Afrika Tikkun, are multidirectional. Community members, their families, and the employees in the PCHP at Afrika Tikkun are all affected.

Challenges Affecting Health Citizenship

Although I have primarily spoken of the positive aspects of health citizenship, the opposite is also salient. The following examples illustrate the multidirectionality that I
have mentioned in regards to establishing a sense of health citizenship in the community. All community members and CCWs are affected by feelings of disempowerment as a result of the challenges that the CCWs face while conducting IMCI visits. I will discuss the role that stigma plays in limiting the CCWs’ ability to complete their health talks as well as why the fear of “disclosure” produces misconceptions of the CCWs with respect to their professional relation with HIV/AIDS.

After Priska, Leti, and I had completed a few successful IMCI visits, we ran into the following issue. A mother living with several children (I am unsure of the exact number) stood outside her door conversing with another woman while her children played outside. When she caught sight of Priska, Leti, and I approaching, the two women immediately rushed inside the house with the children and shut the door. I looked over at Priska and Leti and noticed that they, too, had witnessed this. Priska walked up to the closed door and knocked anyway, greeting the women with the usual “xho xho.” There was no answer. When Priska rejoined Leti and me, I asked them, dumbfounded, if they had any ideas to explain what had just happened. As Leti encouraged us to continue walking, she explained that this was not the first time that she had seen someone react this way. Priska told me that this was one of the challenges that they faced as CCWs and that some community members think that the only work that Afrika Tikkun does is in regards to diagnosing and treating HIV/AIDS. When people who think this way see the CCWs walking through the community, they expect that the CCWs are only visiting people who are HIV-positive or are diagnosing community members as HIV-positive. The word “disclosing” was also commonly used by CCWs to describe this, which implies that a positive diagnosis meant that the CCWs would “disclose” this personal information
to others in the community. The CCWs, however, neither diagnosed their patients nor disclosed any information to anyone other than the nurses at Afrika Tikkun. Priska described the sadness and disappointment which she felt toward some community members who think this way, because she works hard to provide vital services to her community. She told me that she is usually proud to wear her Afrika Tikkun uniform in the community because “it makes me feel like good and wow,” but in cases like this, she does not feel this way. Leti then expressed to me that she feels unappreciated when she is unable to give her health talks. The next home that we visited on that day presented more of the same. The CCWs and I heard voices coming from inside the house, but we did not receive an answer when we knocked at the door.

The misconception that the CCWs only work with HIV-positive individuals was one of the most frustrating challenges that the CCWs faced. During my interviews with other CCWs, both in Mfuleni and in Delft, they expressed the disempowerment that they felt because community members would not open their doors to them and allow them to do their health talks due to this misconception. When I sat down to interview two CCWs in Delft, Rochell and Honest (pseudonyms), they expressed to me the extent of the challenge, from outright denial to being lied to by patients in regards to their home addresses. The following is an excerpt of that interview.

Rochell: The biggest challenges here in the community, people…they are still in denial and now that makes very

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31. The only health professionals certified to test and diagnose a patient with HIV/AIDS, or any other ailment, are the nurses at Afrika Tikkun and the doctors and nurses working at the clinics and hospitals.

32. The expression “good and wow” was also used by other CCWs. I believe that the two words used together are meant to express the excitement and empowerment that CCWs feel when wearing the Afrika Tikkun uniform.
difficult for us to reach them because...they don't accept their status, they don't want anyone to come nearby because they refuse us to go in their home as they are saying we are going to disclose them. So that, that is the biggest challenge and if now they accepted that yes they are positive...well now they just give the wrong address so that when we are going out there to do the home assessment, now it can be difficult for us to reach them because when you are there to that address, they say ‘We are never know about that client, that person is never staying here.’ So is the other thing...there is still a stigma of them, that now they are saying that if we come to their houses wearing the uniform, they don't want us to wear the uniform because of...they are afraid of their neighbors, you see...but the thing is one who refuse the CCWs...they don't want us to pay visit because they are in denial. And those people, they are in need of us because to help them, you see, to accept that they are HIV positive, and also to give them HIV education, but they refuse the CCWs...at the moment, it's our biggest challenge and now we are sitting with few clients because of that...but so many of them are infected with the virus and need help.

LW: What do you think would help...even for the neighbors so they think you are not there for HIV, but that you might just be checking for the kids? For immunizations or, you know, other...

Honest: The thing is to help the community understand HIV...to be more informed, like, to know that HIV doesn't jump...and most of them they say, even if it's not us, they'll always say ‘Oh that one is on ARVs, she's HIV positive.’ We are not going only for those people, we are also going for TB clients. Sometimes we are wearing our uniform for the purpose that we can be seen that way we can go out...and it's not only for us doing IMCI, it's our home-based...that they always say ‘They went there to that one which means that one is HIV positive.’ I think they need more education.

Rochell and Honest make the challenges that the CCWs face very clear in regards to completing their IMCI visits. The primary issue remains tied to the stigma that HIV carries in the Mfuleni community. HIV-positive community members who are taking
ARVs and who openly speak about their diagnosis and treatments do exist in the community, as I demonstrated in Chapter 4. However, as Rochell states, there are many community members who are in denial of their “status,” who may not have the knowledge or support needed to attain help, or who attempt to escape from the issue by providing a false address to the CCWs.

Furthermore, Rochell describes the added social dimension that community members fear that their neighbors might think that they are HIV-positive if the CCWs stop to visit their homes. She states that, “they refuse us to go in their home as they are saying we are going to disclose them.” The misconception that the CCWs will “disclose” someone’s HIV “status” is closely tied to the stigma of the disease. Although many programs are set up to educate the community on what the disease entails, as Rochell also states, it is the lack of education that still exists within the community that perpetuates this misconception. As I stated earlier, it is not the duty of a CCW to provide diagnoses of any illness to members of the community. The only way that they would know of someone’s “status” during an IMCI visit would be through their Road to Health Card(s). If a CCW found that the community member whom they were visiting was HIV-positive, the Road to Health Card(s) would also indicate whether they were taking ARVs or were on ART. Leti told me during a regular home visit that in the case in which a community member was HIV-positive, but not taking any medication, the CCWs would refer that patient to the nurses at Afrika Tikkun for M & E. I never experienced this latter situation during my time at Afrika Tikkun and therefore, I am unsure of the processes and reactions that would follow the referral to the nurses.
As I have illustrated throughout the many examples from my fieldwork, most of my experiences in Mfuleni involved a collectivity of people. Community members often visit and spend time in each other’s homes, their children come and go from one house to the next, and other than a few very specific cases, I did not observe anyone who was sitting in their home, completely alone. In a small community such as Mfuleni, it comes as no surprise then, that the chance of people knowing each other is high and the prospect of others finding out about one’s HIV “status” can be socially devastating. During an interview with Deneo, one of the BFSS with whom I worked, she admitted that she, too, believed the misconception by stating that if she were to become affiliated with the CCWs, they would “disclose” her HIV “status.” For example, after asking her how she became involved with Afrika Tikkun, she told me the following.

Deneo: First, I was not interested in this home-based--

LW: You were not interested?

Deneo: I was not interested, really...because I thought it was for the people who were HIV positive. Then in my mind I said, 'If I go and ask for a job there, people think I am HIV positive.' But as the times goes on, I see no, it is not for those people. It's for everyone in the community. Then I'm getting more interested.

The fact that Deneo provided her own perspective on the misconception illustrates how salient it is within the community and how much the stigma of HIV/AIDS affects those who have not received the education and the support that the PHCP at Afrika Tikkun provides.

Due to the intimacy and trust that is established between the BFSS and their patients through their abundance of health support and frequent health education talks, I
propose that the BFSS are able to change their patients’ perspectives of HIV/AIDS relatively easily. On the other hand, while the IMCI program’s intention is to provide support and health education to the entirety of the Mfuleni community, it is much more difficult to establish a sense of health citizenship and a “responsibilized citizenry” through IMCI because the same kind of involvement with community members is absent. Through the introduction and use of the Road to Health Card, citizens may feel “responsibilized” in certain dimensions of their children’s health, such as with the immunization records. However, due to the inclusion of HIV “status” for both the mother and her infant, the Road to Health Cards tend to fall short of establishing a sense of health citizenship to community members.

As both Honest and I have described, IMCI visits encompass many challenges due to the position and reputation that the CCWs carry in the community. The ways that community members react when they see the CCWs’ uniforms, for example, can be encouraging and empowering in some health-related contexts and distressing in others. As evidenced, most of the CCWs felt a sense of pride in wearing their uniforms. It established a sense of authority and professionalism that gave the CCWs the “responsibilization” and entitlement to do their health talks in the community. In those cases in which their uniforms became a symbol associated with the stigma of HIV/AIDS, they did not feel the same sense of belonging to a “responsibilized citizenry,” even choosing to end their IMCI visits early due to their lack in motivation. Additionally, the sheer amount of health education that the CCWs provided in the context of the BFSS, as opposed to IMCI, creates discrepancies in the way that health citizenship is established for community members. The amount of involvement that the BFSS have with their
patients strengthens both the establishment and the perpetuation of a health citizenship. Yet, through IMCI, the CCWs meet new community members each week who may be hearing the health education talks for the first time and may be asked to see their Road to Health Card from someone who they fear may “disclose” their HIV “status” to other community members.

It is the intention of IMCI to monitor the health issues that children in the community face and while the program carries many benefits, it is not without its challenges. The use of the Road to Health Card, as a tool to help measure the progress of children’s health through several stages of their lives, also produces many challenges as a consequence of its contents for both CCWs and community members in Mfuleni. While IMCI does provide a health education for some community members on specific topics, it also interferes with the CCWs’ ability to establish a sense of health citizenship to the Mfuleni community in the context of HIV/AIDS.
CHAPTER 6

CONCLUSION:
REFLECTIONS AND FUTURE DIRECTIONS

“…every view is a view from somewhere and every act of speaking a speaking from somewhere.”

The goal of this research has been to demonstrate how definitions of citizenship are constructed and implemented based on culturally specific processes. In the context of South Africa, health became the motivating factor for an empowered citizenry because it focused more on the biological processes of the individual and less on the political dimensions of poverty and racial segregation. By directing the South African government’s attention toward health during the transformation of the “new democracy,” citizens were able to create a form of citizenship that was easily attainable and could act as a negotiator between themselves and the higher political structure of the “new” South African government. Health citizenship did not place the same strain on the government that other political issues may have and, therefore, appealed toward the country’s transformative climate. The notion of health citizenship remains unique to South Africa primarily due to the country’s distinct political transformation and the effects it has had on its citizens’ identities. As Robins and von Leires argued, health citizenship allowed for
citizens to “unmake” their previous identity as marginalized individuals bound by the legal enforcement of exclusion and “remake” their identities as active, participatory citizens in the “new” South Africa (Robins and von Lieres 2004).

South Africa continues to embrace a climate of change, which supports the activist groups and social movements that have established themselves since the beginning of the “new democracy” in 1994. Afrika Tikkun remains one of these important groups. By observing the Primary Health Care Program and the various outreach projects it encompassed, I was able to gain a deeper understanding of the ways that a sense of health citizenship has been established in the Mfuleni community. This research highlights the ways in which definitions of citizenship in local contexts interact with, accommodate, and are perpetuated by citizens themselves and how citizenship can lead to a sense of empowerment that transpires into larger, political dimensions.

Beginning in Chapter 3, I provided details on the various groups of employees who work within the Primary Health Care Program (PHCP) and how they work together in order to provide the best support for the Mfuleni community. The PHCP also shares the most current data with the Western Cape Department of Health in order to assure the continuation of funding for the PHCP at Afrika Tikkun. This chapter demonstrates the ways in which the nurses categorize each of the patients affiliated with the PHCP in order to adequately serve them as well as the ways in which the CCWs practice the comprehensive HCBC model by conducting daily home visits within the community.

Chapter 4 explores the ways in which the Breast Feeding Support Specialists (BFSS), a specific group of CCWs trained in antenatal health care, establish a sense of health citizenship to new and existing mothers in the community. By providing health
education for breastfeeding mothers and encouraging the use of antiretroviral therapy (ART) for HIV-positive mothers, both the BFSS and the mothers whom they provide these services become “responsibilized” in their own health as well as their children’s health.

In Chapter 5, I examined how the Integrated Management of Childhood Illnesses (IMCI) program, while providing certain benefits, presents many challenges for the CCWs participating in the program. This chapter illustrates how the greater issue of stigma, in regards to HIV/AIDS, makes health citizenship inaccessible for some community members. Additionally, the CCWs become discouraged and disempowered due to the limitations that they encounter in their ability to provide their supports and services to these members.

This research remains important within cultural anthropology as well as in academia more broadly because it provides an answer to the question: “What does it mean to be a citizen?” in one particular context. This research shows that there are a variety of cultural processes at play in defining citizenship and that the empowerment, the sense of belonging, and the participation involved within the definition of citizenship are also culturally constructed. Within the context of South Africa, marginalized populations are able to achieve a sense of citizenship and become the active participants that they have fought to become through negotiations of health. Health, therefore, has become a “new site of participation…that poor people fashion themselves…in which they gain a sense of political and moral legitimacy of their concerns, and of their own power and capabilities” (Robins and von Lieres 2004: 585). Furthermore, in the context of activism, transformation, and change, this research is useful in establishing the ways in which
communities are empowered to achieve the changes that they wish to see in their communities and in the world. Local processes, such as these, can also influence global processes by providing human rights organizations such as UNAIDS and the World Health Organization with the knowledge needed to implement appropriate policy changes for the diversity of cultures that exist in the world.

Ethnographic research is celebrated for its ability to generate rich and meaningful representations of humanity through its holistic approach. However, one of the pitfalls that qualitative research must continuously consider are those stories, voices, and details that may be left out. Often this knowledge is inaccessible due to the nature of being positioned as a researcher, an “other” in many respects. In the following section, I will explore the notion of positionality and reflexivity and examine how my role as researcher may have had an effect on my own research.

Positionality and the Reflexive Approach

Anthropologists have written on the subject of positionality in a variety of contexts and have illustrated how much the researcher’s position truly does influence an ethnographer’s objectivity. In the introductory chapter of her book A Thrice-Told Tale (1992), Margery Wolf explains that “some…critics question the very possibility of ethnographers representing the experience of another culture, and others question the ethics of even attempting to do so, seeing the process itself as an exercise…in domination” (Wolf 1992: 5). Although the field has adapted its methodologies to reflect an ethos of humanity and ethics, it is left with ongoing questions and critiques of how to do anthropological work and conduct ethnographic research without contributing to the “dominating” effect that has been so fiercely contested in the field. By calling into
question the researcher’s own position within ethnographic fieldwork, anthropologists are able to confront these issues and regain objectivity.

Positionality and reflexivity are used to reflect on the information and experiences that researchers have gathered from their fieldwork and are used to situate themselves as active participants within their own data. Wolf states that it is precisely the questioning of ethnographic research that is of utmost importance, “the answers less so” (Wolf 1992: 5). By questioning the researcher’s position, a plethora of immutable forces are brought to the forefront of the researcher’s awareness, which provide considerable meaning in the interactions between the researcher, his or her collaborators, and the data that is collected during fieldwork.

When I began my research in South Africa, I knew that it might be impossible to gain access to certain situations or types of knowledge due to my position as a researcher, my gender, my ethnicity, and possibly even my age. Therefore, by including a reflexive approach and analyzing my own position while I conducted my fieldwork, as many anthropologists have done before me, it will contribute to a greater understanding as to why certain information has been “left out.”

First and foremost, the most obvious omission within this research is the role of the male figure. Where are the men? As mentioned in Chapter 3, most of the CCWs with whom I worked were women, most of the administrative personnel in the PHCP were women, and most of the patients with whom we visited were also women. During my time at Afrika Tikkun, it was apparent that the role of carer was gendered toward women and several CCWs made it clear to me that they applied for the job because it fit into their community’s already established gender roles. They told me that very few men apply for
the job of a CCW because “that is just not what they do.” Men, at Afrika Tikkun, were usually found in authoritative positions, such as a manager or chief executive, or as teachers who worked in the Child and Youth Development Program (CYDP) or in the Job Readiness Program. Furthermore, due to the invasive and intimate nature of many of the health issues evident in the Mfuleni community, women patients were more comfortable speaking to women CCWs about those issues. On the few occasions in which I accompanied the CCWs to visit their male patients, these men reacted in one of two ways. Either the men would leave the home completely or refuse to speak to us, or the men would sit quietly with minimal communication about their health concerns. I met one male CCW in the Delft branch and I asked him why such a discrepancy existed between men and women working for Afrika Tikkun as well as in the ratio of patients of the CCWs. He told me that, in the first place, it is uncommon in South Africa for men to tell women of their health concerns and that secondly, the added fact of speaking to a female trained in health education does not correlate to the roles that many South Africans are familiar with. He told me that many male patients also do not take the female CCWs seriously when they give their health talks, especially in the case of condom usage. He added that he feels that more men should apply to the position of a CCW in order to meet the needs of more men in the community. Due to these discrepancies, very few male patients are involved in the PHCP and are therefore severely deficient in the health education that many women in the communities of both Delft and Mfuleni receive.

As a woman, I also struggled to speak to men in the community. Freez, a male Family Support Services employee whom I mentioned in Chapter 1, established a men’s
support group called “Men Making A Difference,” which met once a week in the boardroom at Afrika Tikkun in Mfuleni to discuss health-related issues with other men. I asked him twice if I could observe one of these meetings. The first time I asked, he agreed and told me that he would need to obtain the consent of the men in the group before I could enter the room. On the day of the meeting, he spoke to the men about my requests as I waited patiently outside of the boardroom for an answer. When he opened the door a few minutes later, however, he told me that I would not be able to do any observations that day. When I asked Freez a second time if I could join his meeting, he told me somewhat indirectly that the men in his support group did not want me there. The men who worked at Afrika Tikkun, however, were very accommodating and I spent many afternoons in their company. I helped Aija (a pseudonym), the CYDP Computer Center Facilitator, teach his computer classes to high-school aged children in the community, Aija and Kaydo (who preferred that I use his given name) visited me in my office during some of their breaks, and I was able to speak to the general manager of Afrika Tikkun on several occasions. I was especially grateful to speak to the men working in the CYDP because they provided me with the male perspective on a variety of topics that I would not have been able to access through home visits in the community due to my position as a female researcher.

My age did not play a major role in the restriction of access to certain types of knowledge. My ethnicity as an ‘uMlungu in a township’ did, but not in the ways that I

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33 “uMlungu in a Township” is a phrase borrowed from Steven Otter’s book Khayelitsha: uMlungu in a Township (2008). uMlungu, means “white person” in Xhosa. Although, the term is usually used through the perspective of an individual who is not white, Otter
would have expected. First, many community members whom I met during my
fieldwork, told me that they do not usually encounter white individuals in the townships,
but when they do, it immediately draws on the attention of the community. Honest, the
CCW from Delft, seemed to be especially concerned about this fact. The following
excerpt, taken from my interview with her, expresses her expectation that my ethnicity
would draw negative attention from community members.

Honest: When I saw you...part of me was like shock...you
are not a colored, firstly, now I said maybe she's coming
with something, money, or come to give something to this
organization or...I was also worried a little bit that we were
going in to the community. I was not comforted because
you are not...people are going to say...maybe people will
try to take chances, but when I go to the community this
morning with you, I was feel proud because people say ‘Oh
that black one, she is working with that uMlungu...now she
is more like, now you make me to be, like, proud or up.
Because they never saw people like you in the community,
like working, only driving. ‘Okay, she's working with this
one now...now if I can be like her, maybe I can also work
with you.’ So makes me to be proud also. Even the carers, I
saw, they are smiling this morning. Even those who we
were working with, they say ‘Oh we are so special because
we are going with this lady and she was not funny with us.’
And I said ‘Okay, but we were also speaking some Xhosa.’

Although Honest’s perception may seem as though my ethnic identity may be cause for
concern that some community members may “take chances” with me while attending
home visits, a deeper meaning can be drawn from her statement. “White” is not only a
racial classification, but a class distinction as well. “Whiteness,” a term used by Catherine
Besteman, a fellow anthropologist studying South Africa (2008), is associated with the
“Western” world more broadly. Along with Honest’s concern, she also mentions that “I

incorporates the term into his own identity through his experience as a white male living
among individuals of the primarily black township of Khayelitsha.
was feel proud because people say ‘Oh that black one, she is working with that uMlungu...now she is more like, now you make me to be, like, proud or up.” Besteman argues that this conception of “whiteness,” in South Africa, is attributed to modernity. She writes that the “young black people aspiring to consume material goods and media images formerly available to white people are not trying to be white; they are trying to be modern, global, ‘new South Africans’” (Besteman 2008: 167). Besteman includes that it is this desire for the modern that shifts “whiteness” from being a racial identity to one of class (2008: 167).

Furthermore, my position as an ethnographer compared to other visitors who have been involved with Afrika Tikkun, granted me a different kind of access than I had expected. For example, during a conversation with Tandie, one of BFSS, she told me the following about her experiences with other visitors who have come to the NGO to give a monetary donation or wanted to receive a tour Mfuleni.

Tandie: You know what, Lynn? Sometimes they like to do the M & E when they visit...where they must come out with us to visit like the way we go with you. They want to go to assess what we usually do. The one time they was there, it was too much for them. That donor who it was. You see the houses...most of the time we are exposed to dangers like, you see this person have TB, we don't have mask, we are at risk. If you go with them, ten minutes, they even can't take ten...after ten minutes they want to come back because the smelling is...they can't even take it. For me, that says a lot. They can't take it. They earn more salary than me, but they cannot even take five minutes because of the smelling. Other house, there are five children on diarrhea, you see, the house is mess up, the health...the environment is not good, because of the hygiene and then you see the house is messed. We are exposed to those situations and we don't care. We just sit and do our job.
Afterward, she told me that she thought of me as a different uMlungu than others because I did not express the same aversion to her community and I was not afraid to accompany the CCWs on home visits. Additionally, many other CCWs asked me if I was afraid to attend home visits in the community, but the longer I stayed and the more home visits that I attended, the more I was told by the CCWs that they thought of me as fearless. Once I was given this characteristic, those CCWs who were hesitant to speak to me toward the beginning of my research came to talk to me about their day during our lunch break or would stretch out their hands during the morning meeting to announce that they had a story to tell me. As Besteman writes in her book *Transforming Cape Town* (2008), “anthropologists narrate the stories of others, translate experience, acknowledge unrecognized or marginalized truths, and provide witness to people’s struggles, hardships, and joys” (Besteman 2008: 149). Therefore, I do not think it was my fearlessness that allowed me this access, but my position as an ethnographer to show those whom I worked with that I cared about their lives, their thoughts, and their stories.

The beauty of ethnography, or the “writing of culture,” is that it is essentially an interpretation: a story of sorts. As Clifford Geertz describes, “They are…fictions; fictions, in the sense that they are ‘something made,’ ‘something fashioned’ – the original meaning of fictiō – not that they are false, unfactual, or merely ‘as if’ thought experiments” (Geertz 1973: 15). Anthropologists are master storytellers, but as is the nature of a story, anthropologists must consider which elements may change or may be left out. I have addressed a few of these instances in the examples above, through a reflexive approach in my anthropological research. Moreover, by situating myself within my research, I am able to analyze the meaning that my position holds in respect to my
collaborators and the community in which I worked. By discussing positionality and reflexivity, the observer is transformed into the observed on an ethnographic stage. Reflexivity gives the researcher a deeper understanding of the complexities at work in anthropology and in ethnographic writing. Reflexivity does not transcend other theoretical perspectives or ways of doing anthropology. It is an addition to anthropology, woven through ethnography, that situates the researcher on the cultural stage on which they are studying while simultaneously affording the researcher with the ability to analyze their “situatedness” on this complex stage.

Future Directions

As I have alluded to throughout this thesis, Afrika Tikkun represents an abundance of programs that promote child and youth development and primary health care in the communities in which they serve. Although I chose to focus on the Primary Health Care Program (PHCP) in Mfuleni, conducting future research within the many other programs as well as within other branches of the NGO across South Africa, would offer valuable perspectives on their affects in each of the contexts in which they exist. In the PHCP in Mfuleni, specifically, I experienced several important dimensions of the program that I would like to examine further. One of these is the role that condoms play in encouraging sexual health in the community. I attended a training session led by a visiting instructor on sexual health, sexually transmitted infections (STIs), and condom usage, which was not only interesting in and of itself, but even more so due to the reactions that the CCWs expressed on the subject. Furthermore, I spoke to the men working in the Child and Youth Development Program (CYDP) about this specific training and they provided me interesting insights into their own perspectives on the
condom culture of Mfuleni. I did not gain adequate knowledge on the subject to speak to it in this thesis, and therefore, might wish to explore the topic further. The research in my thesis can also be used to explore larger, global processes that are at play in regards to health care, activism, and policy change. For example, this research is very helpful in providing a glimpse into how local communities have reacted or have been influenced by the South African health policies that are already in place. Future research could consider the challenges that the CCWs have faced within the PHCP and provide new ideas on how to spread the health education that the CCWs are so fond of sharing.

Anthropology’s strength lies in the potential that our ethnographies have not only to provide an abundance of cultural information to our audiences, but to reflect on the complexities that are central to our existence as human beings. I hope that this thesis has accomplished these larger notions by contributing rich, “on the ground” examples of the lived lives and experiences of the community that I studied. I hope that this research is used to present a deeper understanding of the local community of Mfuleni, to provide meaning to the definitions of health in South Africa, and to broaden the scope of human rights activism on a global stage.
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Farmer, Paul

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Foucault, Michel.

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Holston, James.

Isandla Institute

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Memmi, Albert.

Messer, Ellen.
Moola, Sarifa.  

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Navarro, Vicente. 

O’Malley, Pat. 

Ong, Aihwa. 

Otter, Steven. 

Petryna, Adriana. 

Petryna, Adriana. 

Robins, Steven 

Robins, Steven, and Bettina von Lieres. 
Robins, Steven, and Bettina von Lieres.  

Robins, Steven.  

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Wilson, Richard A.  

Wittman, Hannah.  

Wolf, Margery.  

# APPENDIX

A. 1.1 Afrika Tikkun Home Based Care Assessment Form (Front)

![AFRIKA TIKKUN LOGO]

**HOME BASED CARE ASSESSMENT FORM**

<table>
<thead>
<tr>
<th>NAME:</th>
<th>DIAGNOSIS:</th>
<th>CATEGORY</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADDRESS:</td>
<td>DATE OF BIRTH:</td>
<td>NEXT OF KIN</td>
</tr>
<tr>
<td>TELEPHONE:</td>
<td>LD. NUMBER:</td>
<td></td>
</tr>
<tr>
<td>REFERRED FROM:</td>
<td>ASSESSED BY:</td>
<td>REASSESSMENT DUE:</td>
</tr>
</tbody>
</table>

**REASON FOR REFERRAL**

<table>
<thead>
<tr>
<th>BP</th>
<th>HGT</th>
<th>HB</th>
<th>TEMP</th>
<th>PULSE / RESP</th>
</tr>
</thead>
</table>

**TOTAL SCORE** | **CATEGORY** | **CATEGORY DESCRIPTION & HBC SERVICE**
---|---|---
14 | 1 | Independent; educate family, refer to support groups
15 - 28 | 2 | Requires minimum assistance; moderate HBC
29 - 42 | 3 | Requires maximum assistance; intense HBC

**SCORE** | 1 | 2 | 3
---|---|---|---
MOBILITY | WASHING | COMPREHENSION
COMMUNICATION | SHAVING | COPING MECHANISM
TOILETING | EATING AND DRINKING | BEHAVIOUR
MOUTH CARE | MEDICATION
HAIRCARE | ORIENTATION
DRESSING | MEMORY

**ALLOCATED TO CCW:**

[Type text]
Home based care plan

Medications

REFER TO:
SOCIAL WORKER
FOOD KITCHEN
PHYSIO
OCCUPATIONAL
SOCIAL GRANT

CONSENT OF FAMILY: ____________________________
DATE: ____________________________ PRINT ____________________________ SIGNATURE ____________________________

[Type text]
B. 1.1 The Road to Health Card for female patient (Front Cover)

IMPORTANT: Always bring this booklet when you visit any health clinic, doctor or hospital.

ROAD
TO
HEALTH
GIRLS

Child's first name and surname:

Date of Birth:

This booklet must be issued at birth by the health services concerned. If birth takes place at home, the first opportunity after delivery should be used to issue the booklet. The booklet must be issued FREE OF CHARGE, irrespective of delivery, taking place at a public or private health facility.
B. 1.2 The Road to Health Card, pages two and three.
### IMMUNISATIONS

<table>
<thead>
<tr>
<th>Age group</th>
<th>Batch no.</th>
<th>Vaccine</th>
<th>Site</th>
<th>Date given dd/mm/yy</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth</td>
<td></td>
<td>BCG</td>
<td>Right arm</td>
<td></td>
<td></td>
</tr>
<tr>
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<td>OPV0</td>
<td>Oral</td>
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<td></td>
<td></td>
<td>OPV1</td>
<td>Oral</td>
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<td></td>
<td></td>
<td>RV1</td>
<td>Oral</td>
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<tr>
<td>6 weeks</td>
<td></td>
<td>D Tap-IPV-Hb1</td>
<td>Left thigh</td>
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<td></td>
<td></td>
<td>Hep B1</td>
<td>Right thigh</td>
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<td></td>
<td></td>
<td>PCV 1</td>
<td>Right thigh</td>
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<tr>
<td>10 weeks</td>
<td></td>
<td>D Tap-IPV-Hb2</td>
<td>Left thigh</td>
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<td></td>
<td></td>
<td>Hep B2</td>
<td>Right thigh</td>
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<td></td>
<td></td>
<td>D Tap-IPV-Hb3</td>
<td>Left thigh</td>
<td></td>
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<tr>
<td>14 weeks</td>
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<td>Hep B3</td>
<td>Right thigh</td>
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<td></td>
<td></td>
<td>PCV2</td>
<td>Right thigh</td>
<td></td>
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<td></td>
<td></td>
<td>RV2</td>
<td>Oral</td>
<td></td>
<td></td>
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<tr>
<td>9 months</td>
<td></td>
<td>Massoles1</td>
<td>Left thigh</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>PCV3</td>
<td>Right thigh</td>
<td></td>
<td></td>
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<tr>
<td>18 months</td>
<td></td>
<td>D Tap-IPV-Hb4</td>
<td>Left arm</td>
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<tr>
<td>6 years</td>
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<td>Td</td>
<td>Left arm</td>
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<tr>
<td>12 years</td>
<td></td>
<td>Td</td>
<td>Left arm</td>
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</tbody>
</table>

### HEAD CIRCUMFERENCE AT 14 WEEKS AND AT 12 MONTHS

14 Weeks: ________ (Range: 37 - 42 cm) 12 Months: ________ (Range: 42 - 47.5 cm)

REFER if head circumference is outside range

---

**DETAILS OF CHILD AND FAMILY (To be completed at birth)**

- **Child's first name and surname:**
- **Child's ID number:**
- **Mother's ID number:**
- **Date of birth** / dd mm yyyy
- **Name of facility where child was born:**
- **Child's residential address:**
- **Mother's name:**
- **Mother's birth date:**
- **Father's name:**
- **Who does the child live with?**
- **How many children has the mother had (including this child?):**
- **Number born (including stillbirths):**
- **Reason(s) for death(s):**
- **Number alive now:**
- **Date information given:** / dd mm yyyy
- **Child in need of special care (mark with X)**
  - (Complete at delivery or at first contact with health services)
- **Is the baby a twin, triplet, etc?** Yes No
- **Does the mother need additional support to care for the child?** Yes No
- **Any disability present (including birth defects):**
  - (Specify) Yes No
- **Other (Specify):**

**Stamp of facility and name and signature of official who issued booklet**
**NEONATAL INFORMATION**

<table>
<thead>
<tr>
<th>Birth weight:</th>
<th>Birth length:</th>
<th>Head circumference at birth:</th>
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<tbody>
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</table>

<table>
<thead>
<tr>
<th>Gestational age (weeks)</th>
<th>Rh factor</th>
<th>Mother's RPR</th>
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<tbody>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Antenatal (Maternal history):</th>
<th>Intrapartum (including mode of delivery):</th>
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<tbody>
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<td></td>
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</table>

**APGAR**

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<tr>
<th>1 min</th>
<th>5 min</th>
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</thead>
</table>

**Neonatal problems:** (Identify high risk problems):

- [ ] 

**Neonatal Feeding:**

- [ ] Exclusive breast
- [ ] Exclusive formula

**Special care plan / input required (e.g. Kangaroo Mother Care):**

<table>
<thead>
<tr>
<th>Specify:</th>
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<tbody>
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</table>

**Post-discharge plan (if baby was admitted in a neonatal ward/premature):**

<p>| |</p>
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</table>

**PMTCT/HIV INFORMATION**

- **Child's first name and surname:** [ ]
- **Child's ID Number:** [ ]
- **Signature of consent:** [ ]
- **Date:**

**Fill in this section on discharge from Midwife Obstetric Unit (MOU) or obstetric ward at first subsequent visit: if not yet done**

- **Mother's latest HIV test result:**
  - Positive
  - Negative
  - To be done

- **When did mother have the test?**
  - [ ] Before pregnancy
  - [ ] During pregnancy
  - [ ] At delivery

- **Is the mother on lifelong ART?**
  - Yes
  - No

- **If yes, duration of lifelong ART at time of delivery:**
  - [ ] < 4 weeks
  - [ ] > 4 weeks
  - [ ] Before pregnancy

**Document ARVs the mother received:**

- **Did the mother receive infant feeding counseling?**
  - Yes
  - No

- **Decision about infant feeding:**
  - [ ] Exclusive breast
  - [ ] Exclusive formula

- **Document Nevirapine given:**

- **All HIV exposed infants should receive Nevirapine for a minimum of 6 weeks**

- **Has the mother disclosed to anyone in the household?**
  - Yes
  - No

- **Has the mother's partner been tested?**
  - Yes
  - No

**Remember to offer testing for all the mother's other children if not yet done**

- Offer a mother with unknown HIV status a rapid HIV test.
- If mother's HIV rapid test is positive, perform an HIV DNA PCR test on infant if ≥ 6/2
**VITAMIN A SUPPLEMENTATION**

<table>
<thead>
<tr>
<th>Dose</th>
<th>At age</th>
<th>Date given (dd/mm/yy)</th>
<th>Signature</th>
<th>At age</th>
<th>Date given (dd/mm/yy)</th>
<th>Signature</th>
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</thead>
<tbody>
<tr>
<td>100 000 IU</td>
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<td>6 mths</td>
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<td>200 000 IU</td>
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<td>every 6 months</td>
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<td>12 mths</td>
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<td>19 mths</td>
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<td>24 mths</td>
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<td>30 mths</td>
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<td>35 mths</td>
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</table>

**ADDITIONAL DOSES:**

For conditions such as measles, severe malnutrition, xerophthalmia and persistent diarrhoea. Omit if dose has been given in last month.

Measles and xerophthalmia: Give one dose daily for two consecutive days. Record the reason and dose given below.

<table>
<thead>
<tr>
<th>Date</th>
<th>Dose given</th>
<th>Reason</th>
<th>Signature</th>
<th>Date</th>
<th>Dose given</th>
<th>Reason</th>
<th>Signature</th>
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**DEWORMING TREATMENT (Mebendazole or Albendazole)**

<table>
<thead>
<tr>
<th>Dose</th>
<th>At age</th>
<th>Date given (dd/mm/yy)</th>
<th>Signature</th>
<th>At age</th>
<th>Date given (dd/mm/yy)</th>
<th>Signature</th>
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<td>36 mths</td>
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<td>42 mths</td>
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