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ABANYASIDA: EMERGENT SUBJECTIVITIES AND SOCIALITIES IN RWANDAN ASSOCIATIONS FOR PEOPLE LIVING WITH HIV

by

JENNIFER ILO VAN NUIL

DISSERTATION

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

in partial fulfillment of the requirements

for the degree of

DOCTOR OF PHILOSOPHY

2015

MAJOR: ANTHROPOLOGY

Approved By:

Advisor

Date

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DEDICATION

For my grandmother, Wave Bearl Heyboer and the members of all the Rwandan HIV support associations

ACKNOWLEDGEMENTS

There are so many people who have assisted in the completion of this work both academically and emotionally. This process was isolating and challenging and I was fortunate to have a solid support network. Without the academic and personal support of so many mentors and friends I never would have succeeded in writing this dissertation and completing my doctorate degree. First I would like to extend my extreme gratitude to Dr. Andrea Sankar, my advisor and mentor. Andrea diligently read and reread countless reworking of these data and this work would not have been possible without her guidance and encouragement. I also deeply appreciate the comments and critique from my committee, Dr. Mark Luborsky, Dr. Todd Meyers, and Dr. Julia Gluesing. Each one gave me valuable insight for this work and helped me to not only think critically about my research topics but also place my work within the larger field of anthropology. The critique was not always easy to hear but it certainly made this dissertation stronger and for that, I am forever grateful.

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Finally and importantly, the work would not have been possible without the support of RRP+ and the members of the associations who allowed me to experience their lives for a short while.

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CHAPTER 1 *ABANYASIDA*

Introduction

Several months after beginning fieldwork in Rwanda, I drove, along with my research assistant, to one of my field sites in the southern part of Rwanda to conduct formal interviews with members of an *ishyirahamwe*¹ for people living with human immunodeficiency virus (HIV). Rwanda is a small landlocked country located just south of the equator tucked in between Democratic Republic of Congo, Uganda, Tanzania, and Burundi (see Figure 1). The country is known for its picturesque landscape of over one thousand hills with diverse environments across the country in one of the highest areas in the Central Rift Valley in the continent of Africa (Lemarchand 1970). There are different landscapes in Rwanda however the country as a whole features rolling hills. The western and northern area of Rwanda includes tall mountains and steep valleys, including the Congo-Nile Divide, Virunga volcanoes, and highlands; Central Rwanda is made up of kilometers of hills; Eastern Rwanda is made up of flat low lands with some lakes and hills (NISR, et al. 2011).

¹ *Ishyirahamwe* is the Kinyarwanda word for association, in plural it is *amashyirahamwe*. I use the Kinyarwanda terminology throughout the dissertation.



Figure 1: Map of Rwanda (United Nations 2008)

The group I was visiting was called *Humura*², a Kinyarwanda word meaning “be comforted” in English. This group was one of over 1,400 *amashyirahamwe* for people living with HIV in Rwanda at that time³. In addition to monthly meetings, the members of this group cultivated maize on a plot of land on Saturday mornings for both personal consumption as well as sales in the local community. *Humura* members worked together every Saturday from sunrise until around 11am or 12pm when the equatorial sun became too intense to work. Felicien⁴, my research assistant, and I decided to meet the *ishyirahamwe* members in the maize field on that particular Saturday after their work activities had ended to schedule interviews with members.

We drove down the winding hill past the town center where the *ishyirahamwe* meetings were

² Pseudonym. All specific association names used in this dissertation were pseudonyms.

³ The field research took place from January 2012 - December 2012, with follow up site visits in November 2013. I lived fulltime in Rwanda from January 2012 until the publication of this dissertation (November 2015).

⁴ This is his real name, used with permission.

held. I made this drive many times over the course of my fieldwork. We turned onto a small red dirt road where people were always waiting: to catch a bus, to walk into the village by foot, to converse with others. The road was only wide enough for one car to pass but there were rarely other cars on the road. Instead, the dust-covered road normally hosted pedestrians, bicyclists, and motorcycles. As we drove over bump after bump, I pointed to the small footpath that led to the maize field where the group worked; Felicien had never been to the maize field before that day. He only accompanied me at the very beginning of the project and for the formal interviews to help with translation, which was why we were going to the site on this day. After about 15 minutes of slowly driving over potholes and bumps, we arrived at the small village center where I always parked the car when I joined the members in their field. I parked the car next to a small clay house surrounded by thick green bushes, called *imiyenzi*, that are often used to fence off homes in rural Rwanda. I parked with the driver side faced out toward the village square and the passenger side quite close next to the bushes. I usually visited this site on Saturdays and there was normally a group of young men sitting on the broken cement stoop of the building, just across the dusty dirt road from this home. They always smiled and greeted me loudly: *amakuru* (what's the news?) or *mwaramutse* (good morning, literally did you wake up well?) and I responded in Kinyarwanda each time. They smiled, laughed, and exclaimed that I now speak Kinyarwanda. This day was no different. Felicien and I got out of the car, crossed the dirt road and greeted the young men one by one. Then we started to walk down the road back toward the small footpath that led to the field to find the *Humura* members. The bright Rwandan sun was beginning to shine down more intensely indicating that the members' work would soon be finished.

Before we reached the footpath, two members of *Humura*, Berchmans⁵ and Julius, greeted us on the road. Berchmans, a 54-year-old man, was the president of *Humura* and I coordinated all site visits with him. He was a tall man, his cheeks sunk into his face and his smile was like no other. When he grinned, his whole face lit up and emotions could be seen in his eyes. It was no surprise that he was watching for us to drive past the field and raced out to the road to meet us before we arrived at the field. He was a proud leader of the group and enjoyed having visitors. We greeted each other. Berchmans informed us that the group had finished the work in the field but we should leave Julius to watch the car before meeting the other members to brief them about the interviews. Julius was always working with *Humura* in the field. He was in his early 20s and was hard of hearing but that did not stop him from participating with the group. Julius wrote me a very kind two-page letter at the end of my fieldwork thanking me for the time spent with the group and wondering if I would come back to the village to teach him English. When I went back to visit the field site with to present preliminary results he did not attend the meeting but Berchmans assured me that Julius was still active with the group.

We walked back to the car and left Julius perched, smiling with pride, on the front bumper of the car. On 9 June 2012, I got a flat tire while parked in this same spot. Everyday at least a few, if not all, members of *Humura* walked me to my car after I visited their site. On that day, one of the members who was walking a bit ahead of us, rushed back to me and told me to come quickly, there was a problem. It was a flat tire. We went to investigate, which resulted in a crowd of people from the village surrounding the car. A few young men changed the tire and Berchmans negotiated a small amount that I would pay them for their help. When a few members and I drove off (I always drove a few people back up the hill to the town center off the

⁵ Pseudonym. All members' names used in this dissertation were pseudonyms, unless specified.

main road), someone from the village ran after us and told me to stop driving. The spare tire's rim was bent and the wheel was wobbling as we drove. The members of *Humura* waited patiently with me while they tried to remedy the problem. After a few hours of what seemed like the entire village trying to fix the spare tire by beating the rim with various tools, they told me to drive *buhoro buhoro* (slowly slowly) back to Kigali on the bent rim. Ever since that time, *Humura* members decided to have someone watch the car when I visited them in the field. Julius was always selected to watch the car but he did not seem to mind. Berchmans said it was just a precaution but he later told me that they actually were worried that someone in the community had punctured my tire on purpose that day. He never told me why.

On the path to the maize field, we met three more *Humura* members: two women, Uwase and Epiphanie, 49 and 59 years old respectively, and a 63-year-old man named Claude. We walked together to the field and showed Felicien the maize that had grown since earlier that season. Then we sat down in the grass to discuss what the interviews entailed and to see if any of the members wanted to participate in this part of the research study. There were only five people present, including Julius who was watching the car, so I suggested that we interview all five members over the next few days, if they all agreed. Felicien told me that Julius was hard of hearing and therefore it would be too difficult to interview him so we asked the other four members if they were willing to participate. They all agreed happily. Claude offered his home as an interview site because *Humura* did not have its own meeting location. They held their meetings at the sector office, which was never open on weekends unless it was arranged in advance.

The *Humura* members waited by the footpath entrance while I walked back to the village center to retrieve the car. Claude's home was too far to leave the car in this village so we decided

to drive together, except Claude. Claude always rode his bike. Julius got into the car with me and we drove to pick up Felicien and the two people who would be interviewed that day. Claude jumped on his well-decorated bike and we headed to his home in the car. His house was not even a kilometer down the main paved road away from Kigali. Julius left us on the main road before we arrived to Claude's house. The members told me to turn at what looked like a footpath that went up the side of the hill. I pulled into the grass just off the main road and they instructed me to park near a small clay house. There was no access to Claude's house by car so we had to leave the car near the main road and walked up the hill by foot. When Epiphanie got out of the car she called me over to the passenger side of the car. She was holding her hand over her mouth shaking her head. I walked over to her and looked where she was looking. There was something etched into the blue paint on the passenger door of the car: *abanyesida [sic]* (people with acquired immune deficiency syndrome (AIDS), literally people with SIDA, the French acronym for AIDS); the word was misspelled (see figure 2). The correct spelling was *abanyasida*. It must have been scratched into the side of the car with a key or knife while we were in the field discussing our plans. It was obvious that the person who etched the word was literate, even though they misspelled the word they at least could write. It also must have taken several minutes to etch it into the car but the car was parked in a way that the side that was vandalized was next to the bushes. The person who wrote it could have been hidden from public view while writing it. Julius may not have noticed that someone had snuck behind the car but he was there the whole time. The town square was always busy with people so it might have been difficult for the person to sneak behind the car but maybe not. Once the person was back there, they could have easily crouched down and done it without being seen by anyone. Or others may have watched the person do it and said nothing, even though Julius was standing right there at the

front of the car. More likely than not, at least someone other than the person who did it saw them do it. I never investigated it further but I am sure that if I had, we could have figured out who had done it. The country of Rwanda was known for its high level of security and surveillance of its population. It was not uncommon to have a computer stolen and the police recover it within a day or two.

We did not see the etching until after we had driven away so I did not have a photo of the exact location where it happened. Figure 2 was taken at my house in my driveway after I returned home from the field site. The brick wall that was reflected in the photo was much farther away than the bushes would have been if I had taken the photo at the exact location. It would not even have been possible to photo it well from the original location. There was probably only a very small space - perhaps one foot - between the car and the thick bushes of the house. Julius did not notice it when he got into my car at the site likely because I was parked so close to the bushes.

Epiphanie told me *wihangane* (have patience) and Berchmans shook his head speechless. Felicien looked at the word and laughed. I did not know what to think but I felt a bit threatened. The car was vandalized; it was not even my car. I borrowed the car from a good friend. Clearly the members were not happy about the incident but we all remained silent and walked to Claude's house. One of Claude's neighbors walked back down the hill and stood by the car while we conducted interviews with two members into the evening hours. I will never know the truth about why someone would do this to the car but it certainly said something about the attitudes toward people living with HIV in that particular community. Perhaps it was a jealous community member who thought I was bringing funding to the group. I was told before that community members were jealous of the funding and resources that people living with HIV accessed.

Perhaps it was the group of young men who were always there and meant no real harm to the members or me. It could have been a practical joke, at the expense of the people living with HIV. But it ruined the paint so it was a lasting joke. Whatever the individual motive for the action, it demonstrated the complexities of the community: who was included, who was not and how did people deal with living in that unequal reality? Part of this dissertation examines these questions and the subjectivities that were reshaped and emerged within this context. Following Biehl and Good (2007:5) in their discussion about subjectivity, I also asked broad questions about the lived experience of people living with HIV in the associations: “What is life for? What is an adequate life?”

Subjectivity, or the subject, has not always had a prominent role in anthropological thinking. Backing up to the beginning of the 20th century, Durkheim tended to focus on the social level and the subjects or individuals, although present in his work, were those upon which the larger society worked but not much more than that (Ortner 2005). Levi-Strauss attempted to completely remove the subject from analysis because it was, in his thinking, the larger structure that governed everything (Ortner 2005). From here, the subject was brought into anthropological thinking by post-structuralists but that subject was always framed universally in terms of power and domination (Ortner 2005). Others, for example Bourdieu and Sahlins, focused on how the subject was driven by social forces, not on their own will while other scholars including Giddens, focused on the agency of the subject and how subjects are aware of the impact or power of larger structures (Ortner 2005). However, Geertz in the 60’s and 70s contributed a theory focused primarily on subjectivity itself (Biehl, et al. 2007; Biehl and Moran-Thomas 2009; Ortner 2005). One of Geertz’s key contributions to the study of subjectivity was that culture was essentially the output of people trying to make sense of their social worlds therefore in order to

understand a culture, we must see things from the perspectives of those who live within that culture (Ortner 1984). From these starting points, subjectivity became a line of analysis within anthropology; the subject and their perspectives entered the focus of inquiry.

Ortner (2005:34) defined subjectivity as twofold: “a specifically cultural and historical consciousness” where individuals had at least some reflexivity about their circumstances (individual consciousness, from a psychological perspective) and were embedded in a social system or “the collective sensibility of some set of socially interrelated actors” (collective consciousness, from Marx and Durkheim). Part of subjectivity, according to Ortner, was how individuals made sense of their individual circumstances and the other part was wrapped up within public culture and the collective. Studies of subjectivities explored “the complex ways in which people’s inner states reflect lived experience within everyday worlds as well as within temporary spaces and transitions - moments of crisis and states of exception - can disturb and enlarge presumed understandings of what is socially possible and desirable” (Biehl, et al. 2007:5). In reference to violence, Das (2008:284) defined subjectivity as “how the subject comes to be attached to larger collectivities giving range to an astonishing range of emotions” (Das 2008). In these definitions, the subject and their emotions were always linked to the larger collective.

Studies “of individual subjectivity as both a strategy of existence and a material and means of sociality and governance helps to recast totalizing assumptions of the working of collectivities and institutions” (Biehl and Moran-Thomas 2009:270) By examining the subjectivity of individual association members, we can begin to unpack the inner workings of the collectives and institutions in which the individuals live. In this case, the collectives were the HIV association, the “community”, the government, international NGOs, and so on. Studying

individual subjectivity questions what people in a society really want or what they think is even possible within their social worlds (Biehl and Moran-Thomas 2009). In this dissertation, by subjectivity, I combined aspects of the aforementioned definitions and examined the lived experiences of people living with HIV and the ways in which they formed attachments to the *ishyirahamwe* and other socialities and importantly how they made sense of their everyday lived experiences. Additionally, I followed the “moments of crisis and states of exception” (Biehl et al. 2007:5) for people living with HIV to examine the emergent subjectivities that arise within the support group for people living with HIV in Rwanda.

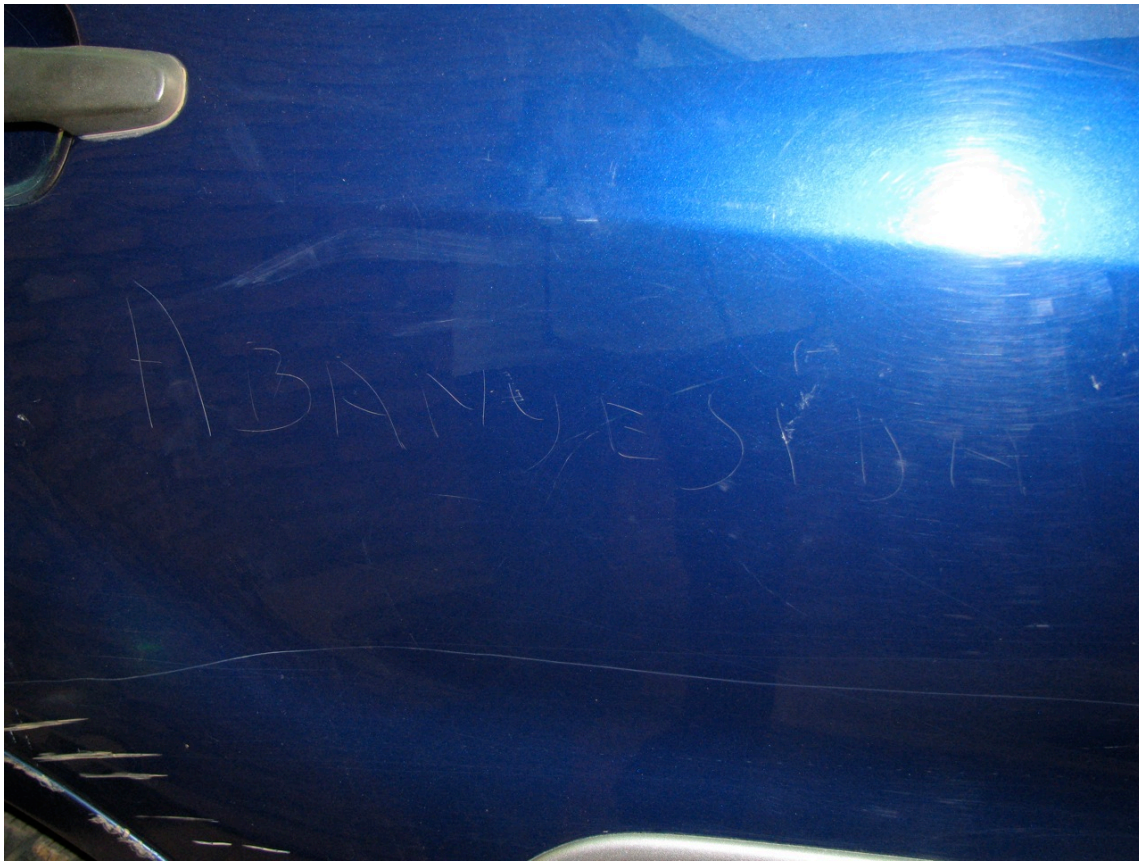


Figure 2: Photo of “Abanyesida” etched onto the side of the car. (Photo by Jennifer Ilo Van Nuil)

Following these lines of inquiry, the incident with the car made me think about what it really meant to belong to an *ishyirahamwe* for people living with HIV and the ways in which the

ishyirahamwe shaped the life experiences of its members but also how the members and their life and cultures shaped the *amashyirahamwe*. Obviously belonging to the *ishyirahamwe* created some new experiences for members and members also helped to somewhat redefine the *amashyirahamwe* to which they belonged. But importantly, how did the *ishyirahamwe* for people living with HIV create a space (if it indeed did) for members to envision new futures, or as Biehl and Moran-Thomas (2009) put it, “open possibilities for an alternate future.” The new futures, in the literature, often were in reference to the new possibilities offered through medical interventions, namely ARV treatment for the research done regarding HIV (c.f. Nguyen 2010) or psycho pharmaceuticals (c.f. (Biehl 2004b)). How did the members of Rwandan *amashyirahamwe* envision their futures or new possibilities offered from the groups as these groups did not provide access to medication at the time of the research but often provided other forms of support and at what expense?

The Rwandan *amashyirahamwe* indeed provided material and social support for its members but at the expense of being known as living with HIV in the community. People in the communities certainly knew who the *amashyirahamwe* for people living with HIV were. The members themselves relayed this fact to me and I often heard people in the communities saying things about how I was visiting the people with HIV. Further, I did not go unnoticed in the communities in which I had research sites. I was an outsider to the community and I visited the *amashyirahamwe* for people living with HIV, also outsiders in the community. Add to that the fact that I drove into these small villages in a relatively new, expensive car down roads that were normally traveled by motos and pedestrians. People in the villages talked, especially about outsiders, and Epiphanie from *Humura* even told me that when villagers saw *abazungu* (foreigners), they assumed they were coming with money or material resources. The day after I

visited Epiphanie in her home, her neighbors came to see what goodies I had left for her. Incidentally I left her home with an enormous bunch of bananas to bring back to Kigali but left her family nothing in return.

Beyond subjectivity, in this dissertation I use Foucault's notion of biopower to examine how subjectivities were shaped and reshaped by discourse and practice, both individually and collectively focusing on "[k]nowledge, technologies, and control" (Whyte 2009:10). There was a range of discourse surrounding the *amashyirahamwe* from the educational speeches given by the local *amashyirahamwe* leaders to the reconciliation and development rhetoric at the government level. This discourse influenced and managed the people living with HIV and more generally the population as a whole. Directly related to biopower, biopolitical theories focus on those who have power over others and the ways in which those subjects (i.e. the population under those in power) were "shaped for the benefit of each and all" (Rose 2001:17). In addition to biopolitics, I am also concerned with Fassin's (2012) notion of the politics of life. The politics of life analyze the meaning of life and the value placed on life whereas biopolitics explore the practices applied to populations (Fassin 2012). The context under which Fassin (2012) discussed the politics of life was regarding the inequalities made visible in humanitarianism interventions: whose lives were worth saving (e.g. aid workers versus the population, ex-patriate staff versus local staff)? In this work, I work between the two theories. I am interested in the meaning and value of individual lives (e.g. association members versus those cast out of the group) as well as the practices and techniques applied as such.

Up until the incident with the car, the members and community leaders with whom I had discussions all relayed relatively positive things about belonging to an *ishyirahamwe*, people came together locally and solved their problems. Members and leaders argued that this problem

solving by coming together was part of “Rwandan tradition.” By “Rwandan tradition” the leaders meant part of a unified Rwandan custom from pre-colonial times. Coming together was the overarching rhetoric surrounding not only the *amashyirahamwe* for people living with HIV but also nationwide development and national reconciliation programs. Rwandans, and in this specific case people living with HIV, were forced to live in a reality where they were urged by the government to come together with neighbors to solve issues, yet these same people were the ones who killed or were killed during the 1994 genocide. All the discourse was about solving problems by coming together but the unspoken truth was that it was not that easy to come together in a post-genocide context, let alone disclose one’s HIV status to the village by joining the *amashyirahamwe*. Yet in order to live within this social world, according to the Government of Rwanda (GoR), coming together was the best precisely because it was the way of the past.

Another form of discourse was relayed through the health centers in the villages. The message was that joining an *ishyirahamwe* was the “right” thing to do after being diagnosed with HIV. The doctors and nurses at the local health clinics often referred people to the *amashyirahamwe* after a positive diagnosis and people tended to adhere to their doctors’ advice. Those who did not join were known within the association as the people who were spreading the HIV epidemic. These were two examples of the types of discourse being relayed at the government level to all Rwandans (i.e. talk about Rwandan “culture” and “tradition”) and at the individual level aimed at the people living with HIV. These forms of discourse influenced how HIV was intervened upon, for example the insistence of joining a group after diagnosis, how knowledge about HIV was dispersed through the community, and the forms of social control at play for those living with HIV. These topics are further described in the pages that follow.

The Rwandan *amashyirahamwe* for people living with HIV raised a different set of questions than those described by other scholars studying groupings of people based on conditions for various biological ailments, often referred to as biosociality. Rabinow (1996:102) described biosociality in reference to the social relationships and identities that potentially could be created based on genetics and/or biological conditions. Rabinow (1996) studied the Human Genome Project and the “truths” that could be made reality by implementing genetic screenings for newly discovered genetic predispositions. In "biosociality nature is modeled on culture understood as practice" (1996:99). In other words, culture is the basis or foundation for nature and it is understood and applied as such. Biosociality is contrasted to sociobiology in that "sociobiology is culture constructed on the basis of a metaphor of nature" (1996:99). As such, with sociobiology, nature or biology creates culture and behaviors are determined by genetics. Everything goes back to biology. Conversely, biosociality is the sociality that is formed based on biology “as revealed and controlled by science” (Whyte 2009:10). When Rabinow first wrote about biosociality, it was somewhat of a joke to argue against the sociobiological thinking of the past years (Hacking 2006). The first studies of biosociality encompassed genetic studies during the time when geneticists were looking for a biological/genetic source for everything but obviously it was not the case (Hacking 2006).

The original studies of biosociality led scholars to theorize about similar situations in other contexts, extending the concept. One such example is the concept of biological citizenship. Biological citizenship refers to citizenship claimed on the basis of a biological condition as a way to demand basic human rights in the face of the specific health condition (Petryna 2002). Petryna (2002) specifically examined how people whose health was affected by the Chernobyl disaster used their shared damaged biological identity to demand resources from the state.

Biological citizenship groups are distinct from other types of patient support groups insofar as they extend beyond the internal support and form relationships with scientists and experts (Rose and Novas 2004). These scholars stressed the importance of how groups mobilize politically, interact with scientific communities, and create forms of entitlement to state resources (Epstein 1996; Petryna 2002). The overarching idea then was that people come together based on a biological condition as a way to cope with their new identity, as well as make claims on the state for resources to help them to live with such conditions. In turn, these people become more reliant on the state for the resources and their ultimate destiny, based on that biological condition. These identities were created not only by medical institutions but also shaped by those who subsume the identity (Whyte 2009). In essence, the identities were “made up” to quote Ian Hacking’s well-known concept (Hacking 1999 [1986]).

Other anthropologists have used the concept of biological citizenship to talk about the HIV epidemic and issues such as social exclusion and claiming rights. Part of the biological citizenship includes people actively seeking out state support, not unlike those Petryna studied in Ukraine, by identifying themselves as people living with HIV (Whyte 2009). Additionally, Biehl (2004a:119) studied “how technical and political interventions make people invisible” and the impact of this invisibility on the individuals’ life experiences. The people made invisible were important to consider. As the *amashyirahamwe* and members were praised for all the good being done in the communities, there were the forgotten people, the ones who became invisible because of their nonparticipation.

Similarly, in West Africa (specifically Burkina Faso, Cote d’Ivoire, and Mali), Nguyen (2010) explored how those living with HIV learned how to make public testimonies regarding their HIV status as a way of gaining access to antiretroviral therapy (ART) within the context of

support-type groups, which he termed “therapeutic citizenship.” He argued that those who were active in the groups and made a compelling public testimony about living with HIV were the ones selected to receive HIV therapy because they were the ones who could potentially attract more donations, as well as be considered better candidates for ART (Nguyen 2010; Nguyen, et al. 2007). Further, Nguyen (2010) discussed how people were “triaged” for the limited resources, which at that time was mostly antiretroviral (ARVs). The HIV-related groups in West Africa functioned to help some people living with HIV gain access to resources, including medication therapy, and resulted in people who were active in the community and international health processes. But at the same time, those most vulnerable and those who could not easily articulate a compelling testimony were again left to die (Nguyen, et al. 2007). The people living with HIV via the support groups created an experiential terrain allowing new therapeutic subjectivities to emerge. As therapeutic citizens, people living with HIV viewed access to ART as a “set of rights and responsibilities” (Nguyen, et al. 2007). However ART was only accessible for those who could create connections that gave them access to the clinics or groups who in turn had access to ART. For those without such connections, receiving ART was even more challenging. Nguyen’s initial research (2004, 2007, 2010) took place when access to ART was extremely limited in West Africa and therefore the triage provided through the groups offered therapeutic sovereignty over who would receive medication meaning a handful of people had control over the very few people living with HIV who accessed medication.

When access to ARV medication was limited in Rwanda, the case was the same as in these West African contexts (c.f. Nguyen 2010) where the *ishyirahamwe* was a route through which one could access ARVs, though not without joining the group, disclosing their status, and adhering to the rules and regulations of the *ishyirahamwe*. However, at the time of this research

project, access to ARVs was not dependent upon membership in the *ishyirahamwe* as anyone meeting the requirements for ARVs could access ARVs in Rwanda.

Over the years, ARV access changed dramatically, globally as a whole and locally in Rwanda. At the end of 2009, Rwanda had 88% ARV coverage, one of the highest of the low and middle income countries (WHO, et al. 2010). People living with HIV continued to join the *ishyirahamwe* for other reasons, including material and social support and others were, in a sense, forced to join the association through the suggestion of their doctor and/or neighbors. Membership still had consequences, such as public disclosure of HIV status. And, as will be explored later in the chapters that follow, the *ishyirahamwe* members were expected to act in a certain way or they risked being expelled from the group and further marginalized from their communities.

The *amashyirahamwe* in Rwanda no longer relied on the state for monetary assistance nor did they rely on nongovernmental organizations (NGO) financial support, as was the case in the past for the Rwandan *amashyirahamwe* for people living with HIV and groups in other contexts where there was a material value of HIV (c.f. (Marsland 2012)). Even though the material support was gone, people still joined the group. However, if there were support available, the *amashyirahamwe* would certainly not turn it down. Members and others living with HIV did rely on the state, however, for their healthcare and medication. Their great reliance on the state led to rumors and fear about losing the healthcare that was giving them life. As the support from NGOs decreased over time, the *amashyirahamwe* in Rwanda focused more on the social support aspects of membership. In addition, the groups often tried to maintain projects that would bring income to supplement the loss from the NGO support. Unfortunately these projects were often not sustained and did not provide steady income to the groups.

The members of the *amashyirahamwe* lived in a very morally charged social world. For example, via the local *amashyirahamwe*, members remained accountable to one another and made sure that members were living according to the living positively health campaign supported by Rwandan Network of People Living with HIV/AIDS (RRP+) and the GoR. Members were expected to live in a certain way according to the Ministry of Health (MoH) and international community standards as part of international health campaigns about the “right” way to live and how to be a healthy person living with HIV yet these new ways of living were often in contradiction to their everyday moral codes. The morality tied in directly with the politics of life theory mentioned earlier in this chapter in that morality is at the center of analysis (Fassin 2012) because the meaning and value of life for people living with HIV changed as moralities changed. But the moral worlds were also products of the management of the population or biopolitics. The study of morality in anthropology has an interesting history because although many anthropologists claim to study morality, it was usually done under the guise of culture or society more broadly. Zigon (2007) argued that because anthropologists tended to study issues surrounding morality (e.g. religion, kinship, culture), morality has always had its place in anthropology but not stated as such. For example, the study of religion is a study of morality because morality, in Durkheimian thought, was equated with society. Zigon (2007) proposed a framework for studying morality, which examined moments of moral breakdown. Zigon (2007) argued that in everyday life, people are not reflective about their morality but it is in these moments of moral breakdown where people must consciously make ethical decisions about something in their life so that they can return to the everyday nonreflective mode that we can observe and analyze morality (Zigon 2007). This framework works on the level of the social

and the individual. For the purpose of this dissertation, I use Zigon's moral breakdowns to capture an anthropology of morality within the *ishyirahamwe* for people living with HIV.

The *amashyirahamwe* were subject to government interventions, such as a nationwide *koperative*⁶ movement and eventually the members were expected to be productive members of society as a whole not just within the *ishyirahamwe*. Further the *amashyirahamwe*, at the time of the research, were beginning to be less reliant on donor funding because the majority of the individual funding had been pulled and encouraged to be self-reliant through the emergence of *koperative*, the government initiative promoting *kwigira*, or self-reliance. At the start of the research I learned that the GoR was urging all *amashyirahamwe*, not just those for people living with HIV, to become fully functional and registered income generating *koperative*. This type of rhetoric was used in many governmental policies (see chapters 2 and 5) and the era of creating a self-reliant Rwanda was part of the landscape of the *ishyirahamwe* at the time of the research. Most of the groups under study were not receiving funding from the government or NGOs yet they still relied on the state for their healthcare and the state still required them to act in a certain way, individually as responsible citizens living positively with HIV and collectively as economically responsible groups and members.

Another consequence of an individual's identification with the group and/or access to treatment or other resources was that membership could create tensions in traditional social relations and stimulate the development of alternative social positions (Biehl 2009). For example, access to resources for some people in a community but not others created jealousy and other problems in the community. In a study conducted by Thurman et al (2008), Rwandan children whose parents died of HIV who received NGO assistance were often isolated from their

⁶ *Koperative* is the Kinyarwanda word for cooperative and cooperatives. It is *koperative* in the singular and plural. I use the Kinyarwanda term for cooperatives throughout the dissertation.

communities as the other families became jealous and viewed the NGO as the orphans' primary caretaker instead of assisting the children (Thurman, et al. 2008). The same scenario applied when the HIV funding was streamed into Rwanda and only those living with HIV benefited from the support⁷. Part of the research was to understand how these groups intersected with the healthcare community but also to understand the lived experiences of the people involved in the groups within the larger Rwandan context but also within the smaller communities, as this was the space where the experiences of HIV emerged. These every day experiences of living with HIV and belonging to an *ishyirahamwe* became the most fascinating data.

Beyond the individual experience, there were also other influences on the groups. The form of the group itself was one such example. The groups that were studied in the aforementioned contexts and in this research included people divided into groups based on a health condition. The division of people into groups based on a single health condition demonstrates the influence of Western notions of disease categories. Classifying a person by a single health condition does not map onto the nature of one's real life because it does not take into account the autonomous individual experience in protean engagements of ongoing daily life. Western ideas regarding the labeling of disease and illness often isolate and control for single factors and use biomedical values as the key to the way the person or body is conceptualized and treated. The categories themselves constitute a way of stripping away local context. Further, support type groups, for example HIV related groups, are partially conceived as a product of global public health that comes pre-packaged with a standardized set of problems and solutions created by the global community (Cassidy and Leach 2009). An example of this is the Living Positively campaign where the social norms of the *amashyirahamwe* conflicted with the social

⁷ Discussed in more detail in the findings section.

norms of Rwandan culture. Nonetheless, the cultural landscapes in which the *amashyirahamwe* operated were culturally specific, defined by social relationships of the past and the ever-changing values, beliefs and practices over time. The alternate social positions created by these *amashyirahamwe* existed in their traditional geographies albeit with a reshaped subjectivity. At this juncture, between global public health agendas and culturally specific contexts, there was an interesting mingling between the local *ishyirahamwe* and the global structures.

In addition to the realities on the local level within the *ishyirahamwe* and the global agendas, Rwandan development policies and other larger governmental objectives impacted the groups. Rwanda prided itself on using what they termed “home grown solutions” to address its development issues. The solutions were “culturally owned practices translated into sustainable development programs” used not only to develop the country of Rwanda but also to cultivate one national identity after severe ethnic conflict (RGB 2014d). Essentially the development programs were created using aspects of Rwandan culture with the aim that the citizens themselves worked together to find solutions to their problems on a local level. Within this culture, leaders emphasized, there was a large focus on coming together. But how could a society that had such an emphasis on coming together in the past have faced such extreme ethnic tensions and violence? Was the “tradition” created as a way to cultivate one national identity and build pride? Or did this culture of coming together stem from longstanding “tradition” that existed before colonialism? Then switching back to the *amashyirahamwe* for people living with HIV, how do these ideologies impact how the *amashyirahamwe* were structured and importantly how did people speak about the *amashyirahamwe* within their own communities and to outsiders, like myself?

Throughout the project, I encountered situations where the reality on the ground was not the same as what people told me. Or I was told the scripted response to questions until much later in my fieldwork. One example is the situation regarding *akato*⁸, or the Rwandan version of something like stigma, and the ways in which people were treated in their communities before and after they were known as having HIV. Members told me that even being known in the community as a person living with HIV was not a problem anymore because there was no *akato* against people living with HIV, as if this was the only issue that people living with HIV faced. This was not the case at all. There were many other issues that plagued those living with HIV. I did not think it was possible to have a country where *akato* did not exist. Up until the incident with the car, no one would talk about it. The incident with the car became a topic of conversation with members and leaders and led to interesting discussions regarding the realities of living with HIV and how *akato* against people living with HIV was indeed an issue for not only the members but also other people living with HIV who decided, perhaps precisely because of the *akato*, to not join an *ishyirahamwe* and have their HIV status known in the community. The incident with the car also confirmed that the community members knew who belonged to the groups. By joining an *ishyirahamwe* for people living with HIV, such as *Humura*, one would be known, at least in that community and/or nearby communities, as being a person living with HIV, regardless of his or her actual HIV status.

I introduced this dissertation with the situation with the car to provide a small glimpse into the complexities surrounding the *amashyirahamwe* for people living with HIV in Rwanda: the reshaped individual subjectivities, the emergent socialities, and the influences of the governmental and nongovernmental institutions in the wider context. The experience showed

⁸ Stigma is the closest English word to describe *akato* although it does not capture the full meaning of *akato*. See chapter seven for a full discussion of *akato*.

how people came together and their motives for doing so, which was normally not because it was in their “culture” to come together. It showed how people moved apart within villages and within families. It showed the tensions in the community including jealousy over resources, *akato*, poverty, and ethnic conflict. It showed how people overcame these tensions, if they ever did or how they altered their reality in order to live within this social and very moral world. It showed the enduring and reshaped forms of sociality based on HIV status, all embedded within the context of the *ishyirahamwe* for people living with HIV in Rwanda but also within the broader context of Rwanda, a country that faced ethnic conflict that ultimately ended with the genocide in 1994. The GoR and its strategy of development and reconciliation impacted the way in which the *amashyirahamwe* were molded over time. The notion of coming together, as a “Rwandan tradition” urged people to join these groups. Further the ways in which HIV was talked about at all levels, from international NGOs to the individual living with HIV in rural Rwanda, demonstrated the peculiarities of this social form, the *ishyirahamwe*, but also the myriad ways that HIV was intervened upon in this context resulting in a unique set of socialities and experiences.

Methodology

The study design combined three main features – historical research and key informant interviews on the historical forms and practices of coming together in Rwanda, ethnography on the daily activities of five specific *amashyirahamwe*, and ethnographic research on the ways in which the *amashyirahamwe* shaped the experiences of HIV for its members and maintained the guidance of the shifting local and national policies.

I focused my research on the *amashyirahamwe* for people living with HIV as a way to examine broader issues surrounding how Rwandan society dealt with a life-altering disease,

HIV, in a context of a life-altering situation, genocide. Further, in this work I sought to examine if the Rwandan *amashyirahamwe* were indeed based on longstanding values and practices that promoted coming together to solve local issues, as was the stance behind many other government programs. To answer this inquiry, I conducted historical research on ways that Rwandans came together through time. I consulted with historical documents and texts as much as possible although there was not a great deal of primary sources. In addition, I gathered information on the current programs that were based on past programs to obtain not only a description of the past practices but also the new programs. I often gathered information on these practices through key informant interviews and informal discussions with members of the *amashyirahamwe* and leaders in the communities. The key informants were happy to discuss the “traditions” of Rwanda. This data collection method resulted in a variety of pictures of traditional Rwanda, which represented some of the multiple “traditions” of Rwanda.

Following Didier Fassin’s research on HIV in South Africa, I wanted to understand the boarder context of Rwanda to gain a full appreciation of the HIV epidemic in Rwanda (Fassin 2007). In Fassin’s (2007) work in South Africa, he stressed that the political context, colonial history, among many other factors were very much necessary to understand the HIV epidemic in South Africa. It would not make sense outside of that complicated context. As such, I gathered data on Rwandan politics, history, and current events that surround the HIV epidemic in Rwanda but also broader considerations about global realities related to HIV.

Additionally I examined whether or not the HIV support *amashyirahamwe* created a space for alternative or refashioned forms of subjectivities and the ways in which this occurred. To frame it as a question: how do the *amashyirahamwe* mold the experience of HIV for people living with HIV in Rwanda? I also questioned whether the Rwandan version of therapeutic

citizenship was reliant on values that promoted self-reliance or *kwigira*⁹ as expressed through the recent government policy that all *amashyirahamwe* in Rwanda must become fully registered *koperative*. To learn about the experiences of being in an *ishyirahamwe* as well as the shift to *koperative*, I used ethnographic methods including participant observation at five *amashyirahamwe* for people living with HIV. I also conducted in depth interviews with 21 members of the five *amashyirahamwe*, in addition to countless informal discussions with members, community leaders, and key informants.

I worked in Rwanda on two previous occasions prior to the start of this research on short-term projects. I was in Rwanda for the summers of 2008 and 2009 to work on a project conducted by Family Health International (FHI) and Wayne State University (WSU), Department of Anthropology. The project focused on improving secondary HIV prevention programs with an overall goal of promoting positive prevention messages and building Rwandan capacity in qualitative methods. My primary role was to analyze over 60 life history narratives of people living with HIV. In brief, we found that secondary prevention should go beyond the individual and include partners and community members. We also noted the importance of the *ishyirahamwe* for the members but nothing beyond this point. Though these narrative excerpts showed a small glimpse into the life of someone living with HIV through a narrative account, so much more depth could be gained from using ethnographic methods, in addition to in-depth interviews. The interviews from the summers of 2008 and 2009 were the first inspiration for this project but I wanted to probe deeper into the *amashyirahamwe* and the best way to obtain this type of data was from ethnography. For example, I wanted to understand *akato*: beyond that it

⁹English: literally to have oneself but often translated as self-reliance. This concept is explored more in chapter 8.

existed or not. I wanted to have an idea of what it looked like for members and within the community. Participant observation allowed me to obtain these data.

Methodologically, I learned many things from conducting the research in this manner. I noticed that the interviews in the groups with whom I conducted more participant observation were much more detailed and rich than in one group where I did not spend a lot of time with members in their daily activities. Members told stories of our times in the field (literally) and gave examples of how much we accomplished together. I also realized that over time, I felt like part of the *ishyirahamwe*, which helped me, to some extent, grasp a sense of what it was like to belong to an *ishyirahamwe* in Rwanda. However, I could never really understand fully what it was like to truly be a member or how that impacted their experience in the community. Upon reflection, I could have obtained more data about the daily lives of people if I had spent extensive time with a few members, not just in the context of the *ishyirahamwe* but also in the community as a whole. I could have moved into the village where the rural *amashyirahamwe* were based to integrate further into the community as a whole. This was not feasible in the context of this research because most of my sites were located outside Kigali and I was based in Kigali City and conducted research simultaneously within the five groups.

Outline

The outline of the dissertation is as follows. In the following chapter, I discuss the discourse surrounding the notion of coming together to solve problems juxtaposed with Rwanda's recent history of ethnic conflict. It is surprising that a country with such a strong emphasis on working together and resolving issues on a local level could have passed through years of violent conflict at the very same local level. In chapter two, I begin the chapter by discussing the difficulties when discussing one Rwandan culture or "Rwandan tradition" because

of the multiple influences over time. Next, I talk about the context of Rwanda beginning with a brief discussion of the early Kingdom of Rwanda followed by some basic characteristics of Rwandan society. Then, I discuss ethnicity and the ethnic conflict that Rwandan society faced in the recent past beginning with a discussion of ethnicity in pre-colonial times. Following I discuss how the colonial powers were instrumental in creating an ethnic divide in Rwandan society that ultimately led to the 1994 genocide. This chapter is meant to provide a brief understanding of the context in which the *amashyirahamwe* for people living with HIV were formed and operated.

Next, I discuss the sample and the rationale of how I selected the sample of *amashyirahamwe* that became the focus of the research (chapter three). In this chapter I also provide a brief description of each *amashyirahamwe*, as well as an example of a home visit afternoon I experienced with *Abihuje*, the *ishyirahamwe* in Kigali. In chapter four, I discuss the emergence of the *amashyirahamwe* for people living with HIV in Rwanda specifically and the formation of the umbrella group that managed all the *amashyirahamwe* in Rwanda. In addition, I discuss the activities of the *amashyirahamwe* to provide an idea of what the groups accomplished on a daily and monthly basis, according to the umbrella group's regulations and laws. The *amashyirahamwe* were located within communities scattered throughout the country of Rwanda but they all existed within a web of more formal and informal relationships, from local health clinics to governmental entities to informal networks within the local communities. These relationships are explored in this chapter as well. To end this chapter, I discuss the recent push to create income-generating *koperative* from all *amashyirahamwe*.

In chapter five, I discuss the theme of coming together and the conflicting realities members dealt with on a regular basis. I discuss coming together by introducing one government program that was reliant on the idea of coming together and used a "traditional" practice upon

which to base the program. I trace the original practice's origins and compare and contrast the recent version with the older practice. Then I examine it alongside the HIV *amashyirahamwe* to see how the government programs and the *amashyirahamwe* mirror certain aspects, such as exposing vulnerabilities to neighbors. Within the HIV support group, this equated to disclosure of HIV status, often leading to *akato*, Rwanda's version of "stigma", the focus of chapter six. I examine the concept of *akato* from the perspective of members and the ways in which *akato* existed both now and in the past.

In chapter seven I review how the *amashyirahamwe* molded a social order under which the members were expected to live through educational campaigns, accountability within the *ishyirahamwe* and the wider community, as well as the ways in which moral standards were imposed on its members. Here I demonstrate the times of "moral breakdown" (Zigon 2007) within the *amashyirahamwe*. Finally in chapter eight, I discuss the recent motivation to transform all *amashyirahamwe* into *koperative*. I come back to the theme of self-reliance in this chapter and try to unpack what this meant for the *amashyirahamwe* specifically and for Rwanda in general. This chapter also includes how the transition to *koperative* occurred, if the groups were successful in the transformation or not, and the ways in which the members viewed this "ideal" of being a newly formed *koperative*, while also striving to remain *amashyirahamwe* for people living with HIV. This chapter is followed by a case study of one participant to explore how the *ishyirahamwe* impacted one member from the time when he joined until the time of the research. To conclude the dissertation, there is a discussion section to tie all the chapters back together. I focus on the themes of coming together, in both practice and rhetoric, inclusion and exclusion in the groups and wider community, and vulnerability. I question who is vulnerable in the context of the *amashyirahamwe* and what does that mean for those vulnerable. I discuss the

inequalities on a local and global level regarding AIDS exceptionalism and access to ARVs. Next I discuss the complicated moral order for the people living with HIV in Rwanda. To conclude, I compare how the Rwandan groups for people living with HIV stand in contrast to other scholars' work in this arena and propose a theory as to why there were such great differences. This idea is called fluid subjectivities and focuses on the stage of a global epidemic and the local response and the subjectivities that emerge within each stage.

CHAPTER 2 HISTORY AND CONTEXT

Gushyirahamwe ni byiza [To come together is great]

Rugamba Sipiryani was a Rwandan musician who wrote songs about unity, human rights, and Rwandan culture during the 1960s. One song was called *Gushyirahamwe ni Byiza*, meaning “to come together is great”. Sipiryani was considered a revolutionary singer/writer because he wrote the majority of his songs during the 1960s after large ethnic tensions broke out in the country of Rwanda and many of his lyrics went against the ideologies of the then current regime. Sipiryani, a moderate Hutu, was killed during the 1994 genocide because of his resistance to join the Hutu extremists but also because of the sentiment behind his song lyrics. The themes of Rwandan unity and reconciliation became part of the dialogue of the new regime that came into power after the 1994 genocide. Sipiryani’s song about coming together was an indication that, at the time (during the 1960s), coming together was not part of Rwandan life.

Rwandans as a whole were divided along ethnic lines. Yet the new Rwandan government maintained that past Rwandan culture included coming together collectively as Rwandans, not Tutsi or Hutu or Twa, the three main social groups in Rwanda, to solve local problems. Coming together became a theme in this research, not only as applied in the formation of government programs but also as a strategy to make people join the *amashyirahamwe* for people living with HIV. The ideas I focus on in this chapter include the historical forms of Rwandans coming together coupled with the ways in which Rwanda was divided giving way to ethnic conflict from pre-colonial to postcolonial times. I conclude the chapter with a short discussion about the aftermath of genocide and the GoR’s reconciliation and development plans to create a united Rwanda using what they term “home grown initiatives or solutions”.

Many landscapes are discussed in this chapter that set the stage for the formation of the HIV related groups in Rwanda: the logistics of the hilly landscape, marriage rules, kinship structures, and the constant cultural change brought forth when cultures merged, after conquering a new territory, for example or the cultural changes that were the result of colonialism. It was difficult to discuss a “Rwandan culture” as the culture itself had changed dramatically over the past centuries. To discuss even “Rwanda culture” or “tradition” before colonialism was not possible because the cultures of Rwanda were in constant flux. This type of talk was definitely used by key informants in discussions as well as by the GoR in policy and development plans.

The hill, literally the landscape of Rwanda, separated some people from each other logistically yet brought others together depending on the hill. Figure 3 shows the hilly landscape of Rwanda. This image was taken near one of my field sites in Kigali Province in the early morning before the fog had lifted. Felicien and I were on the main road, which ran across the top of one range of hills, looking out to multiple hills and valleys beyond Kigali City. The Nyabarongo River flowed through the valley below. This was the landscape in which the Kingdom of Rwanda flourished.

The marriage and kinship patterns, as documented from the past, demonstrated that the family was larger than the nuclear family and was sometimes not based on direct blood relationships. The history of ethnic conflict also played an enormous role shaping the current landscape because ethnicity ultimately divided Rwandans, led to mass killings, and eventual genocide in 1994. These remnants formed the basis of the formation of HIV related groups as well as other inequalities in the community that stemmed from such groupings. The genocide was strewn with ongoing public health issues, remnants of colonial power, a strong ethnic divide, and a variety of ideologies all nestled into the one thousand hills of Rwanda.



Figure 3: The 1,000 hills of Rwanda (photo by Jennifer Ilo Van Nuil)

The rise of Rwanda

I first go back in time and set the stage for the current discussion. The first inhabitants of the area making up the current country of Rwanda (and surrounding areas to some extent) were estimated to have settled in the region over 10,000 years ago (Vansina 2004). There was evidence of regional settlements during the Early Iron Age as early as the third century (Oliver and Fagan 1978). The Urewe culture, a Bantu culture, resided in the Rwanda-Burundi Central Plateau during this time, was known for decorative pottery and iron-smelting techniques (Van Grunderbeek and Roche 2009). The Bantu pottery design included sophisticated beveled rims and dimple impressions (Oliver and Fagan 1978). There was also evidence of farming initially during the early iron age based on material culture finds “suggestive of relatively high levels of economic, political and social organization” (Van Grunderbeek and Roche 2009:299). The earliest Urewe ware finds from this time were followed by pottery that was inferiorly designed possibly indicating a migration of people, likely pastoralists and/or farmers from the north

(Oliver and Fagan 1978). There are ongoing debates regarding the migration patterns and ethnicity.

During the seventeenth and eighteenth centuries, Rwanda began to expand under the rule of King Ndori leading to doubling in size and influence over five or six decades (Alpers and Ehret 1975). By the eighteenth century, Rwanda was three times the size of the Republic of Rwanda at present (Kamatali 2013). Through conquering the local areas, different populations were integrated into the kingdom which led to the creation of defined social and political roles for the various populations (Alpers and Ehret 1975). The King of Rwanda was assisted and limited by the Queen Mother and *abiru*, who were the guardians of Rwandan rituals and culture (Kamatali 2013). *Ubwiru* referred to the verbal accounts of the rituals of the kingship and *umwiru or abiru* (in plural) referred to those who memorized sections of the rituals to later pass on to future *abiru* (Vansina 2000). Essentially the *abiru* held the kingdom's dynastic secrets regarding various traditions, secrets that not even the King nor Queen Mother knew (Kamatali 2013). Alexis Kagame, a well known Rwandan historian, documented the rituals in writing in 1945, however it was kept a secret until 1964 when a version was released in both Kinyarwanda and French (Vansina 2000). The *abiru* represented **a** Rwandan culture, though at the expense of many lost traditions from those conquered as well as other traditions not formally recorded. Because the *abiru* had legitimacy within the kingdom, their version of Rwandan history became the official version. However, during the reign of King Rwabugiri in the late nineteenth century, the legitimacy of the *abiru* weakened and was no longer considered as important as in the past (Mamdani 2001). Although the *abiru* represented only one history (and culture) of Rwanda, *abiru* was one way in which the history of Rwanda was shaped and documented over time. This system of recording history was completely oral until well after colonization. Because there was

no written history, missionaries and those who first colonized areas in sub-Saharan Africa mistakenly assumed that those without Western histories (i.e. written) have been living the same way for centuries (Vansina 1990). This was obviously not the case in Rwanda. The very first written accounts of these countries, written most often by missionaries, were often biased in their historical accounts of pre-colonial and early colonial times (Comaroff and Comaroff 1991). These accounts, in Rwanda, also instilled a version of Rwandan history and ideas about ethnicity into the population at that time (Longman 2009).

During the same time, the nineteenth century, Rwanda had developed into the largest pre-colonial state in the region with a complex political system ruling a population of over 2 million (Oliver 1977). Because of the intricate political and social system, Rwanda was one of the few areas in sub-Saharan Africa that was not involved in the slave trade (Rusagara 2009). However, the area making up the kingdom of Rwanda fell victim to the grips of colonialism, described below.

The hills of Rwanda

The Kingdom of Rwanda was strong as a political unit but the individual social systems were integrated as well. Because Rwanda was physically situated among one thousand hills, the hill became an important geographic feature that influenced settlement patterns and culture. The hill became the unit of settlement and neighborhoods were formed by the boundaries of the hill, often isolating families and neighborhoods (Vansina 2004). There were no bound villages¹⁰; instead communities were formed by the families who lived together on one hill (Longman 2009). The basic social unit of the family was termed *urugo* and the extended family was termed

¹⁰ This was beginning to change in 2012 and has caused problems in bringing electricity lines, for example, to all homes, as they are located quite far from each other.

*inzu*¹¹. One *urugo*, including several *inzu* at times, would occupy one hill or a section of a hill (Vansina 2004). The *umuryango*¹² or lineage was the next largest social unit (Newbury 1980) followed by *ubwoko* or clan (Mamdani 2001).

Each *umuryango* was ruled by a patriarchal chief, *Umutware w'Umuryango* (Rusagara 2009). When one *umuryango* became too large (normally over 20 *inzu*) quarrels were more common and then the *umuryango* would split taking the name of the founder (Vansina 2004). These familial structures kept much of the problem solving within the family at the local level or on the hill. The hill was also the unit of political activity, again isolating families and neighborhoods from each other leaving “relatively little sense of unity among the rural communities” (Lemarchand 1970:17).

The military system in Rwanda also became a way of linking lineages and bringing people together, despite being separated by the hill. Individuals did not join the military; families joined together and became a strong institution (Kamatali 2013). As mentioned above, the lineage heads were the military representatives. There was one military representative who became the regional military chief (*Umutware w'Umuheto*) linking many different lineages from the same area (Rusagara 2009). The military was greatly strengthened during the reign of Rujugira during the eighteenth century resulting in a regional powerful Rwanda (Mamdani 2001).

In addition to the military, marriage also provided an instrument to integrate different lineages. Rwandan society followed exogamic patrilineage (Vansina 2004) meaning the bride

¹¹ *Inzu* is the word for house also.

¹² Note that the word *umuryango* is the same word for gate and also lineage however the pronunciation is different. This word pronounced as gate was also used to express membership in the HIV ishyirahamwe. When I first worked with the groups, they welcomed me to the group using the term, *umuryango wacu* or our family.

would move and live with the husband's family after marriage. The woman and their children also took the social identity of the husband (Mamdani 2001). Bridewealth was paid to the bride's family in the form of cows (see Figure 4) after a series of intricate ceremonies. The cow was a very important signifier of wealth in Rwanda. The more cows one had, the wealthier they were considered. The photo below shows a special kind of cow, *inyambo*, which was normally used during the wedding ceremonies. During one of the wedding ceremonies, there was a cow poet who came and sang to the cows that were given to the bride's family. The cow was an important symbol in Rwanda. Having many cows made one's family a herding family, or in the past *abatutsi*, impacting their ethnic group (see below).



Figure 4: Traditional cows at the King's Palace Museum (photo by Jennifer Ilo Van Nuil)

The kinship terms for the extended family or *inzu* are listed in the table below. The family members from these relationships sometimes lived on the same hill but not always. On the father's side, for example, the relationships were based on your own father's siblings. Normally your father's brother's children would be considered your siblings also. However the children of your father's sister were considered your cousins. If you were a male, then your

brother's children were also considered your children and you were expected to help care for their children should something happen to your brother. The same terms are used for siblings from the same father, forming the *urugo*. *Mukuru wanjye* is used for the same sex older sibling and this is the same prefix used for the son of the father's brother, see Tables 1 and 2. The same applies for the mother's relationships, that is, one's mother's sisters' children were also considered your siblings but your mother's brothers' children were considered your cousins.

Kinship Terminologies: Inzu	
Kinyarwanda	English
<i>Data wacu</i>	My father's brother (literally "our dad")
<i>Masenge</i>	My father's sister
<i>Mukuru wanjye wo kwa data wacu</i>	The son of my father's brother (older than me)
<i>Murumuna wanjye wo kwa data wacu</i>	The son of my father's brother (younger than me)
<i>Mushiki wanjye wo kwa data wacu</i>	The daughter of my father's brother (older or younger)
<i>Mubyara wanjye wo kwa masenge</i>	The son or daughter of my father's sister (cousin)
<i>Sogokuru</i>	My grand father
<i>Nyogokuru</i>	My grand mother

Table 1: Kinship terminology *Inzu*¹³

Kinship Terminologies: Sibling Relationship	
<i>Urugo</i>	
Kinyarwanda	English
<i>Mukuru wanjye</i>	My older same sex sibling
<i>Murumuna wanjye</i>	My younger same sex sibling
<i>Musaza wanjye</i>	My brother (any age) if female
<i>Mushiki wanjye</i>	My sister (any age) if male

Table 2: Kinship terminologies sibling relationships

The basic kinship demonstrates that the family unit was much larger than a nuclear family and the lineage was very important in family relationships, especially the male lineage. From my experiences in Rwanda, I learned that many people acknowledged each other as blood

¹³ From SCALI course, Bayingana 2010

relatives, even though the relationship was often quite distant. There were only 18 *ubwoko* in all of Rwanda (Harrow 2005). Therefore to be distantly related to someone in a system of only 18 lineages was not too surprising. In a country of about 11 million, it was no surprise that almost everyone in one social circle was distantly related through the lineage.

Rwandans normally have two names: a Rwandan name given at birth and a religious name provided at baptism (Longman 2009). There were no family or surnames to link people to one family, at least in one's legal name, as documented on legal paperwork. However before colonialism, people had multiple names including their lineage name as one of their formal names and obviously people did not have a religious name from the Bible as they had their own religion. During colonialism, the lineage names were dropped and religious names were added. People still knew their lineage name but it became termed *izina ry'iripagani* or "pagan names" in English perhaps so that people would stop formally using them. However, if you asked people today what their pagan name was, the majority knew. The reason for omitting the pagan name was not documented, however, it could be one of the ways the colonial powers tried to erase the relatedness of the population. In each clan, one could find members of both Tutsi and Hutu groups (Newbury 1978). Newbury (1978) does not indicate whether or not Twa were included also but considering the social nature of the terms, one would expect that Twa were also included within each clan.

Ethnic divide

This brings us to the complicated topic of ethnicity in Rwanda. Ethnic groups, in the past, were fluid and based on social class (Vansina 2004). There were three main social groups: the farmers (*abahutu*), herders (*abatutsi*), and hunters (*abatwa*) although the characteristics of each group were not entirely clear, there was a division of people based on these three groups (PRI

2004). There was each of the three social groups within one clan and intermarriage was common among all groups but especially between the Hutu and Tutsi (Mamdani 2001). These three groups all lived within the same hills of Rwanda, there was no division based on the hill (Harrow 2005).

Vansina (2004:175) cites an example: of the fluidity of ethnicity from pre-colonial times. There was a major Rinderpest outbreak during the rule of Rwabugiri, which caused many cattle to die. Because so many cattle had died, the *ubuhake*¹⁴ relationships were broken. The king then gathered all the surviving cattle and redistributed them to the most powerful chiefs leaving the small herders with no cattle. These herders then became Hutu farmers because they no longer had cattle in their possession (Vansina 2004). Other scholars argued that these relationships were indeed fluid, however migrating from one group to another did not happen that often but occasionally a Hutu could gain cattle and migrate from being a Hutu to a Tutsi during a process called *kwihutura* (remove Hutuness) (Mamdani 2001). There was no Kinyarwanda word for the migration from a Tutsi to a Hutu, as described by Vansina. There was only a word for the migration from Hutu to Tutsi. These examples indicated that the social groups were fluid and it was possible indeed to change social groups. The fact that there was only a word to describe the move from Hutu to Tutsi demonstrated that perhaps this change occurred more often.

Rwandans could obtain a loan of cattle but acquiring cattle in this manner could not shift one's social status to *umututsi*. This relationship between the loaner and the loaned was called *ubuhake* relationships (Oliver 1977). Loans were also used among the population in times of disaster, such as generalized famine. The social fabric would deteriorate, many people would die, but the herders who survived often took loans from colleagues to rebuild the society (Vansina

¹⁴ *Ubuha* is a traditional contract of loaning cattle. *Ubuha* is derived from the verb *guhaka*, which means to be pregnant but is only used in reference to cattle.

2004). Servitude and loans were a few examples of the ways in which Rwandans came together to solve issues. Yet these same relationships also created an economic divide among people.

Kinyarwanda: The language that unites

Before colonialism, everyone in the region¹⁵ spoke one language, Kinyarwanda. Kinyarwanda is a Bantu language essentially the same as Kirundi, the language spoken in Burundi, the country located just south of Rwanda. The fact that the whole of Rwanda speaks one language is a unique feature in the region as most countries in Sub-Saharan Africa have multiple local languages and dialects. At present these groups communicate through a national language, such as Swahili or English in East Africa or French in West Africa¹⁶. But in Rwanda, there was only one local language, Kinyarwanda. The common language was and continues to be the “language that unites” all of Rwanda (Muzungu 2012). Kinyarwanda was prized as being the vehicle of unity and culture for all Rwandans as well as “an important factor of protection against cultural alienation, and of intercultural exchange, the reason for which it must be preserved with pride” (Gakuba 1996:51). Alexis Kagame studied Kinyarwanda as a vehicle to understand ways of being for Rwandans (Ukwamedua 2011). The language of Kinyarwanda was an important component to this research, not only as a mode of communication, but also as a way of trying to understand different concepts of Rwanda.

Colonialism, Independence, and Genocide

The Germans arrived in the territory of Rwanda in 1897 when King Yuhi V Musinga had only recently taken the throne (Longman 2009). Not long after, missionaries first arrived in

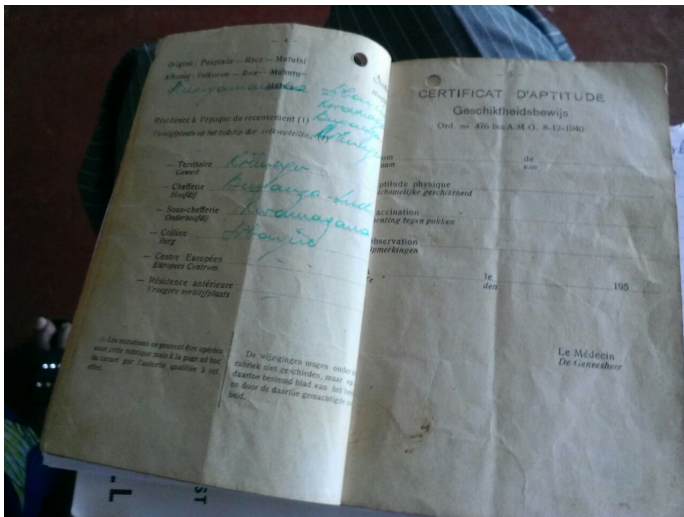
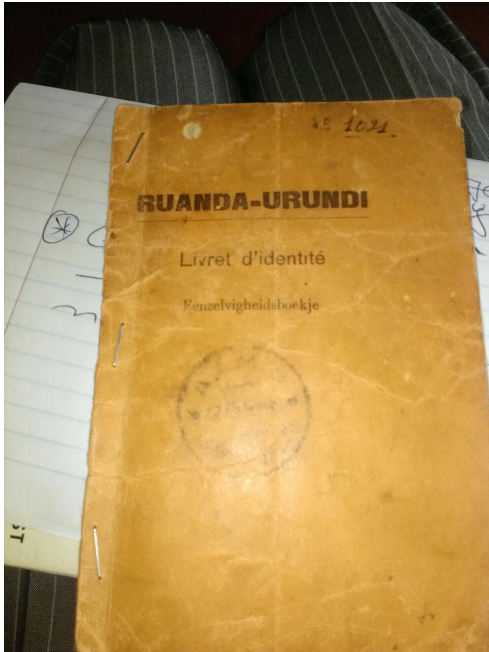
¹⁵ Kinyarwanda speakers include those residing in modern day Rwanda but also areas Eastern Congo (Kivu north and south), Southern Uganda, Western Tanzania, and the whole of Burundi.

¹⁶ The official languages used in Rwanda were Kinyarwanda, French and English. The official language was French until 2009 when the government switched the official language to English although French was still recognized as an official language.

Rwanda, in 1900 (Longman 2009). After the first world war, Germany lost the current territory of Rwanda and Burundi to Belgium (Meredith 2011). During colonization, colonists used traditional practices to help rule the population. One such example was the court system and the use of a local court procedure called *gacaca*¹⁷. Western style courts were introduced by Belgium but *gacaca* courts were used at local levels though the “legitimacy of the *gacaca* waned when the king and chiefs lost authority” (Clark 2010). The colonists also realized that there were three different groups in Rwanda, including the Tutsi, Hutu, and Twa groups.

Colonists and anthropologists started to base/classify everything on the three ethnic groups, Tutsi, Hutu and Twa (Mamdani 2001). To provide an idea how ethnicity in Rwanda was reinforced by the colonial powers, I provide examples of identity cards that were introduced and used by the Germans, then later cards that were used by the Belgians, and finally identity cards that were given to families who fled Rwanda and came back. The classifications of each person were listed on the identity cards that were first introduced by the Germans (see Figures 5 and 6). The cards were meant for those people residing in the areas of what is now Rwanda and Burundi. Note on the inside of the card, the “origin” or “race” was listed as *Mututsi, Muhutu, or Mutwa*. This followed the migration hypothesis indicating that each group came from a different place or origin. Also interesting was the fact that this designation line was not specified in Kinyarwanda, but in German, French and Afrikaans. The majority of the population did not speak the languages on the card so all they could understand was their social group listed.

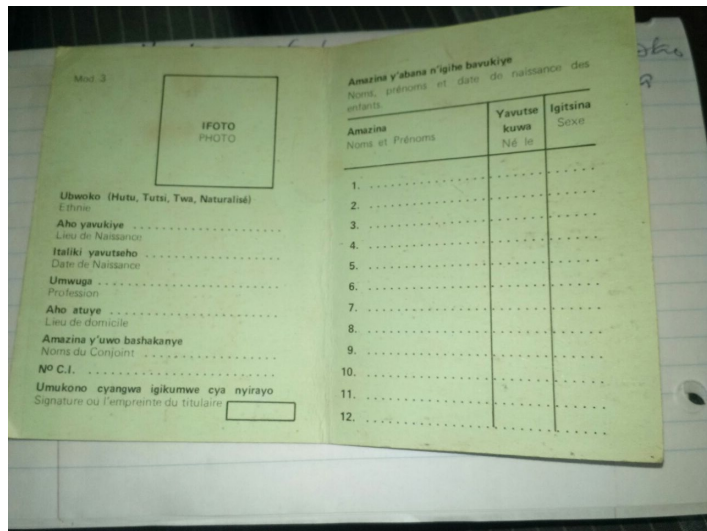
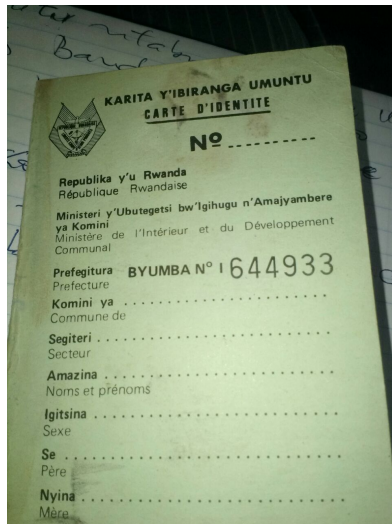
¹⁷ *Gacaca* is again discussed in chapter four.



Figures 5 and 6: The first identity cards introduced by the German in the late nineteenth century (photos by Peterson Gasangwa)

The next example was a card introduced by the Belgians (see Figures 7 and 8). On these cards, the social groups are listed as clans or *ubwoko* in Kinyarwanda. As mentioned previously, there were only 18 clans in all of Rwanda, however, on the identity cards, the clans listed were the three social groups, Mututsi, Muhutu, or Mutwa. By this time, the clans had been reduced to

the three social groups indicating to the population that these affiliations were clans, not social groups. The changes on the cards and the card itself were part of the process of instilling these social groups into the population and it is clear that there were multiple influences on ethnicity in Rwanda, as well as the culture in general.

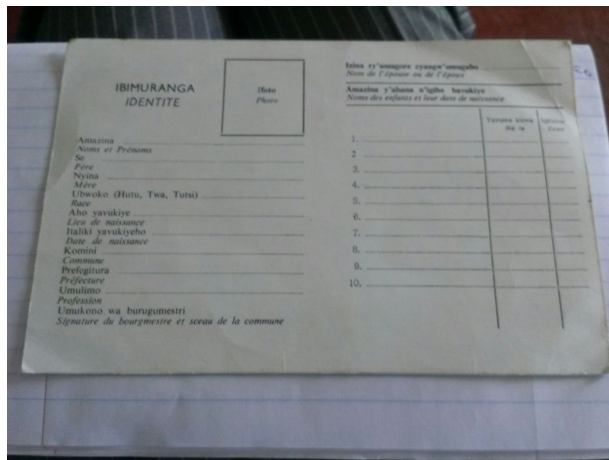
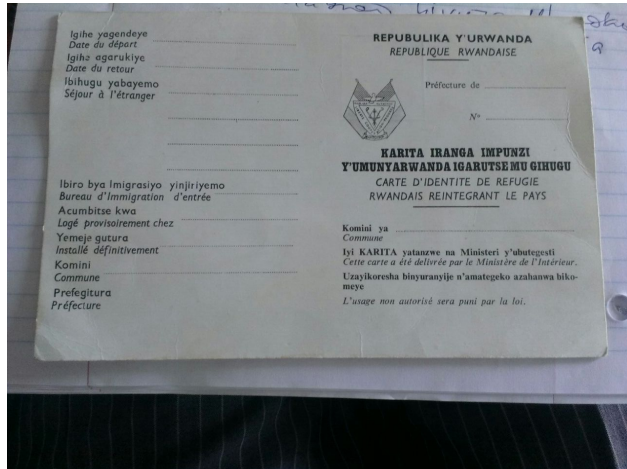


Figures 7 and 8: The identity cards introduced by the Belgians in the early twentieth century (photos by Peterson Gasangwa)

At the end of the 1930s, ethnicity was a defining feature in life in both Rwanda and Burundi and collective identity “shriveled and died” by the 1950s (Meredith 2011). The economic and political structures were challenged with the publication of BaHutu Manifesto in 1957 (Meredith 2011). In 1959 the first Hutu Revolution in which mainly Tutsi chiefs and sub chiefs were killed led to the foundation of the First Republic in 1962 after the coup d’état of Gitarama in 1961 (Desrosiers 2014). There were several other instances where many Tutsi were killed, the largest in 1963, resulting in Tutsi families leaving Rwanda to other countries (Desrosiers 2014).

Habyarimana came into rule in Rwanda in 1973 after a coup (Desrosiers 2014). During the reign of Habyarimana from 1973 - 1994 some of the Rwandans who fled, many from

Uganda, came back. The Rwandans who fled to Uganda faced violence in the 1980s from President Milton Obote and although Habyarimana blocked the border, some refugees returned to Rwanda (Longman 2009). However, upon their return, they received a special identity card from the government that indicated that they were refugees, not Rwandans. The card still listed the three social groups as *ubwoko*, now translated as race (see Figures 9 and 10).



Figures 9 and 10: The identity cards for returning refugees during Habyarimana's regime (photos by Peterson Gasangwa)

This was all taking place during the same time as when Rugamba, the artist presented in the introduction to the chapter, wrote and performed songs to remind Rwandans that

“gushyirahamwe ni byiza” or to come together is great. This same type of rhetoric calling for the unity of all Rwandans was used by Habyarimana during the Second Republic, even the same “we are all Rwandans” talk (Desrosiers 2014). However one main difference was that Habyarimana’s regime did not look to “traditional” Rwandan values; it favored a “renovated” culture (Desrosiers 2014).

Despite the promotion of unity, tensions remained in Rwanda from independence until ultimately the 1994 genocide. This coincided with the advent of the HIV epidemic in Rwanda. The first confirmed HIV/AIDS cases were reported in Rwanda in 1983 (USAID 2012) just two years after clinicians first identified the five cases of *Pneumocystis carinii* pneumonia in USA (Pepin 2011). Only three years later, in 1986, Rwanda was considered one of the top countries in Africa hardest hit by the epidemic with urban rates at 17.8 percent and rural rates around 1.3 percent (USAID 2012). The dramatic levels of HIV prompted the MoH to build educational prevention campaigns and to create a National Commission for AIDS (USAID 1999). The HIV epidemic also brought many health related NGOs and larger scale projects to enter Rwanda to provide assistance, as was the case in many countries around the globe.

In 1986, Rwanda conducted its first national prevalence survey from which educational programs were designed (Kayirangwa, et al. 2006). Shortly thereafter in 1987, the MoH alongside the World Health Organization’s (WHO) Global Program on AIDS, began to develop the First Medium Term plan (1988-1992) with an emphasis on HIV prevention targeting blood transfusions, health education and epidemiology (USAID 1999). The Second Medium Term Plan (1993-1997) focused once again on HIV prevention but also prioritized helping affected families economically (USAID 1999).

All these efforts were disrupted by the continued political chaos in the early 1990s and completely halted by the genocide in 1994¹⁸. During the 1994 genocide in 100 days over 1,000,000 Tutsi and moderate Hutu were killed. The Rwandan Patriotic Front (RFP), at that time a liberation group formed in Uganda, came into Rwanda, stopped the genocide, and took leadership of the country (Longman 2009).

The high levels of social integration, like a united language for example, that were used for good were also used for bad. Radio announcements became one of the main venues to spread ethnic propaganda, especially leading up to the 1994 genocide (Li 2006). A community works day called *umuganda*, discussed further in chapter four, was used during the civil war and 1994 genocide as a place to identify people to kill (Twagilimana 2007). The high levels of social integration could not stop genocide or the hatred that led up to it because the social integration in part fueled the genocide.

The longstanding conflict had an enormous impact on HIV rates, especially in the rural areas. During the genocide, rape was used as a weapon of war. *Interahamwe*¹⁹ who knew or assumed they had HIV would rape women to spread the disease and “guarantee long-suffering and tormented deaths” (Donovan 2002:s17). The HIV rates in rural areas increased from 1.3 percent in 1986 to almost 11 percent in 1998 (USAID 1999). Figure 11 at the end of this chapter provides a timeline of events regarding basics of the *amashyirahamwe*, ARV accessibility, and HIV prevalence and how each overlaps with the others over time, from 1995 - 2015.

Imagine a world where the country was physically destroyed, the social fabric was completely destroyed. Trust among neighbors and families had completely eroded. If the rhetoric of coming together was indeed a part of “Rwandan traditional culture” then Rwanda had a long

¹⁸ The conflict in Rwanda began in 1957 and lasted until after the 1994 genocide.

¹⁹ Describe: note the same suffix “hamwe” as in *amashyirahamwe*.

way to go to come back together as suspicion among the community took the front line: this was the new Rwandan landscape.

The aftermath

After the new government was established, the leaders of Rwanda stressed reconciliation. Part of this push was to bring all Rwandans back together, regardless of their ethnicity, to reconcile and realize that they were always and will continue to be part of the same country, Rwanda. Everyone was Rwandan. But this was no easy task, especially because this same rhetoric was used, although in a very different way, during Habyarimana's early regime (Desrosiers 2014). Within the context of reconciliation were remnants of genocide ideologies and constant reminders of colonialism, which was blamed by some for the genocide itself: "If there wasn't colonialism, there would not have been a genocide" (Muzungu 2012).

During the aftermath of the genocide, the international community shifted funding priority to reconciliation and justice issues (Uvin 2001). Some donors did not want to give funding to Rwanda fearing the country's stability or viewed Rwanda as a "lost cause" (Binagwaho, et al. 2014).

In other contexts, a national foreign language was used to unite the cultural groups but in Rwanda, Kinyarwanda, the local language, was the language in which most Rwandans could communicate with each other. However, as noted by Gakuba (1996), after the genocide, people in Rwanda, especially in work scenarios, tended to group based on the foreign language that they spoke (i.e. French or English). Gakuba (1996:53) warned Rwandans that this linguistic division "will end up leading us to the Babel Tour" and later to a country with no language, hence no culture.

Shortly after the genocide, United States Agency for International Development (USAID) continued HIV related programs and assistance in Rwanda in 1995, allowing for rapid activities to begin shortly after the conflict ended (USAID 1999). Additionally ARVs became available in Rwanda in 1996 to a limited number of people (GHF and Development 2009), normally administered to the wealthy and those based on membership in *amashyirahamwe* (FHI 2003). At this point, *amashyirahamwe* slowly began to emerge and became one way for people to access not only ARVs but also other resources that were being streamed in through NGOs. In 1997, National AIDS Control Commission²⁰ (CNLS) was formed coupled with the decentralization of health services. HIV became a national priority as well as a national tragedy as AIDS became one of the three principal causes of death in Rwanda claiming 36,000 people's lives in 1997 alone as well as reducing "life expectancy from 54 to 42 years" (USAID 1999). By 1999, there was a 23% increase in the MoH budget overall, with a large priority placed on HIV services (USAID 1999).

Rwanda after year 2000

By 2003, still only those living in Kigali had reliable access to ARVs (Binagwaho, et al. 2014). However, there was a dramatic scale up of ARV access in Rwanda in the years that followed. There were two international programs, the Global Fund to Fight AIDS, Tuberculosis, and Malaria and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) that dramatically increased access to ARVs in Africa beginning in 2004 (Crane 2013). The number of people on ART increased from 870 people in 2002 to 44,400 people (59% women) in 2007, and Rwanda achieved "the highest coverage of any low-income country for ART (71 percent) in that

²⁰ CNLS has now become part of Rwanda Biomedical Center (RBC) but in 2003 CNLS was the government agency under the Ministry of Health responsible for HIV/AIDS programs and research.

year” (GHF and Development 2009). Then by the end of 2009, Rwanda had 88% ARV coverage and was one of only eight low- to middle-income countries²¹ that had realized the WHO’s 2010 guidelines for ARV treatment access, specifically providing treatment to at least 80% of people who need it (WHO, et al. 2010). The leaders of the G8 countries discussed the goals of universal access to care and treatment by 2010 (WHO 2006). Rwanda had one of the more successful responses to ARV access and also managed to keep the HIV prevalence quite low compared to other developing countries.

Between 2005 and 2010, the overall HIV prevalence remained unchanged at 3% as documented in the Rwandan Demographic Health Surveys. Also unchanged was the gender balance with 2% men infected with HIV between the ages of 15-59 and 4% females aged 15-49 (NISR, et al. 2011). According to more recent data from 2011, about 3% of the total population (total population was estimated in 2010 at around 10,400,000 people) was living with HIV in the country, with rates much higher in the city of Kigali (around 7%) than in the more rural areas (rates ranged from 2.1%-2.7%) (NISR, et al. 2011).

In the years that followed, Rwanda continued to develop and build its reputation among the development world. Rwanda became a poster child for development and was often referred to in popular culture as the new Singapore because of its rapid development efforts, specifically in business and infrastructure (Anonymous 2012; Caryl 2015). At the same time, Rwanda was also very much remembered for the genocide. Rwanda was often still considered a “war-torn” country, even 21 years after the genocide with many years of peace and stability since that time. There were references in popular culture about “war-torn Rwanda” including an account in

²¹ The eight countries included Botswana, Cambodia, Croatia, Cuba, Guyana, Oman, Romania and Rwanda (WHO, et al 2010). However, by the end of 2010, this had increased to ten countries to include Namibia, Chile, and Nicaragua (WHO, et al 2011).

People magazine where Christina Aguilera, a famous American musician, stated that she had visited “war-torn Rwanda” (Leonard 2013). Although misinformed, these references indicated that the world still has a perception of Rwanda as being under conflict while at the same time, a land of opportunity.

Homegrown solutions

April 2014 marked the 20th anniversary of the 1994 genocide in Rwanda and despite the mass violence and complete societal destruction, Rwanda rebuilt its society and healthcare infrastructure, using what officials termed as “participatory approaches” that focused on incorporating local populations in its design and implementation, specifically “inclusion, people-centered development, and social cohesion” (Binagwaho, et al. 2014:1). These policies were all initiated by the GoR and have been implemented countrywide since the early 2000s.

The homegrown initiatives and/or solutions used similar language that revolved around the idea that the policies were created using Rwandan traditions and cultural practices. The Rwanda Governance Board (RGB) described these home grown initiatives/solutions on its website and included ten examples of different policies: *abunzi* (mediators), *gacaca* (community based courts), *girinka* (one cow per family), *imihigo* (performance evaluation), *ingando*, *itorero*, *ubudehe* (poverty reduction, described in the beginning of chapter 5), *umuganda* (community works day), *umushyikirano* (national dialogue), and *umwiherero* (national leadership retreat) (RGB 2014a). Other examples in the health sector included the community-based health insurance (*mutuelles de sante*²²) and community health workers (*abakorana bushake b’ubuzima*²³), among others (Binagwaho, et al. 2014). The RGB website listed several of the

²² French. Commonly known by locals as *mutuelles*. In English: community health.

²³ English: Voluntary health workers. These health workers are normally not paid, they are volunteers from the community.

aforementioned policies that were “being used as best examples of how a country and its citizens can solve their own problems using their tradition and culture” (RGB 2014a). Further, RGB stressed how these programs helped to “reconstruct Rwanda and nurture a shared national identity” precisely because the programs used “aspects of Rwandan culture and traditional practices to enrich and adapt its development programs to the country’s needs and context” (RGB 2014c). However, the “traditional practices” were seldom explained and if they were, it was not that closely related to the current policy. For example, *umuganda*, or community works day, was a mandatory day of work each month for all citizens in Rwanda where neighbors would work on a given project in their neighborhood together as a group. RGB claimed that the “traditional” practice upon which *umuganda* was based included when “members of the community would call upon their family, friends and neighbors to help them complete a difficult task” (RGB 2014a). However, Barnhart (2011) argued that in the past, the most closely associated practice to *umuganda* was *uburetwa* where families would work for the chief two days of every week (Barnhart 2011). *Uburetwa*²⁴ as a definition, was essentially slavery or forced labor (Twagilimana 2007). Professor Bernardin Umuzungu, a Rwandan professor and historian, informed me that the past *umuganda* was regulated by the king and organized within the lineage and involved working for the country (Muzungu 2012). More recently, *umuganda* was initiated by Habyarimana in 1974 as a community development initiative (Twagilimana 2007). As mentioned earlier in this chapter, *umuganda* was used during the genocide to identify Tutsi to kill. In the area of Gisenyi (north western Rwanda) from 1990-1992, the majority of the killings were done at “special *umuganda*” sessions in the community (Twagilimana 2007:164).

²⁴ In Kinyarwanda *umuretwa/abaretwa* means a slave/slaves.

The histories of Rwanda were recreated in a way of demonstrating to the Rwandan population that they could all exist peacefully together just like their ancestors did before colonial times. The picture of Rwandan history was painted in a way that did not exclude ethnic groups from the history (although it also did not mention ethnicity outright) but stressed the importance of the home grown solutions from the past as a way of convincing the population that they could go back to their pre-colonial roots where everyone came together to solve the problems. This was in contrast to another government program called “Ndi Umunyarwanda” (I am Rwandan) that essentially encouraged everyone to acknowledge that he or she was a Rwandan, in contrast to a Tutsi or a Hutu or a Twa.

Conclusion

The language used to encourage people to come together and solve problems locally was one of the GoR’s attempts to bring people back together, after years of ethnic separation and create national unity. This use of language in creating a new Rwanda was a performative act by the government. The “home grown” initiatives gave the population the impression that creating *amashyirahamwe* and other collectives were the ways of the past and the way to move forward, like in the past. Speaking in this way about the programs provided legitimacy for the social forms but in reality it was a strategic manner to reconcile on some level. In this chapter, I tried to give a brief history of how Rwandans came together (and apart) in the past while at the same time provided a brief understanding of the multiple influences on Rwandan culture and its documentation over time including *abiru*, colonialism, religion and politics concerning the ethnic tension. Certainly there were divisions based on the three ethnic groups before the colonists arrived; these divisions were part of the history of Rwanda. The impact of the divisions was enhanced by the colonial powers for their own interests, as was the case in other contexts across

the continent of Africa. The years of subtle violence and discrimination surely remained in people’s minds and certainly the devastating effects of the genocide remained readily apparent on the surface of people’s lives. These experiences, though not always expressed, played a role in shaping the experience of everything in people’s lives, including membership in the HIV *ishyirahamwe*.

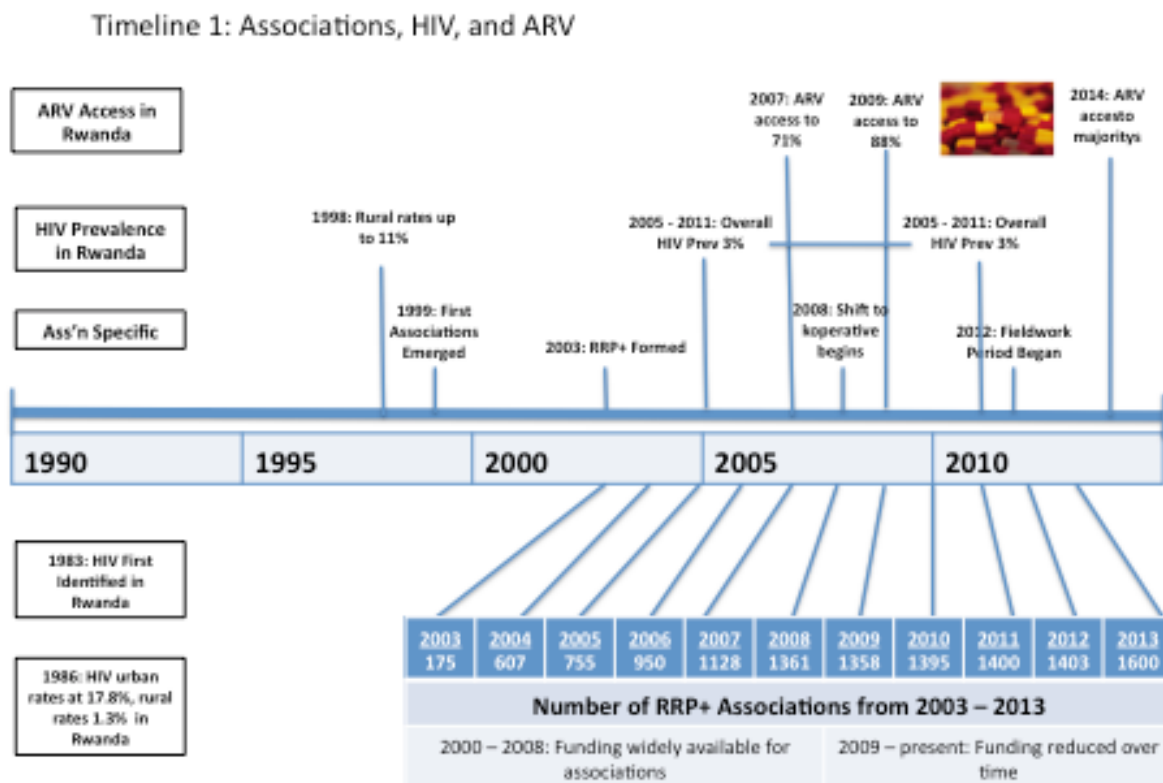


Figure 11: Timeline of Associations, HIV and ARVs

CHAPTER 3 SAMPLE

Introduction

When I first arrived in Rwanda to conduct my research, I already had contacted Felicien who was, at that time, working with RRP+, the umbrella group for all *amashyirahamwe* for people living with HIV. We met in person shortly after I arrived in Rwanda in 2012 at a popular coffee shop known to cater to ex-pats and wealthy Rwandans. In our first meeting, we discussed how to gain access to individual *amashyirahamwe*. Felicien suggested that I first obtain my approvals from the government officials and then approach the executive secretary of RRP+ and request to conduct research among *amashyirahamwe*. The process to gain the necessary approvals in Rwanda took about three months so during this time I met informally with other people who had access to *amashyirahamwe* to see if I could also work with some other types of *amashyirahamwe*. During my work with FHI, I heard of an *ishyirahamwe* for people living with HIV who were also genocide survivors but this *ishyirahamwe* was under a different umbrella group, *Ibuka*²⁵ Rwanda. *Ibuka* Rwanda was an umbrella group for all the *amashyirahamwe* related to genocide survivors.

I spent some time with the executive secretary of *Ibuka* Rwanda. At that time (early 2012), there were 15-member *amashyirahamwe* under the umbrella. *Ibuka* Rwanda began in 1995 when 13 separate *amashyirahamwe* for genocide survivors merged together, much like RRP+ only on a smaller scale, to speak and advocate for the survivors of the 1994 genocide. *Ibuka* Rwanda was the voice of the survivors and responded to survivors' concerns. One member *ishyirahamwe* was AVEGA²⁶, the *ishyirahamwe* for widows from genocide. AVEGA was

²⁵ *Ibuka* is a Kinyarwanda word meaning remember. *Kwibuka* means to remember.

²⁶ AVEGA is a French acronym "Ishyirahamwe des Veuves du Genocide", or in English, Association of the Widows of Genocide.

known informally as the *ishyirahamwe* for people living with HIV for genocide survivors. The executive secretary told me in our first meeting that I could conduct my research project with their *amashyirahamwe* as well. When I told Felicien that we could add an *Ibuka* Rwanda site to our sample, he told me that it would cause too much confusion. Based on bureaucratic rules of research in Rwanda, I would have to choose either *Ibuka* Rwanda or RRP+ to be my primary contact organization. I decided to focus this project on the *amashyirahamwe* under the umbrella group RRP+ because I had already started the process of gaining access with them and also because they had many more *amashyirahamwe* within the network.

Site Selection

According to RRP+ records, as of November 2011, there were over 1,400 registered *amashyirahamwe* and/or *koperative*²⁷ for people living with HIV in Rwanda (see table 3 below). At this time, there were around 80,000 members and about 25% of the members were documented as not living with HIV. Based on these same data, there were two times as many women than men in *amashyirahamwe*. The gender imbalance was a concern for RRP+ and RRP+ leaders told me that they wanted to focus their future efforts on encouraging more men to join the groups to even out the gender imbalance.

I worked with the executive secretary of RRP+ to select the *amashyirahamwe* that would be included in the study. I wanted to include groups that had current membership with RRP+ and that actively worked in the community at least two times per month. Considering there were over 1,400 *amashyirahamwe* in Rwanda at that time, I narrowed the focus to include one group from each province. I decided to select one *ishyirahamwe* from each province so that the research sites would be spread across the country. When I first went to Rwanda in 2008, I was told that each

²⁷ The intricacy of *koperative* is fully described elsewhere (chapter 9).

area of Rwanda, which corresponded with each province, had different issues, for better or worse. The Eastern Province had problems with malaria, the West with high fertility rates, etc. These little “facts” were not true at all but I still decided to select one *ishyirahamwe* from each province as a way to gain a perspective from different areas.

From each province, the *amashyirahamwe* were selected from a district with an HIV rate over the national average of 3%. In addition, I selected sites that had over 25 regular members and those that were not part of another RRP+ affiliated study²⁸. Table 3 lists the HIV prevalence in each district in Rwanda (far right column) as noted in the Demographic Health Survey²⁹ (DHS) in 2010. The highlighted rows are the districts from which we selected the specific *amashyirahamwe*. The Kigali City province included three districts: Gasabo, Kicukiro, and Nyarugenge, each with HIV rates well above the national average: 6.4%, 7.9%, and 8.3% respectively and as such, I selected a group from Nyarugenge because the rate was the highest. I selected groups from the areas with higher HIV rates because I thought that these districts would have more *amashyirahamwe* from which to select the five *amashyirahamwe*.

²⁸ This was a request from the director of RRP+ as there was another active study going on at the same time.

²⁹ The DHS is a nation-wide health survey that has been conducted since 1992 by the Government of Rwanda through collaboration with National Institute of Statistics of Rwanda and Rwanda Ministry of Health with technical assistance from ICF International. It was done in 1992, 2000, 2005, 2007-08, and the most recently in 2010.

No	District	Total in district	Total members	Total HIV+	Females	Males	HIV Prev in District
1	Bugesera	61	3784	2754	2714	1070	1
2	Burera	28	1749	1704	1149	557	3.5
3	Gakenke	45	3162	2910	2043	1121	1.4
4	Gasabo	69	5549	2578	1998	580	6.4
5	Gatsibo	34	3281	2968	2075	1206	0.9
6	Gicumbi	78	3903	2920	2039	881	3.4
7	Gisagara	24	1194	1123	869	261	1.1
8	Huye	51	2443	1541	1970	484	3.5
9	Kamonyi	18	920	892	667	209	3.1
10	Karongi	40	1980	1858	1402	578	3.3
11	Kayonza	61	3320	2734	2109	625	3.7
12	Kicukiro	69	4241	3160	3165	1076	7.9
13	Kirehe	68	3187	1955	1195	734	1
14	Muhanga	46	2008	1773	1477	531	2.9
15	Musanze	57	1984	1786	1211	575	2.7
16	Ngoma	57	2330	1632	1159	482	2.6
17	Ngororero	46	2765	2195	1938	821	2.1
18	Nyabihu	46	2103		546	1333	2.7
19	Nyamagabe	24	1969	1443	1294	675	2.8
20	Nyamasheke	66	4185	3550	2883	1302	3.6
21	Nyanza	24	1327	1086	770	217	2.1
22	Nyarugenge	76	5918	3995	4282	1539	8.3
23	Nyaruguru	23	1464	1066	952	512	0.9
24	Rabavu	55	2709	1964	1901	808	2.8
25	Ruhango	30	1378	1322	973	385	2.5
26	Rulindo	40	2035	553	1630	406	1.7
27	Rusizi	48	3202	2812	1944	868	2.8
28	Rutsiro	46	4737	2272	1942	2795	3.4
29	Rwamagana	70	1989	1989	1318	671	4.6
30	Nyagatare						1.9
		1400	80816	58535	49615	23302	3.02
Dated November 2011							

Table 3: HIV prevalence and selected associations districts. Highlighted rows indicate the districts where research was conducted within the associations.

I gave the criteria listed above, including the districts in which I wanted to select the *amashyirahamwe*, to the executive secretary of RRP+ and he selected the *amashyirahamwe*

where I would conduct the research. He provided the basic demographic information of each group as well as the leaders' names and phone numbers. I was concerned that the executive secretary gave me *amashyirahamwe* that he knew were working well (whatever that meant) in the community, like the model *amashyirahamwe* or groups that he knew had successfully completed the transition to *koperative*, as this was a goal of RRP+ at that time. I never fully understood how he chose the *amashyirahamwe* that were selected, however, this was our agreement and the only way I could access the groups.

After a few months, I no longer thought that he gave me model *amashyirahamwe* for two reasons. First, when we first contacted the Kigali *ishyirahamwe*, called *Abihuje*, that was given to us, the president of the *ishyirahamwe*, a female named Berte, was hesitant to set a meeting time and date. She changed the date several times and told us that the group only met formally a few times in a year. Later Berte informed me that she did not understand what I wanted and thought I only wanted to meet the members once or twice. While this was occurring, I asked the Executive Secretary of RRP+ if we could select another group in Kigali because I really wanted groups that actively met on a regular basis to be part of the sample. He stated that we could select another group and Felicien suggested a group that he had worked with in the past. This new plan was okay with the Executive Secretary although we ended up selecting the original Kigali group after Berte better understood the research plan. Second, as will be demonstrated throughout this work, the *amashyirahamwe* he selected were struggling with the transition to *koperative*. These cases made me think that he did not select the model *amashyirahamwe* to join the study but I cannot confirm this either way. He may also have had a different definition of “model” than me.

Permission from the community

Although my official affiliation with RRP+ granted me access to all *amashyirahamwe*, there were certain people who had to be aware of the research in the communities in which I worked. RRP+ informed their district representatives about the research who informed their district *amashyirahamwe* that research would be conducted across RRP+ *amashyirahamwe* in that district. I had the opportunity to meet with each RRP+ district representative at least one time throughout the course of the study. In addition, before the initial site visits, I had to inform the mayor of each district and the executive secretary of each sector that I would be in their district and sector for the purpose of my dissertation research. In one case, the mayor requested a meeting to welcome me to the district. In another case, the executive secretary of the sector went to visit the research site when I was there to visit. He gave a small speech on the exceptional work of that particular *ishyirahamwe* and helped the group to cultivate a field for a few minutes.

After all officials were notified and no objections were declared, we then contacted the individual *amashyirahamwe* that were selected. I visited with each of the five specific *amashyirahamwe* that were provided to me by RRP+ first with an introduction meeting. Before the visit, Felicien contacted the *ishyirahamwe* leader, explained the project, and requested a meeting time to meet the leaders and the members so that we could fully explain the study and request consent for participant observation within that group. After the meeting time and date were set up Felicien and I visited the *ishyirahamwe*.

Before the first meeting, I wrote a speech in Kinyarwanda and rehearsed it several times. At this early stage in the research, my Kinyarwanda was very basic but conversational³⁰. I started

³⁰ Before beginning the fieldwork in 2012, I studied Kinyarwanda informally during my first trips to Rwanda (summers of 2008 and 2009) although after coming home after each trip I knew only a handful of words and phrases. I learned basic conversation and grammar at the Summer

by stating that I am a student from a university in USA and I study anthropology, which is the study of people and culture. Then I explained that I wanted to learn what it is like to belong to an *ishyirahamwe* for people living with HIV. I wanted to learn by participating in their activities and being with them over the course of the fieldwork. Then Felicien spoke to the group about how I came to work in Rwanda in 2008 until present times and the duties and accomplishments of all the past work. Importantly, he explained how I had obtained permission from all the various agencies and leaders in the community. At this point in his talk, he took out the original documents from the government agencies and showed them to the members. Having these official documents from all levels made the access to the *amashyirahamwe* quite simple, we had no objections. We explicitly stated that participation was voluntary and members did not have to participate. However, these letters may have made it seem like there was no choice in participation. Because the letters were from officials, leaders, mayors, and RRP+, their umbrella group, members may have thought that they had to participate, especially because all the leaders supported the research. In retrospect, individual members may have not said anything, even if they did not agree with the research, because no one else was objecting. Not one group leader mentioned that members stopped coming to meetings or activities after the research started so I hope this was not the case³¹.

Finally Felicien detailed how I would attend the group meetings and activities, just like a member. If the group had a plan to work in the field, I would be there with them. If the group had a community meeting, I would attend. At the end of the meeting Felicien asked the members if

Cooperative African Language Institute (SCALI) Kinyarwanda course during the summer of 2010. The course was an 8-week immersion course at Michigan State University funded by Foreign Language Area Studies (FLAS).

³¹ The level of participation in research in Rwanda was normally very high. For example, the household response rate for the Demographic Health Survey conducted in Rwanda in 2010 was 99.8% (NISR 2011).

they accepted me as a temporary “member” of their group. All groups stated that yes I could temporarily “join” their *ishyirahamwe* but this meant different things to different *amashyirahamwe*. In all the groups, except the group in the Western Province, I attended meetings, income generating activities, and other events in the community. In the Kigali group *Abihuje*, I paid dues for *ikimena*, the rotating funding scheme, but I never took the entire amount, and I only contributed. In the other groups, I did not contribute any money for anything (e.g. *ikimena*, membership dues). In the North, I was supposed to attend all meetings and activities with the advisory nun although she normally attended everything anyway. Other instances of the level of participation in the groups are described in the chapters that follow.

I also conducted individual interviews across all research sites but the interviews were held toward the end of the field research phase, except in the West when I conducted the interviews to pilot the interview questions. I recruited for the individual interviews within the *ishyirahamwe* for the first round of interviews using a random sampling strategy. Later we selected interviewees based on specific criteria (e.g. new members or leaders). The *ishyirahamwe* members were told that we were coming for interviews so people who came to that meeting, typically on a different day than the normal meeting, knew that we were there for that specific reason. At the start of the interview meeting, everyone who was present wrote his/her name on a list. Felicien described in detail what the interview entailed, the types of questions that would be asked, and also that if they did not want to participate, they did not have to. He often began chatting with the group about the work I had done with the group. For example, he would ask the members if I attended the work activities as required or if I knew how to use a hoe. In the groups where I conducted extensive participant observation, the members would energetically tell him a few stories about my times with them. In groups where we used

the random sampling strategy, as Felicien was talking, I chose randomly by selecting participants from a list depending on the total number of people present and the total number of interviews desired for that group.

We then would meet with the four or five people chosen and ask them again if they were interested in participating in an interview. Everyone who was originally selected agreed to participate. Second, we asked them if they were available for an interview either the same day or the following day. Before each interview, we reviewed the research information sheet and obtained official oral consent from each interview participant, as required by Rwanda National Ethics Committee (RNEC).

Description of sites

Each *ishyirahamwe* that was selected is briefly described in the chart below and briefly described at the end of this chapter and in more detail in the findings chapters. The names of all the *amashyirahamwe* that are used in this dissertation were pseudonyms however the names chosen were representative of the types of names that were used for these types of groups. Normally the names used represented emotions that they wished to possess or different ways to be together. For example, *Abakundanye*, the pseudonym of the group in the north, means “we love each other”. The group in the south, *Humura*, as mentioned in chapter one, means “endure”. The group in the Eastern Province was called *Abihanganye* meaning “we have patience together”. In the West, the group was called *Twizere* or “let’s have faith”. Finally the Kigali group was called *Abihuje* meaning “those who brought themselves together”.

Name	<i>Abakundanye</i>	<i>Humura</i>	<i>Abihanganye</i>	<i>Twizere</i>	<i>Abihuje</i>
Province	<i>North</i>	<i>South</i>	<i>East</i>	<i>West</i>	<i>Kigali</i>
District	<i>Gicumbi</i>	<i>Kamonyi</i>	<i>Rwamagana</i>	<i>Rutsiro</i>	<i>Nyarugenge</i>
# Members (2012)	58	36	34	90	57
Year Started	1998	2004	2007	2002	2003
Registered Koperative	<i>Yes</i>	<i>No</i>	<i>No</i>	<i>Yes</i>	<i>No</i>

Table 4: Overview of selected sites, this information obtained from RRP+

Figure 12 below shows the location of each district where I worked within each province but the exact placement was an estimate to protect the confidentiality of the groups.



Figure 12: Districts where the associations were located where research was conducted

I briefly describe each association where the research took place below, beginning with the *ishyirahamwe* in the Eastern Province called *Abihanganye*.



Figure 13: A member's field from the Eastern Association (photo by Jennifer Van Nuil)
Abihanganye began in 2007 with only eight members. The local health providers from the clinic, which was located about one hour walking distance away from these eight people, gave them advice and encouraged them to seek ways to improve their wellbeing after they tested positive for HIV. The providers suggested they form an *ishyirahamwe* because they were poor and suffering from the consequences of HIV. The eight members agreed to start *Abihanganye* to help each other in times when they could not make it to the health clinic for advice.

At the time of the research there were 34 registered members according to RRP+ although the leaders stated that there were only 28 active members. When a member was registered into a group, it does not automatically mean that each member was an active and contributing member. The president of the *ishyirahamwe* told me that 28 members was an increase in membership for *Abihanganye*. In the past there were fewer members. The committee consisted of a president, a secretary, an accountant, and two counters, who were in charge of

counting all monies that crossed over the table to and/or from members for contributions or loan and/or payments. *Abihanganye* did not have an active vice-president so if the president was not available the secretary took on the role of president. The group met for meetings once a month on Fridays. Typically the meeting would begin around 9am and continue until 3pm. The group also worked with each other every week on Tuesday mornings from 7am until around lunchtime on various projects around the community. Normally around ten people were present for the community projects.

Abihanganye also provided social support and by that they meant encouraging new members to come out of isolation, talking with each other and helping each other when they were sick. If a member was sick and unable to tend to their fields, the group would come together and help the member in his/her field.

Some of the project money being saved for the *koperative* was being used to lend to the members if they needed a small loan. The members were charged 5% interest per month on small loans. The total loan amount was typically no more than 10,000 FRW and at each monthly meeting, the person could pay their entire loan and interest, pay only the interest, pay a portion of the loan or pay nothing but then interest would be added to the total amount for the following month. The interest was extra money for the ultimate goal of initiating the chicken project, which was their first idea for the cooperative activities. Basically, they wanted to raise chickens and sell the eggs and/or chickens for extra income.

In addition the group had monthly *ikimina* where each member contributed 600FRW³² and one person took the entire amount for that month. The amount of money given in *ikimina*

³² Less than \$1 (\$1 was about 650 FRW in 2012)

was 10,000 FRW³³ each month. The group also opened bank accounts for each member and taught them how to keep track of their money in their kept track of their own contributions in their booklet. The president of the *amashyirahamwe* would sign off in the bankbook each time they made a deposit or withdrawal. The president of the *amashyirahamwe* attended several meetings at RRP+ to learn how to keep basic records and accounting.



Figure 14: Researcher and Advisory Nun in the Northern Association Field (photo by association member)

Abakundanye, the *ishyirahamwe* in the Northern Province, started out with around 50 members and at their peak, there were over 120 members in 2010. Since that time, the number reduced to 58 at the time of the research. According to a member of this group, the reduction from 120 to 58 members occurred because some members died and others left because the group stopped receiving material support. When the members no longer received flour rations each month, many members stopped regularly attending and eventually dropped out of the group altogether. The group was first started in 1998 with the help of some local nuns who assisted the

³³ 10,000 FRW in 2012 was \$15.38.

amashyirahamwe with bookkeeping and other activities, as needed. The Catholic Church, which provided spiritual guidance, supported *Abakundanye*; however members did not have to be Catholic to join. There was always a nun who was in charge of helping the *ishyirahamwe* and served as a community liaison. The members viewed her as an advisor to the *ishyirahamwe*. Every year, the nun changed and a new sister joined the group. At the time of my research, the nun always accompanied me to the field site for all the meetings and activities I attended.

In addition to the advisory nun, there was also a president, vice-president, and accountant on the committee. The official *amashyirahamwe* meetings were only two times per year however, the committee met monthly on the last Thursday of each month. The members were debriefed immediately after each committee meeting. *Abakundanye* met every Monday morning at 6am for work on their *koperative* projects. Each member was also required to go to the *koperative* site and feed the animals, pigs, once a week with food that they gathered from around their homes. Members also brought food for the pigs whenever they came for a meeting or work but this was not a formal requirement of belonging to *Abakundanye*. There was a monthly prayer meeting where the members prayed, read the Bible, sang, provided spiritual testimonies, and helped each other through tough times. Although one did not have to be Catholic to join this *amashyirahamwe*, all religious proceedings were based on Catholicism.

Abakundanye had a field where they cultivated maize but the crop changed from season to season. This group also had a small boutique shop selling homemade cakes and tea. In addition to the crops, the group also had 32 pigs in small sheds behind the meeting location.

The group in the Southern Province was called *Humura*. Before *Humura* was created, there was not an *ishyirahamwe* in this village. However, there was an *ishyirahamwe* in the vicinity but it was very far away from the current location. Several members of the original

ishyirahamwe decided to start their own *ishyirahamwe*. These members broke off and started *Humura* in 2004. The sector gave the *ishyirahamwe* a small office when they first started so that they would have a place to meet. By 2005, there were 40 members and *Humura* even had several sponsors that helped by providing each member a chicken and a hoe, among other material support.

The committee consisted of a president, vice-president, secretary, and a committee of controllers who controlled the funds. The group did not have a treasurer but planned to elect one when they became a registered *koperative*. At the time of the research there were 36 active members, however, only ten would attend the work meetings on Saturdays. The group had well-attended monthly meetings which were organizational in nature, to plan events and discuss their work or to welcome guests such as district representatives from RRP+ or even district and sector officials. The group also met every Saturday morning to work in their field.



Figure 15: Kigali Association Barn for Goats (photo by Jennifer Van Nuil)

In 2003, there was a large *ishyirahamwe* in the Kigali vicinity called *Abihuje*. Because Kigali City, as a province, was relatively small in area, it was not unimaginable that there were 105 members including members from all three districts in the Province of Kigali. RRP+ helped

them to create the original group when it first started right around the time when RRP+ was first formed. Because the group was so large, they split into smaller groups of about 40 members after several years.

At the time of the research *Abihuje* had 57 members. The group built a barn where they raised goats as one of their income generating projects (see Figure 15). They also started to harvest mushrooms over the course of the research. In addition, they sold food at the market. The committee consisted of a president, vice-president, secretary, and treasurer. The group met on the 1st and 3rd Wednesday of the month and the 2nd and 4th Friday of the month. On Friday, there was *ikimena* in addition to community events such as education and home visits.



Figure 16: Field in Western Association where agricultural research was taking place (photo by Jennifer Van Nuil)

The *ishyirahamwe* in the Western Province was called *Twizere* and was started in 2002 with six members. At the time of the research, there were 120 members and *Twizere* had recently received their registration as a *koperative* in April 2012. In 2002 when the group first started they mobilized others to come together. This was their first task. After one year the six members

increased to 45. After two years the 45 members increased to 60. At the time of the research, there were 90 people in the *koperative* and 120 total members in the *ishyirahamwe*. There was a president, vice-president, secretary and accountant on the committee. The group met every Saturday to work but once a month, they had a meeting after the work to address social issues for those who were living with HIV. As part of their work, *Twizere* also conducted research on agricultural crops to determine which fertilizer was best for different crops.

From these basic descriptions, you can see that the amount of time members actually spent in their *amashyirahamwe* was quite limited. Planned activities were normally held once a week with formal meetings only once a month. Members saw each other informally in their communities, which was no surprise considering members often, but not always, joined the *ishyirahamwe* in their own community. Members, however, attended other social events with their *amashyirahamwe* (e.g. weddings, burials, visiting the sick). Many of the *amashyirahamwe* also conducted home visits if members were sick or not attending the meetings, for whatever reason. I had the chance to go for a day of home visits with the Kigali group, *Abihuje*, on one Friday afternoon, which is described in the next section.

Home Visits

An example of an afternoon of home visits follows. I waited for the Berte, the president of the *Abihuje* (the Kigali *ishyirahamwe*), on the side of the road. Berte, along with an older man, met me there and they both got into my car. She told me to drive north on the road. We waved goodbye to the by-standers and continued on our way. After about 5-6 km she told me to pull over. There was not a turnoff or place to park, just gray gravel on the side of the road. I pulled off and parked the car on the gravel near the edge of the road next to a steep hill. The old man got out of the car and stood there. Berte got out of the car and looked at me and told me that

we were now going. I asked her if I should leave the car there and she said it was not a problem. I turned the car off and locked the doors. The old man said that the location we were going was down the hill. Berte pointed and we walked down the side of the road. We arrived near the metal guardrail and she yelled back at the old man and he confirmed that we were heading down the right path. We jumped over the guardrail and headed down a small path that led down the hill.

Every time we passed a new plant she told me the Kinyarwanda name: banana, papaya, etc. Then we arrived at a house and entered into the compound. The fence surrounding the compound was made out of thick bushes. The house was a typical mud home with a metal roof. An old woman greeted us at the entrance to the compound and Berte asked where the member was. The old woman told us to wait. Berte told me that we were there to visit a member of their family who was sick. We were ushered into the house by a woman in her mid-30s. We sat on a wooden bench with cushions and the woman sat on a wooden chair against the adjacent wall. The floors and walls were dirt and there were no decorations. She was wearing a long *katenge* skirt and a torn tee shirt. She was holding a small child about one year old. The child was wearing a tee shirt only. A sheet covered the door and was the only space where light was let inside the home.

Berte asked the woman about how she was doing. She spoke about the pain in her legs and how she was taking her medication. She also mentioned that the baby was doing fine. Then the dad of the child walked in. He sat on a wooden chair next to the woman. The baby reached for him and he scooped her into his arms. The woman told me that she was very sick but she still had to work or they would not have food. Berte asked the man some questions about his health. Berte took notes on their responses in her small notebook. Then she explained to them my role as they had not been to meetings the entire time I had been conducting research. He smiled and told

me that he was living with HIV and that life continued, no problem. The woman reiterated the fact that she was very sick but still working hard for the family.

Then Berte opened her bag and pulled out two packages of condoms (each package contained four condoms). She explained that they should continue to use condoms. She handed each of them one package. The baby started to play with the package. We laughed and the mom said that it was not a toy. The baby became very upset so the man handed the baby to the woman and she went into the back of the house and retrieved a small piece of papaya for the baby. When she came back she told us that they used condoms to reduce the risk of HIV transmission. We thanked them and left. The couple walked us up the hill, down the road, all the way to the car. The old man was waiting for us there. We greeted the old man, said good-bye to the couple and left.

We continued up the main road toward the next town center. We parked the car on the side of the road near a turnoff and left the car again. The man walked into the grass and sat under a tree near the car. We crossed the road and walked for about one minute. Then we turned onto a small path and walked for another minute. We entered a large compound and Berte poked her head into the second doorway. There was a girl grinding *ubugali*. She smiled and greeted us. There were a few small boys standing around. I greeted them. Another young girl walked out to greet us. They explained that the girl was making *ubugali*. They let me try to grind it and everyone laughed at my attempt.

Then a woman in her 40s walked out with a chair for me. She looked healthy and strong. The girls went into the main house that was behind us and retrieved a bench for the woman and Berte. Berte told the woman about my study and my Kinyarwanda abilities. Then we decided to move to the back of the compound so that we could discuss in private, away from the family. We

passed another small room where there were two young adolescent boys eating food. We entered another space with a huge cow in a stall, about 12 goats, and a handful of chicken. We placed the chairs near a series of cages. Inside were 32 rabbits. The woman opened the cage and I asked if I wanted to touch one. She pulled one out and I held it. They laughed.

Then we sat down and Berte told me that people living with HIV have normal lives: they have rabbits, goats, chicken, cows, they have beans, and they make *ubugali*. Berte told me that both RRP+ and the *ishyirahamwe* helped this family. She said that people living with HIV could work, in fact they all worked very hard. The woman confirmed that she worked a lot, all her kids were in school, and *Abihuje* helped her with her health. She told me that now people living with HIV have higher CD4 counts than in the past and they were healthier than before. Berte took out her book and asked the woman for her phone number. Then Berte told me that we came to get the phone number of this woman because she did not have her updated phone number in her records.

I asked the woman if she had any problems. She said that she had no problem with taking the medicine but sometimes the dispensary had no medicine available. She continued that her *imibereho* (life) was bad because they did not have medication or food. I asked again to verify that it was the pharmacy that did not have medication and she confirmed. I said it was bad and I will tell someone in Kigali³⁴. Then the president told me that this woman was a widow. She ended by saying that life goes on and she will be fine. We thanked her and left after greeting everyone again. The boys were now sitting with the girls in the area between the main house and the other small buildings. The woman walked us out of the compound, down the road, to the car.

³⁴ Upon my arrival back in Kigali, I told my in-country advisor about the medicine and she informed someone at the MoH.

The old man was waiting for us. We greeted each other and said good-bye. I told the woman that I would see her at the next meeting.

We headed back toward the space where I picked up the president earlier. I asked if we would stop there and she said that there was one more person to visit but he lived at the bottom of the hill. We continued down the hill toward Kigali. We turned off the main road at the bottom of the hill where the road forked. When we stopped the car near the member's home, we asked a group of men where this man lived. They pointed down the road but told me to move my car to the other side of the road.

The man stayed with the car and we headed down the road. We turned right at the first path and headed up a steep hill. We asked a few more people where the man lived. Finally the man saw us and welcomed us to his home. We greeted the children in the compound and entered into his home. He was wearing black track pants and a blue t-shirt. He was also wearing sunglasses. He was born in 1965. He had a nice home with solid wood furniture. There were decorations on the walls such as pictures and a large calendar. We sat on the sofa. He began by telling us about the problems with his eyes. He said that there were also problems with his skin, his toenails, his fingernails, and his legs. He then went into the back room and grabbed about ten eye medications that he currently used. One was an antibiotic cream, there were other eye drops and some pills. I looked through the medicine. Then he took it away and came back with his latest lab report. He handed me the paper. His CD4 was 419. The president asked him a few more questions, told him that I was attending the next meeting and he should also come if his eyes were not bothering him. He said that his eyes prevented him from leaving the house.

He walked us down the steep hill, down the road, to the car. We said good-bye. Then we arrived at the car and left. Berte told me to go toward Kigali and drop them on the side of the

road instead of heading north to where I picked them up. They crossed the road and headed into the field that would eventually lead them back up to their homes on the hill.

CHAPTER 4 THE STATE OF *AMASHYIRAHAMWE*

Introduction to *amashyirahamwe*

The first time I encountered any information regarding the *amashyirahamwe* for people living with HIV in Rwanda was during some analysis work I conducted in 2008 with FHI on narratives from people living with HIV who were part of Prevention with Positives Study conducted from 2006 - 2009. The project goal was twofold. The first was to promote positive HIV transmission behaviors of sero-positive persons by means of public messages targeted to particular subgroups of infected persons. The second was to expand Rwanda's institutional capacity for high quality scientific research by providing formal training and curricula as part of the conduct of the research. As part of the research, participants were asked to respond to a broad narrative question: "Tell me the story of your life since you became HIV positive. Start the story of living with HIV where you like and take as much time as you need." These narratives were the focus of the analysis upon which I worked. In the narratives, members often spoke about groups, *amashyirahamwe*, for people living with HIV and most of the stories included at least a small section on how their local group was important in their lives: for access to resources both financial and medical and for social support. However, many, if not most, of the participants in this study were, at the time of the interview, active members of *amashyirahamwe*. As I learned firsthand, the route to conducting research with people living with HIV in Rwanda was through the local *amashyirahamwe* via RRP+. However, this was my first glimpse into the lives of the people living with HIV in Rwanda. I decided later to focus my dissertation research on these groups for people living with HIV so there began the study of *amashyirahamwe*. By the time I had started the dissertation research, I had very little first hand experience with *amashyirahamwe*. I had met several people from RRP+ who were *amashyirahamwe* members

while working with FHI again in 2009 but what I knew about the groups was solely based on the narrative interviews from members of the *amashyirahamwe*.

During the RNEC meeting when I started fieldwork in 2012, the committee questioned my use of terminology regarding the *amashyirahamwe*. Throughout my protocol, I used the Kinyarwanda word *koperative* and English word *ishyirahamwe* interchangeably. There was some confusion on my part prior to fieldwork about the terminology but I sorted this out at the RNEC meeting. When I first wrote my research protocol when I was still in the USA in 2011, I used the word *gahunda*³⁵ to describe the groups as this was the closest word I could find that meant association in Kinyarwanda. I used my Kinyarwanda dictionaries and advice from my Kinyarwanda professor and thought that *gahunda* was the best word without further consultation with someone who had worked with these groups before. The narratives I read from the FHI work had only the English word and I never thought to consult the Kinyarwanda transcripts at that time. Before I arrived in Rwanda, I sent a project summary in English and Kinyarwanda to both a Rwandan colleague from FHI and Felicien. My colleague informed me that the term to use was not *gahunda* but *koperative*; the word *amashyirahamwe* was never mentioned. He stated via email: “The word ‘gahunda’ you used in your Kinyarwanda version doesn’t mean ‘ishyirahamwe.’ Use the word ‘koperative’. We no longer say ‘PLHAs (people living with HIV/AIDS) Associations’ but ‘PLHAs Koperatives.’” I assumed that *koperative* meant the same thing as association in Kinyarwanda even though the word looked suspiciously like cooperative. I also took the change as a change in nomenclature only but I found out when I first arrived in Rwanda and met with Felicien that the change was a full change in both structure and governance, not just a change in name. In discussions, Felicien and other key informants

³⁵ The word *gahunda* actually means plan.

suggested that the government encouraged the change but in reality, this shift to *koperative* was required and a mandate for all *amashyirahamwe* countrywide, not just for groups for people living with HIV.

During the RNEC meeting, a member of the committee asked me about the specifics of the sample. Was I studying *koperative* or *amashyirahamwe*? I said that I was studying *koperative* because this was the terminology provided by colleagues. They said no. If you are studying *koperative* then you are not studying *amashyirahamwe* or associations, you are studying *koperative* or cooperatives. One member stressed that I could not use these words interchangeably because they are very different things. I explained that someone had told me that the Kinyarwanda word for association was *koperative*. They explained that *amashyirahamwe* is the word for association and *koperative* is the word for cooperative. Then they asked again, whom are you going to study? I said that I wanted to study both because the *amashyirahamwe* were supposed to turn into *koperative*, based on information from my recent conversations with Felicien. They told me again that I had to study one or the other but not both as they were two distinct things. I quietly said that I was studying *amashyirahamwe* or associations for people living with HIV. They agreed and told me to change the terminology throughout the protocol. After the meeting, I met with Felicien and asked him what terminology to use in my protocol so that I could study all *amashyirahamwe* under RRP+, even if the group had transformed into a *koperative*. We decided to write that the focus of the study was on “organizations under the umbrella group RRP+” because that would technically cover all *amashyirahamwe* and *koperative* for people living with HIV that were registered with RRP+. The committee accepted this terminology and the protocol was approved³⁶.

³⁶ There were other changes that were required by the RNEC but all were resolved.

This interaction with the RNEC provoked many questions about my sample. Was I studying *amashyirahamwe* or *koperative*? And how could an organization be two completely different things, as suggested by the committee? These discussions also provoked a new line of inquiry regarding the change from *ishyirahamwe* to *koperative*, which was also a concern of RRP+ leaders. The change from *ishyirahamwe* to *koperative* added another dimension to the groups: not only were members supposed to be live positively but also be responsible economically. I became intrigued by the change: how could it be possible and what did it mean to the members and Rwandan society as a whole? This shift to *koperative* thus became another line of inquiry in the project.

After I realized the correct nomenclature to use to refer to *amashyirahamwe*, I researched these groups in a broader context. *Amashyirahamwe* referred to groups of people coming together for a given purpose or to solve a given issue within the community. There was a huge emphasis on coming together; even the word itself means something like coming together. In singular form, the word for association was *ishyirahamwe*. The word was formed from the verb *gushyira* (to put or place) and the adverb *hamwe* (together in one location). These words also made up the song title of Sipiriyani's song referenced in chapter 2. *Amashyirahamwe* was the word used to talk about groups of people who were physically together in a given place for a given purpose. In this dissertation, I used the words *amashyirahamwe* or *ishyirahamwe* to refer to the support associations for people living with HIV found in Rwanda, unless otherwise specified. However, *amashyirahamwe* was a word not strictly used for HIV related groups; it was used for any type of group or *ishyirahamwe* of people coming together. *Amashyirahamwe*, at the time of the research, were not considered formal government institutions and the groups were not NGOs. The *amashyirahamwe* were not even formal registered organizations, meaning that

they did not have to legally pay taxes. *Amashyirahamwe* were part of civil society or grassroots' structures in Rwanda. However, I demonstrate in the chapters that follow how the groups were bound by government mandates, both locally and at the country levels, although the groups had their own rules and regulations through RRP+, as well as obligations in their local communities. The groups were also maintained through the government rhetoric that coming together to solve issues was the best way forward.

There were many other types of associations found in Rwanda, in addition to the ones for people living with HIV. There were a variety of professional associations such as Rwanda Bankers Association, Rwanda Medical Association, Rwanda Bar Association, and so on. In addition to these, there were associations for other causes such as genocide survivors (e.g. AVEGA³⁷ for widows of genocide, AERG³⁸ for student survivors, *Tubahumurize*³⁹ Association for women survivors, etc.), people with disabilities (e.g. General Association for People with Disabilities and Associations for Women with Disabilities), as well as for homosexuals⁴⁰ (Horizon Community Association of Rwanda), among others. Associations, in Rwanda and elsewhere, were a common structure that people used to come together to try to accomplish something. Associations were not something new in Rwanda so it was not surprising that *amashyirahamwe* for people living with HIV also emerged when HIV became a major health problem. These types of groups were also common in other African contexts and emerged for a variety of reasons.

³⁷ AVEGA is a French acronym “Ishyirahamwe des Veuves du Genocide”, or in English, Association of the Widows of Genocide.

³⁸ AERG is a French acronym “Ishyirahamwe des Etudiants Et Éléves Rescapés Du Genocide”, or in English, Ishyirahamwe of Student Survivors of Genocide.

³⁹ In English: Let us console them.

⁴⁰ There is only one *ishyirahamwe* for homosexuals in Rwanda that I could find. It was started in 2003 and there are only 17 members. <http://www.hoca4rwanda.9f.com/index.html>, accessed 29 June 2014.

Often referred to as non-kinship based groups, these types of groups were defined as people grouping together based on shared interests as opposed to kinship and have a long history in cultures through space and time. During the 1960s and 1970s, non-kinship groups were studied extensively in African cities with respect to the organization of the group and their adaptive functions to rapid social change (Anderson 1971; Epstein 1967; Little 1962; Parkin 1966; Schwab 1970). More specifically, in some West African contexts voluntary associations were formed for migrants based primarily on place of origin. Some researchers noted that in East African contexts, specifically in Uganda, the associations reflected the deeper social status systems from the rural areas and that there was a hierarchy of associations based on socioeconomic status (Parkin 1966). It was theorized that these groups emerged to create a fictional bond to replace missing kinship bonds after relocating to an urban center away from the village and kinship ties (Little 1962). In addition, the urban associations were thought to foster village traditions, unite people, and help them to adapt to the city, its rules, and cultures (Anderson 1971). Others argued that associations were formed to relieve anxiety from colonial rule and to help people make the shift from a group perspective to the westernized idea of the individual (Schwab 1970). Regardless of the function, these groups were commonly based on past residence linking people from a common place within a new context, normally a city or urban area.

Rwanda has always had its own version of self-help institutions or as mentioned in chapter 2, home grown solutions. In 1949, there was a cooperative ordinance although it was used to promote the colonial government and after independence, to promote government policies (RCA 2013). The first cooperatives in Rwanda were established in 1956 in the agricultural sector and by the mid-80s there were 241 cooperatives including members

accounting for 4.9% of the population at that time (i.e. 291,368 members) mostly in the credit and savings sector (Shaffer 1999). The cooperative movement, along with most of the infrastructure of Rwanda was destroyed during the genocide in 1994 and became even weaker after NGOs streamed all donor money through these cooperatives groups although the cooperative was meant to generate its own income, not use donor monies. As such, the cooperatives in Rwanda became associated with a way to gain funding from donors, not create sustainable income, which was the whole idea of a cooperative from the beginning (RCA 2013). A “culture of dependency” then was instilled where people began to rely on cooperatives to gain access to resources from NGOs and other funding sources (RCA 2013), similar to the donor situation that occurred with the *amashyirahamwe* for people living with HIV. Shortly after the groups were formed, NGOs and other donors looked to the *amashyirahamwe* as a way of streaming funding to people living with HIV. The story of the first *amashyirahamwe* is described in the section that follows, as well as the past and present funding situation of the *amashyirahamwe*.

The first *amashyirahamwe* and RRP+

The first *amashyirahamwe* for people living with HIV were reported to have formed in or around 1999 and were scattered throughout the country. The exact number of *amashyirahamwe* at this time was unknown as the groups were informally initiated within the communities. The churches in the communities created small groups for people in the neighborhood who were sick in the years that followed the genocide. This was during the time when people were becoming very sick and no one knew exactly what the problem was. The people in the groups were presumably sick with AIDS but HIV testing was not widely available. According to key informants from the *amashyirahamwe*, people often thought that these really sick people were

cursed or the recipient of witchcraft. It was interesting that people went to the church when faced with a problem, especially considering the churches' role in the 1994 genocide.

The country of Rwanda, both before and after the genocide was a predominately Christian nation. During the genocide, the church was used as a place to commit genocide as the perpetrators often used the church building as a place to kill those who sought refuge (Longman 2009). Not only were the physical structures of the churches used for killing but church leaders and church members alike took part in the mass killings (Longman 2009). The first documented *amashyirahamwe* emerged only five short years after the genocide, with the assistance from the church. Why people would turn to the church just years after the genocide was an inquiry that was not resolved. Perhaps the church was trying to gain back the trust of the population or perhaps these people had nowhere else to turn. It was not clear why people trusted the church, however the local churches started the very first *amashyirahamwe* for people living with HIV.

According to RRP+, the churches grouped the sick people into small *amashyirahamwe* because the sick people were being isolated from their families and community. These people sometimes remained living in their homes but other times they lived in the church or with others who were sick. In the local communities, community members avoided the people living with HIV who often had visible signs of the progressing disease. They would not share water or food for fear of acquiring the disease. Colleagues at RRP+ informed me that although the families in Rwanda did not always abandon their family members living with HIV, they often did not offer much assistance, if any at all, to those living with HIV. Perhaps it was not because the family did not want to provide help but many families in Rwanda were living in poverty and it was just a few years after the genocide when the entire nation was undergoing development. I suspect that

there also had to be enormous levels of trauma among the entire nation and HIV was just another concern among the many.

The *amashyirahamwe* stepped in and helped some of the people who were dying from HIV. In these first *amashyirahamwe* or small groups, people met and expressed their problems, health and otherwise, with each other. The church advocated for the groups for assistance including food, counseling, and other financial assistance from the government and also NGOs. Yet during the late nineties, often people would not go for testing because they did not want to be associated as a person living with HIV because of the negative way they were treated in their community. I found out later in the research that this was still the case for some people (see chapter 6). Plus testing was not widely available at this time. Those who went for testing and were living with HIV could benefit from the assistance offered from the *amashyirahamwe*. Again, similar to those in the *amashyirahamwe* with whom I spoke. Those who were not very sick but knew their status sometimes volunteered to care for those who were very sick, taking on a caretaker role but this was not the case early on in the epidemic. People did indeed come together to help each other but the connective link was that they were also sick, presumably with HIV. It almost seemed like it was a last resort for people at this time. People who tested positive and were not physically sick likely did not join the very first groups.

After the genocide, the rural rates of HIV increased greatly. In 1998, the rural rate was estimated at 11% but it may have been much higher. People who had no other choice could go to the *ishyirahamwe* for help. The groups originally emerged as a way to assist those who were dying of HIV and provide sources of financial and emotional support to those who were living with HIV. The initial groups in Rwanda were not set up as a way to make claims on the state based on a biological condition as described by (Petryna 2002) for people exposed to radiation in

Ukraine, nor where they set up as a way to gain access to ARV therapy like in some Western African contexts (Nguyen 2010) or initially as a way to gain access to NGO support like in Kenya (Prince 2012). The very first groups emerged in response to the HIV epidemic as a way to help people dying of HIV. These groups did not have ties with other groups and were not bound by government agencies of any kind. They were independent community based structures running on minimal donations and/or external funding.

However, as time went on, the groups became the outlet through which members gained access to resources including ARVs and NGO support. When ARVs were first introduced in Rwanda, membership helped members to gain access to ARVs. Eventually membership provided access to NGO support, as NGO funding was abundant for HIV related causes at the time, according to RRP+ and members who had joined the *ishyirahamwe* when there were still ample resources. People living with HIV joined the groups to gain access to resources, hence creating more reliance on the state to maintain their lives. HIV as a disease was also changing. Testing was more available and with the advances in medicine, people were living longer and healthier lives. In a poverty-stricken country, it was no surprise that when material support was available through the *amashyirahamwe*, people would join one or two *amashyirahamwe* to gain access to resources. There was a material value to disclosing one's HIV status, similar to recent work done by Marsland (2012) in Tanzania and Prince (2012) in Kenya.

In 2001, HIV testing and counseling became more widely available in more regions throughout the country of Rwanda as the voluntary counseling and testing (VCT) centers expanded to six of the twelve provinces in Rwanda (Web 2002). Implementing AIDS Prevention and Care (IMPACT) project, a USAID funded program run by FHI in Rwanda, set up 3 additional VCT sites in 2000 but by 2006, the VCT sites initiated by this one program had

increased to 53 sites (FHI 2007). But it was not always so simple to have testing because some people still had to travel very far to reach a testing site (c.f. Berchmans' story in chapter 9). Others still feared to be tested due to the negative attitudes surrounding HIV in the community often resulting in *akato*. Those who were diagnosed with HIV had to weigh the possibility of being known as HIV positive with the material and financial resources received. Some people had no choice. The benefits were great for those who accessed them, however, there were also abuses and unequal spreading of funds throughout the country. In addition, some people joined more than one group to access more resources. This was later stopped when RRP+ emerged as an umbrella group for the HIV related *amashyirahamwe*.

Yet the members still helped each other and formed a community together within their own communities. Let me provide one example. Berchmans, a member of *Humura*, explained that in the past the *ishyirahamwe* members helped those in their community who were very sick. Berchmans joined *Humura* in 2002 shortly after he and his wife were diagnosed with HIV. This was a few years after the first *amashyirahamwe* emerged in Rwanda.

They [people living with HIV] were getting sick in their homes and becoming very ill...the volunteers [from the *ishyirahamwe*] would come around them because those [people living with HIV] who recognized it [HIV] before they were very ill were strong. They were becoming strong without any problem. There were some [sick people] who we used to go to their homes and carry them to the hospital. When they were seriously sick, the *ishyirahamwe* could help...

What Berchmans says was interesting for two reasons. First, the people who tested positive for HIV but were not yet physically sick were the ones who helped the sick people in their communities. Second, the volunteers from the *amashyirahamwe* did things that normally family and close friends would do, such as carrying the sick people to the hospital; in Kinyarwanda this act was called *guhaka*. Did the strong *ishyirahamwe* members help the sick members because after testing positive they were known as living with HIV and faced *akato* in the community? Or

was it because they were coming together to solve a problem? These were some of the issues that I tried to understand in the chapters that follow.

In 2003, 175 *ishyirahamwe*⁴¹ leaders came together with leader from the local and global healthcare community in Kigali to join efforts in the fight against HIV. According to RRP+, the groups came together because the *ishyirahamwe* leaders thought that if they were together and had one voice, they could better advocate collectively for their needs to receive funding that had started to stream into the country from foreign donors. This advocacy was likely modeled after the fight for ARVs in USA in the 1980s where AIDS activists gathered with biomedical scientists to advocate for ARV research and access (see Epstein 1996 for an eloquent account on AIDS activists). It was not easy for the individual groups to reach the attention of the international donors but the leaders thought that if they all came together, they would be known in the landscape where international NGO funding collided with national HIV efforts. In this sense, they came together to disclose the HIV statuses of the groups for the purpose of gaining access to the monies that they desperately needed. The collaboration effort was fully supported and likely encouraged by CNLS. The meeting itself was organized by the Rwandan MOH, United Nations Development Program (UNDP), UNAIDS, among other NGOs with a goal of better coordinating HIV services in the fight against HIV. The collaboration also easily facilitated monitoring of where the funding was going and how it was being allocated among the country's people living with HIV. One of the major recommendations of this meeting was to create an umbrella group for the associations of people living with HIV (RRP+ 2012). The

⁴¹ These *amashyirahamwe* were the informal groups that emerged from 1999 onward. They would not be considered formal *amashyirahamwe* until after the umbrella group RRP+ was formed in 2003.

umbrella group gained control of most of the funding and dispensed it among the individual associations throughout Rwanda.

These 175 *amashyirahamwe* became the first members of the newly formed umbrella group RRP+ that emerged as a result of the meeting. RRP+ was considered a non-government organization although they were very much linked with the government organizations and other international organizations. There were other *amashyirahamwe* who did not join RRP+ immediately, however over time, more *amashyirahamwe* joined RRP+. Some of the *amashyirahamwe* were still sponsored by churches but the groups were being sensitized to become independent from the church. The ideas were that RRP+ would eventually replace the churches' role in advocacy and provide one central agency to work with and organize the groups and access to funding and interventions. Both RRP+ and the churches continued to be advocates for the *amashyirahamwe* assisting with identifying potential funding for food, financial support, income generating activities, and so on. Eventually it was the responsibility of RRP+ to link donors to *amashyirahamwe* and other activities related to NGO work and research⁴². The creation of RRP+ was also a way to formalize and standardize the activities of groups with similar aims and purposes. Importantly (and unstated by RRP+) the formalization of the *amashyirahamwe* kept some level of control within the government. Also (and also unstated) the government could then keep track of and monitor the people living with HIV in the communities.

In the early 2000s, there was more financial support for people living with HIV than at the time of the research in 2012 - 2013. NGOs provided monetary support and resources for

⁴² RRP+ had to approve this dissertation research and RRP+ helped me to connect with *amashyirahamwe* in my research study. Similarly RRP+ coordinates other research endeavors and funding opportunities.

people living with HIV and often linked groups individually or identified beneficiaries through RRP+.

Some people joined the *ishyirahamwe* solely as a way to access those resources while others joined more than one *ishyirahamwe* in order to maximize the benefits they received. When people started to financially benefit from membership, others wanted these same resources. Instead of view the *ishyirahamwe* as a way to access social support and care, the groups were repurposed, for some, as a way to gain material and financial resources. RRP+ was initiated, in part, to stop members from joining more than one *ishyirahamwe*. Each member from each *ishyirahamwe* was registered with RRP+ by providing their national identification number so RRP+ was able to monitor if people were members of more than one *ishyirahamwe*. Because RRP+ had each member's identification, those who were members of the groups were all documented in some sort of database. RRP+ was the way through which the government, if necessary, could access those who had HIV in the communities. Whether or not anyone monitored this database and the reasons one might monitor it were not known. The GoR had a reputation of keeping detailed surveillance of its population so it was not too surprising that it was documented. In addition, the name and ID requirement certainly changed the form of the group. Before members joined without providing their name but with the advent of RRP+, this information was all recorded. Joining an *ishyirahamwe* became more than accessing resources after RRP+ was formed. Not only were members outing themselves in the community because that was certainly the case regardless of the documentation requirement, but also within the country as a whole. I come back to the point about disclosure of HIV status in chapter 5.

The vision of RRP+ at the time of the research was: "To encourage positive living among people infected and affected with HIV/AIDS and engage them in the fight against the epidemic."

(RRP+ 2012) The mission of RRP+ was to coordinate all activities of the *amashyirahamwe* and even promote the *amashyirahamwe*.

There were also several objectives:

- To serve as a key coordinating body mandated to orient and facilitate activities of the association members in line with HIV/AIDS national policy.
- To advocate for care and support of people infected and affected by HIV/AIDS to the government of Rwanda and donor community.
- To contribute to the reduction of socio-economic impact imposed by HIV/AIDS on people infected and affected by the disease.
- To implicate the people infected and affected by HIV/AIDS in the fight against stigma and discrimination in particular.
- To facilitate collaboration and exchange of information among associations of people infected and affected by HIV/AIDS. (RRP+ 2012)

Figure 17 shows the organizational structure of RRP+. At the local level, each *ishyirahamwe* was supposed to have a committee of five members from their own *ishyirahamwe*. From those five members of all the *amashyirahamwe* in the sector, five were elected to sit on the people living with HIV committee at the sector level. Seven presidents from all the *amashyirahamwe* in the district were elected to sit on the Administrative Council at the district level. In addition, seven presidents from each district were elected to sit on the Administrative Council at the national level, a total of 210 members. Of those 210 presidents from local *amashyirahamwe*, three were elected to sit on a legal committee and three were elected to sit on an accounting committee. Finally, one president from each district was elected to sit on the General Assembly.

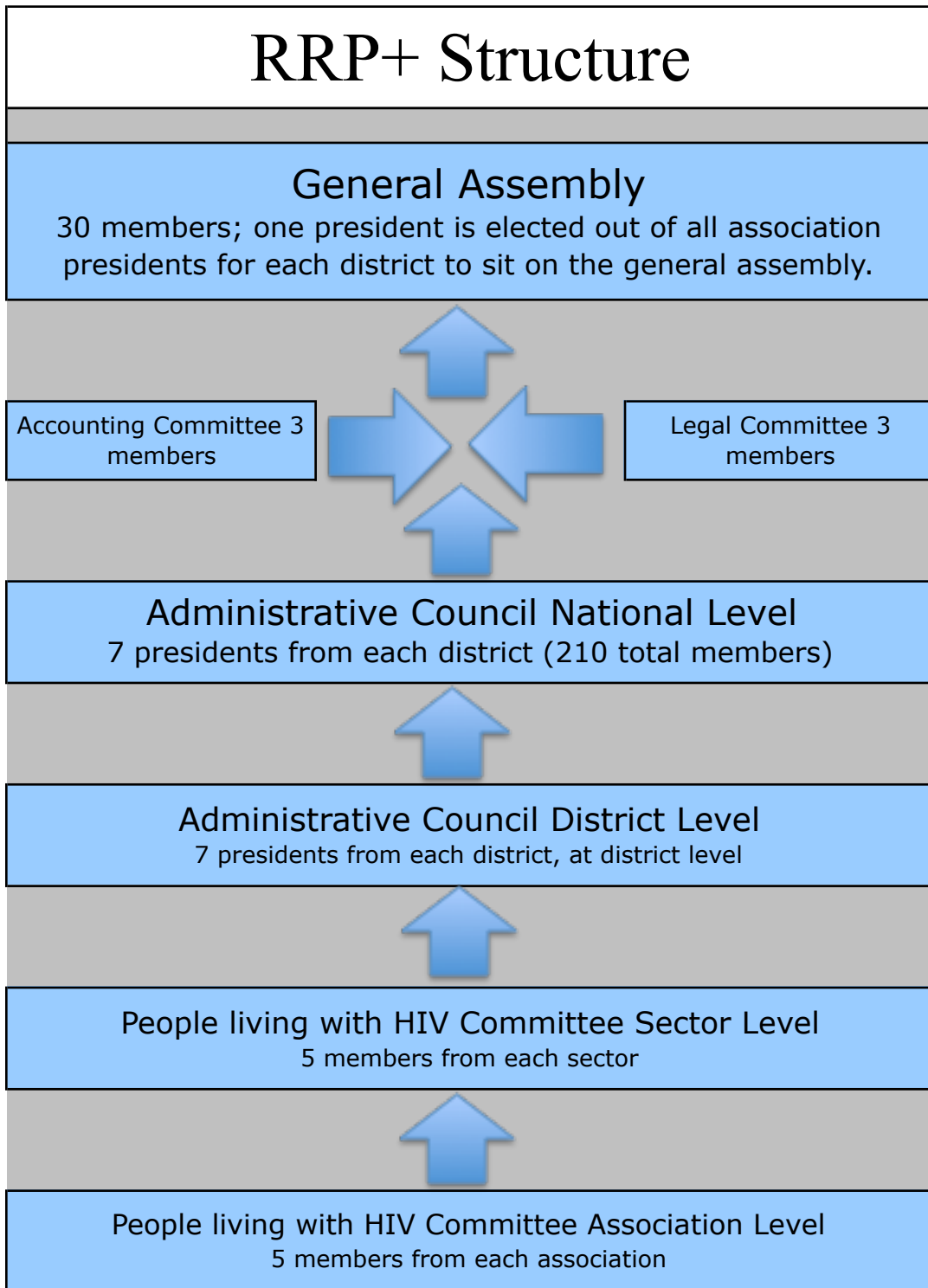


Figure 17: RRP+ Structure

RRP+ has a member on the board of directors with RBC, which was an agency under the MOH. RRP+ also sent representatives to coordinate research, help with NGO work, and linked NGOs and other research partners with member *amashyirahamwe*. For example, when I wanted to conduct research on and with the *amashyirahamwe* for people living with HIV, I used contacts at RRP+ to gain support.

The organizational structure of RRP+, highly hierarchal in nature, mirrored the structure of past families and the military with the representatives at each level. It also mirrored the current decentralized government of Rwanda.

RRP+ had funding from the Global Fund's Multisectoral Action Plan (MAP) from 2003 until 2007 to help members pay school fees for their children and provide materials for their children to attend school. MAP was an international strategy adopted to fight against HIV. MAP also assisted *amashyirahamwe* to set up income generating activities. The MAP funding ended due to lack of continued funds, as was the case with many of the major donor monies that once funded the *amashyirahamwe*. Other past funders of HIV *amashyirahamwe* included World Vision, Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), Global Fund, PSI, CARE, SIPA (Support to International Partnership against AIDS in Africa), USAID, CHF and CHAMP. There were also some funds through the Ministry of Agriculture and Gardens for Hope International but at the time of the research, those funds had finished. The issues surrounding joining the *ishyirahamwe* as a way to gain access to resources is described in more detail in the subsequent chapters but overall when the funding and resources arrived in the local communities, there was an overall increase in the number of members.

RRP+ leaders from the province level helped individual *amashyirahamwe* to register with RRP+. This registration took place when there were ten provinces in Rwanda but at the time of

the research, there were only five. In just five years, from 2003 to 2008, the number of *amashyirahamwe* in RRP+ grew from 175 to 1,361. From 2008 - 2011, the number of *amashyirahamwe* remained roughly the same. At the end of 2011 when I first started the field research, the total number of registered *amashyirahamwe* in RRP+ was 1,400 (see also Figure 11 at the end of chapter 2). By mid 2013, the number of *amashyirahamwe* reached over 1,600. During the early years of RRP+, the government advertised the importance and benefits of *amashyirahamwe* and belonging to the umbrella group RRP+. By 2008, the majority of the HIV related *amashyirahamwe* in Rwanda were aware of RRP+ and the benefits of joining. However, not all *amashyirahamwe* remained under the rules and regulations of RRP+. There were some *amashyirahamwe* that decided to become NGOs and then were registered under RGB. The groups that became NGOs did so because then they could apply for funding on their own and were not required to apply for funding together with RRP+.

By June 2013, the number of *amashyirahamwe* had increased to 1,604 but the overall number of members decreased to about 75,000. Based on these data, 70% of the members were women and 80% were documented as being infected with HIV. The sites for this research were selected from among the 1,400-registered *amashyirahamwe* in January 2012.

***Ishyirahamwe* activities**

The activities that the *amashyirahamwe* were supposed to conduct are listed below. This information was provided through meetings at the head RRP+ office with several key informants. Details were elaborated based on specific information gathered from the individual *amashyirahamwe*, as applicable. However not all *amashyirahamwe* conducted all the activities listed below. In fact, the five *amashyirahamwe* in this research were very different from one

another. The items listed below describes how the utopian *ishyirahamwe* would function according to RRP+ but as described in chapters 5 to 8, this was not always the case.

RRP+ worked with the GoR to advocate for the *amashyirahamwe* with the international donor community and local partners regarding policies and strategies to improve the lives of those living with HIV. These organizations in turn assisted with food support, trainings, financial assistance, counseling, among other activities. Not all members of all *amashyirahamwe* had access to all of the resources because the donor organizations did not fund all the *amashyirahamwe* at the same time. Before 2008, the *amashyirahamwe* waited for support from national and international donors and also the GoR but more recently, as overall aid reduced, the *amashyirahamwe* were urged by the GoR to create registered income generating *koperative*. The push to change from *ishyirahamwe* to *koperative* is fully described in chapter 8, along with the benefits and complications of the transition.

Amashyirahamwe were also expected to provide sensitization and education regarding HIV within their local communities. The *ishyirahamwe* leaders including the presidents at the *ishyirahamwe* level often used materials, such as booklets created and funded by MoH and other partners⁴³, to assist in the education of both the members and the community. The *ishyirahamwe* leaders and members educated community members within their villages regarding the importance of VCT by giving public testimonies. One goal of the *ishyirahamwe* was to show the others in the community that people living with HIV were still living, not dying. The groups were active in the community as a way to demonstrate that they were still living. Members also

⁴³ One such booklet was created based on work with PwP project. The booklet included narratives from people living with HIV specific to various topics including: discordant couples, family planning, disclosure, depression, denial, among others. This booklet was designed so that healthcare providers and leaders could understand better what it was like for people to live with HIV in Rwanda. These booklets were distributed to health centers and local *amashyirahamwe*.

provided testimonies to encourage others in the community to go for HIV testing and know their status.

Another large role of the *ishyirahamwe* was to promote the Living Positively health campaign within *amashyirahamwe*, as described and enforced by RRP+. The *amashyirahamwe* helped their members to be conscious of the fact that HIV was not the only health problem that people faced. There were other problems: cancer, diabetes, and so on. There was no reason to lose hope because of an HIV diagnosis. The members were also taught, through educational sessions normally provided by the president of the *ishyirahamwe*, the benefits of the health center and how to live a positive life with HIV. The president and other leaders of the *amashyirahamwe* were trained at the district or province levels on these topics in formal training sessions. There were also booklets created by RRP+ with topics related to the living positively campaign that the leaders could use to assist with the education.

In addition to the aforementioned activities, one goal of RRP+ was to reduce *akato* in the community. This goal was one of the primary goals set in 2003 at the original meeting that helped to create the umbrella group, RRP+. As mentioned, this was done through testimonies but there were several other ways. According to some *ishyirahamwe* members, the income generating activities also reduced *akato* in the community because the groups were then open to those who were not infected with nor affected by HIV. The idea was that others would see people living with HIV working and producing, indicating that people with HIV lived a life like others. Although this was not always the result and at times, being in the group brought more *akato*. The *amashyirahamwe* also accepted members who were not living with HIV, 80% of members must be living with HIV within the *ishyirahamwe* according to the rules and regulations of RRP+. However, this was in the process of changing because of the transition to

the *koperative*. In a *koperative*, there were no restrictions on who could be a member or not, as long as the person had the required shares to join. There was a different kind of exclusion with *koperative*, economic.

Conclusion

The *amashyirahamwe* for people living with HIV grew out of an immediate need to help those who were sick during a time of political transition in Rwanda. The new government took over and stressed the importance of reconciliation and coming together as one Rwanda. Although the first groups emerged informally with the help of the church, over time the groups became more formalized and dependent on the umbrella group RRP+ for access to resources. RRP+ also structured the groups and provided rules and regulations under which the members were required to live. During this same time, international NGOs began to stream funding through the registered *amashyirahamwe*. The past chapters provided a context for the current study. The following chapters extend the discussion. In the next chapter, I discuss at length the idea of coming together. I discuss this concept within the context of a governmental development program called *Ubudehe* and within the context of the *amashyirahamwe* for people living with HIV as a way to demonstrate the ways in which Rwandans come together in the face of recent ethnic conflict. The discussion also tells a story about the consequences of coming together in these specific programs, one of which is the disclosure of a vulnerable status in the community that has the potential to lead to *akato*, which is discussed in chapter 6.

CHAPTER 5 COMING TOGETHER

Introduction

I want to start this section by briefly discussing the concept of community from an emic perspective. In the previous pages, I often referred to “the community” as if there was a static definition of “the community”. Of course, that was not the case. Communities were always changing. In Kinyarwanda, the two words that were commonly used for “community” included *rubanda* and *umuryango*. The meaning of *rubanda* was a group or crowd of people gathered spontaneously. The word most often used for the relationships based on people grouping together for a purpose was *umuryango*, the same word as lineage. Strictly speaking, *umuryango* was used to talk about a group that was formed by people coming together from different families but within the same lineage. In the past, according to key informants, all lineages were under the rule of one king and the king was like the parent of all lineages. Another term for king in Kinyarwanda, in addition to *umwami*, is *sebantu*, directly translated as father of the people (*se* means father and *abantu* means people). Now, all lineages in Rwanda were under the rule of the GoR. The word for neighbors was *abaturanyi* and sometimes neighbors were included in the *umuryango* but not always because neighbors were not always from the same families.

In recent times, many groups in Rwanda, including the *amashyirahamwe* for people living with HIV, referred to themselves as *umuryango* but with an additional emphasis, beyond different lineages coming together. By using this term, there was an implication that the members within the grouping were somehow the same or related on some level, like relatives but the members did not have to be blood relatives. There were, in the past, ceremonies to strengthen

these non kinship relationships called *kunywana*,⁴⁴ a ceremony where one friend cut his abdomen and placed his blood into a coffee seed and gave it to his friend to consume. That friend did the same with the other half of the coffee seed to represent sharing one shell, each with the other's blood, to bind each other into one shell. This act took place in front of a witness and was done between members of different families and ethnic groups (PRI 2004). The relationships were long-lasting, for example, if grandfathers had done *kunywana*, there would be a special bond between the families for generations to come (PRI 2004). These relationships were said to be strong, however many were easily broken during the 1994 genocide (PRI 2004; Umutesi 2014).

***Ubudehe*, Vulnerable Bodies, and Money**

After the fieldwork period ended at the end of 2012, I remained in Rwanda and obtained a job and started a family. I was never expected to participate in the government programs until after I lived with my husband, who was Rwandan. At that point, our household, most often my husband, was required to attend the village meetings, participate in *Umuganda*, and our household was assessed for the government program called *Ubudehe*. The *Ubudehe* Program was one of the programs that supposedly used a cultural practice, or a homegrown solution, from Rwandan history to inform the current program, like those discussed at the end of Chapter 2. I discuss this program in the context of the HIV support *amashyirahamwe* because of the similarities faced by the community members in response to the programs. In both programs, to access benefits one must publically demonstrate their vulnerability, be it HIV or economic status, in their community. Additionally, both programs stressed the overarching government strategy of coming together locally to solve problems in a context where divisions based on ethnicity were the norm for years. Beyond ethnic divisions, the 1994 genocide was not that long ago. Surely

⁴⁴ English: literally to drink together; refers to the ceremony of exchanging blood with friends to strengthen the bond.

people struggled to make sense of how to accomplish coming together within this context of recent division and with trauma still lingering in their minds from the genocide. Villages, and groups for people living with HIV for that matter, were not divided based on ethnic groups. All these programs were supposed to be initiated with neighbors coming together, the same neighbors who were involved in some way or another in the genocide. This was precisely why, I argue, the GoR used the rhetoric of coming together in the past as a way to encourage people to do so again in recent times.

In this section, first, I provide a few words on the practice of *ubudehe* in the past times and then I provide my own experience with the program. The remainder of the chapter is dedicated to a discussion of the HIV support *ishyirahamwe* and the consequences, both positive and negative, of coming together.

According to the GoR, in the past, the practice of *ubudehe* brought neighbors together to cultivate the fields before the rainy season; a job that required a lot of work in a short period of time. As such, neighbors joined together to get the job done. Normally there was a small celebration following the work involving sharing local beer. According to the GoR, both men and women and all social groups participated in this practice together in the past. The groups were formed based on locality. However, if there was a family that was not able to help, the neighbors worked in their own fields first and would help these families after they had finished (MINECOFIN 2003). *Ubudehe* allowed people to accomplish work that could not be done with one or two people and also gave neighbors a chance to socialize with each other. Although the GoR did not discuss why some families were unable to participate, the practice divided people while others were coming together. Certainly families with sick members would not be able to participate creating more vulnerability and exclusion for that particular family.

According to RGB, the word *ubudehe* referred to a “culture of collective action and mutual support” for problem solving at the local level (RGB 2014c). The word *ubudehe*, linguistically, is derived from the verb *kudeha*, which means to be lazy, and the corresponding class one and two nouns are *umudehe* and *abadehe*, which means a lazy person and lazy people. Following Kinyarwanda linguistic rules, if the stem of the word is the same, the meaning changes only slightly with the prefix. For example, *umukire* is a rich person, *gukira* is to be rich, and *ubukire* is wealth. Following these rules, *ubudehe* means laziness, not mutual assistance. When I asked people about this, they agreed that yes, *umudehe* means a lazy person and indeed *ubudehe* means laziness. According to one of my key informants, the goal of *ubudehe* of the past was to fight laziness in the community but this was not documented in any official sources. There were no other explanations about the terminology.

The *Ubudehe* Program was a government program used to fight poverty (and perhaps laziness?) in Rwanda. The full name of the program was “*Ubudehe mu kurwanya ubukene*”, meaning “*Ubudehe to fight Poverty*” (Niringiye and Ayebale 2012)⁴⁵. RGB described the *Ubudehe* Program as being based on the “Rwandan culture of mutual assistance and conviviality whereby people would come together to address problems facing them” (RGB 2014c). The *Ubudehe* Program started in 2005 after a successful pilot program was initiated in Huye, in the Southern Province of Rwanda. The practice encouraged the local communities to solve problems together using local institutions and resources (NUR 2014). The *Ubudehe* Program involved the local community as a whole in the selection of a community project (chosen out of five potential projects) that directly fought poverty in that particular community (Niringiye and Ayebale 2012). In addition to community projects, the *Ubudehe* Program also focused on providing assistance to

⁴⁵ Note that “*Ubudehe*” is not translated in the English translation, perhaps because it would not make sense: Laziness to fight poverty.

the most vulnerable individuals in each community. The vulnerability was determined by a short survey (described in detail below) that determined the vulnerability based on a scale of 1 - 6 (1 was poorest; 6 was wealthiest). The terminology for the poorest rank (1) was *umutindi nyakujya* or “those in abject poverty” and people in this category were described, in part, as being “Not respected. Discriminated against” (Sabates-Wheeler, et al. 2015). The most vulnerable family was given 600,000 FRW⁴⁶ for an income generating activity of their own choice but they were required to pass on the profit from their project to the next family on the list (Niringiye and Ayebale 2012). For example, if they decided to raise cattle with their money, some of the cattle born from these funds were supposed to be given to the next family on the list.

The sector representatives came to my house on 08 February 2015 to assess our household for the next *Ubudehe* meeting. This experience gave me firsthand knowledge of the process that went beyond the literature and GoR documents on the program. The first step of the *Ubudehe* Program process consisted of a home visit from one or two representatives from the sector who asked the household several questions from a survey. Two representatives came to our house on a Sunday afternoon. First, they documented each family member who lived in our house, everyone’s age, identification number, and whether or not each person was able to work. Then there were 13 additional questions regarding home ownership, access to primary needs (e.g. soap, clothes, and cooking fuel), full time job status of all family members, if anyone was involved in farming, if the family was able to buy their own food on a regular basis, if any family member worked for government or private industry, if anyone was self-employed, doing business (goods and services), owned a factory, and did anyone in the house work or own big machines (e.g. trucks, petrol stations). After these questions were answered, one person from the

⁴⁶ 600,000 FRW is about \$872, <http://www.xe.com/> on 09 Feb 2015.

household was required to sign and date the form. From these questions, the family's vulnerability number was calculated. Next there was a meeting with all the community members where the vulnerable families were identified. We did not attend this meeting and then moved to a new neighborhood so we never knew our vulnerability number but my husband guessed we were either a 3 or 4, which I thought was too low and did not accurately portray our economic vulnerability (or lack thereof).

At the meetings, it was possible for community members to request that their number be changed because they did not agree with the calculation or they thought that they were more or less vulnerable than described by that number. Even the neighbors could comment about the numbers of other families and suggest that the number be raised or lowered. In all cases, they provided reasons for the changes and then the village leader decided if their numbers changed or not. After a long and heated discussion, the families to receive the funding were selected and others were selected to work on other paid projects. If there were government funds available at that time (e.g. for school fees), then families were put on that list to receive those funds as well. In our neighborhood, the older people, generally those over 65 years old, were most often the beneficiaries of the *Ubudehe* Program funding while others received the other benefits, such as a paid position building a road, for example.

The *Ubudehe* Program was the main approach used to identify beneficiaries for all social interventions throughout the entire country of Rwanda (NUR 2014; Sabates-Wheeler, et al. 2015). Although the *Ubudehe* Program was not solely about farming, it was about coming together, as in the past. However, the program today was much different than in the past. Those who were considered vulnerable in their community were the ones to benefit most from the programs whereas in the past, everyone benefited and the vulnerable (e.g. those who could not

participate) were the ones to receive help last. Although the *Ubudehe* Program used a calculated system to determine the most vulnerable families, it was undoubtedly biased. Neighbors could change the number of other people from the village, raising or lowering their “vulnerability”. Plus on a scale of 1 - 6, many families were considered vulnerable with values of 1 or 2 but only few households received the direct assistance. The system also surely caused jealousy in the community.

Although Rwanda was often praised for its development endeavors, it was still a context where the majority of the population lived in poverty. Just examining the *Ubudehe* categories, four of the six categories referred to those who were either: “Below Subsistence” or “Middle Peasantry” groups (Sabates-Wheeler, et al. 2015). According to research conducted by Sabates-Wheeler et al (2015), although overall poverty was reducing, those who lived in extreme poverty still made up 24% of the total population. Therefore the majority of the population sought the small amounts of financial and material resources that were available to the community through programs like the *Ubudehe* Program and through *amashyirahamwe*. It is no wonder that people carefully constructed arguments as to why certain families should receive the funding (or not) during the meetings.

The *Ubudehe* Program also changed the ways in which funding was allocated throughout the community and this impacted the resources allocated to those living with HIV. The *ishyirahamwe* members complained informally about the *Ubudehe* Program because they were receiving less money from the government than before. HIV status was not listed in the *Ubudehe* questionnaire so those families who needed material support based on their HIV status no longer received it. HIV was once the trait for “vulnerability” and access to assistance but this had

changed. The *Ubudehe* Program created a new make-up of what makes one economically vulnerable.

There was a time when the *amashyirahamwe* had funding and resources streamed from NGOs directly to its beneficiaries. Berchmans spoke about the benefits of coming together in the past when funding was more widely available. He started by talking about medication access and then moved to talking about all other benefits received, based on the fact that they had come together:

When you heard the news, they were telling us that someone could access medication through the *amashyirahamwe*. That is a good thing that pushed us to join the *ishyirahamwe* because they were saying that if you put yourselves together, then we will find support for you when you are together, even *mituweli* they gave it to us because we are together. But even NGOs give it [*mituweli*] out after in health centers but it wasn't like that before; they could come and take the people in the *amashyirahamwe*. That is to say when you were infected [with HIV] it is not a must to give you *mituweli*. They could say those are people in the *ishyirahamwe*, they have our support.

RRP+ was indeed organized in part to organize the funding and channel it to people living with HIV. RRP+ then directed where and how monies flowed, similar to the *Ubudehe* Program. One difference between the *Ubudehe* Program and the *amashyirahamwe* was that individuals were not selected as direct beneficiaries of the funding; in the *amashyirahamwe* it was simply membership in the HIV support group that brought the resources to the members but not without exposing one's vulnerability.

The *Ubudehe* Program exposed some of the most vulnerable families to the community. In hopes of gaining the resources, families relayed their financial insecurities to the local leaders, as well as the community as a whole. This was not unlike the HIV support *amashyirahamwe* in that members had to disclose their HIV status in the community in order to access the benefits of the *ishyirahamwe*, be it financial or social. Yet this system left out, in both cases, the most

vulnerable in the communities, similar to work done by Nguyen (2010) in West Africa where the ones who were able to provide testimonies accessed ARVs, yet those who could not articulate a testimony were left without ARVs. This type of exclusion also aligns with Biehl's work in Brazil where the government ARV policy created a new space of exclusion, an invisible HIV epidemic referring to those who did not access the HIV related healthcare (Biehl 2007). These systems in Rwanda also created a new space of exclusion and further marginalized the most vulnerable. For those in the community who were able to "fight" to have their vulnerability number lowered were already a step ahead of those who were most vulnerable. The most vulnerable in the community would not be able to "argue" their status at a meeting. Where were these people? Surely they do not get the limited support that was available; they become overlooked in the process - invisible. They likely could not even attend the meetings, just like those who were unable to participate in the *ubudehe* of the past. In the past, these families eventually received help in their fields, so the story goes, but at the very end of the process. What if time ran out or the rains came early? The same holds true for the support groups for people living with HIV concerning joining the group in the first place but also paying the fees. The fees will undoubtedly transform into more of a pronounced issues when all groups transform into *koperative*. Each group at the time of the research required a fee to join. The poorest people in the community were actually not able to join and reap the benefits of the group, be it social or material. With the *koperative*, the shares to join were typically much more than the fees to join the *amashyirahamwe* so the exclusion will be even greater. In the registered *koperative* where I conducted research, not all *amashyirahamwe* members could afford the shares to join the *koperative*. These members remained part of the *amashyirahamwe* but were excluded from the

koperative. The complexity of being two different legal entities yet one local structure is further explored in chapter 8.

The community integration (and perhaps exclusion?) went beyond the *Ubudehe* Program and *amashyirahamwe* for people living with HIV. All members of a community were expected to participate in *umuganda*, a community works day, as well as other meetings at the village level. So why then do people join the *ishyirahamwe* for people living with HIV? In the past, there was an incentive to join because of the access to medication and other resources but overall the message was that people living with HIV should come together; it was the right thing to do. In the next section, I discuss how and why members joined the *amashyirahamwe*.

Joining: “Just coming together”

Although members had individual reasons for joining the *ishyirahamwe*, coming together was the overarching mantra that guided people to the *ishyirahamwe*. The rhetoric flowed something like this: at the national level, Rwandans should come together to solve their local problems through government programs based on “home grown solutions,” like the nationwide *Ubudehe* Program. These programs stressed bringing back the culture of unity that was lost since the colonial era (RGB 2014c). As such, these programs were part of the larger government initiative of reconciliation. Within local communities, neighbors should come together to solve problems, in *umuganda* or at the community meetings. This same concept was also used with the *gacaca* courts after the genocide. For better or worse, the community held genocide hearings for their neighbors, a type of participatory justice. The debates regarding the legitimacy of using community-based justice to resolve cases as serious as genocide crimes are very much present in the scholarly literature but these debates were beyond the scope of this dissertation. However, the *gacaca* courts used for genocide cases were another example of a Rwandan home grown

solution. General Frank Rusagara (2009) described the *gacaca* courts in the following way: “Rooted in society, the *Gacaca* derived its impetus and legitimacy from *ubumwe bw’ Abanyarwanda* (Rwandan unity), and complemented the same unity by being the cement that strengthened social relations in the name of justice.” This form of justice, Rusagara argued, maintained its legitimacy from a “traditional” unity from Rwandan history and strengthened relationships in the community. The pre-colonial *gacaca* courts were used to “restore order and harmony” within the community by dealing with minor disputes among families (Ingelaere 2012:392). *Gacaca* in the context of the genocide were very different as the disputes were not minor. *Gacaca* was a constantly evolving practice that was used from pre-colonial times until recent as “*gacaca* remoulds tradition to suit current situations” (Clark 2010:71).

Within the clinic, people who were living with HIV should come together to be with others who had similar problems (i.e. HIV). Early on, people living with HIV were encouraged to come together and as a result of coming together, they gained access to precious resources. More recently, people living with HIV were encouraged to come together to be a “responsible” member of the community as joining the *amashyirahamwe* was the best thing to do, so the members were told at the clinic. Finally, with the *koperative* movement, people living with HIV were encouraged to come together with others (i.e. with people who were not living with HIV) to be economically self-sufficient. The outlet kept changing but the message continued to stress the importance of coming together.

In the context of Rwanda, the notion of coming together was complicated for a variety of reasons. Even if in the past “culture” of Rwanda, people easily came together, the country was torn apart in the years leading up to the 1994 genocide. The aftermath of the 1994 genocide, though the fight had officially ended, impacted Rwandans in many different ways: many lost

loved ones, others were raped and acquired HIV, others lost part of their family to migration, others had family members who went to jail, and many people witnessed horrific acts committed by their family members and neighbors. How could it be possible to come together with these thoughts and consequences of genocide lingering in their minds? Yet there was not really a choice. In order to obtain access to resources, the family had to participate in the *Ubudehe* Program with their neighbors. For those living with HIV, they had to join the *ishyirahamwe*, with their neighbors, to obtain financial and social support. Although these conflicting realities were never outright discussed by participants, these were the larger realities of their every day existence. These experiences within a system of conflicting realities were similar to Fassin's (2006:xv) concept about the body and remembering, about "the inscribing of historical time onto flesh" and how people give meaning to their lives. In this sense, following Fassin (2006), the silence about the unofficial past, the past not promoted by officials, remained part of and influenced the members' daily life experiences.

When it came to joining the *ishyirahamwe*, there were several ways that people came together in the *ishyirahamwe*. Most members with whom I spoke heard about the *ishyirahamwe* from their healthcare provider at the local clinic. The knowledge relayed from the healthcare provider did not always lead to joining the *ishyirahamwe* but there was a lot of sensitization about the *amashyirahamwe* in the communities from the local health centers. After a positive HIV test, the healthcare providers normally gave the *ishyirahamwe* details to the person and encouraged them to join. In some cases, the members joined because they felt like they had to follow their doctors' advice and join the group.

In addition, people heard about the *amashyirahamwe* from other people who were living with HIV and/or peer educators from the *ishyirahamwe* in the community. In some cases, the

ishyirahamwe members, usually leaders or peer educators, confronted and recruited people they suspected to have HIV. Their suspicions were based on the fact that the person was really sick or the leaders heard that someone's spouse was living with HIV. In these cases, the leaders sensitized the community member to be tested for HIV and offered the *ishyirahamwe* as an option in case they tested positive. In other cases, the peer educators or community health workers in the village, that is, outside the *ishyirahamwe*, sensitized people from the community to be tested for HIV, whether they were sick or not. Emmanuel, a 23-year-old male from the Western *Ishyirahamwe*, *Twizere*, went for testing at the local clinic with several of his friends after encouragement from the peer educator. When they received their test results, his colleagues were infected with HIV and the peer educator was there and helped them and informed them about the *ishyirahamwe*. Emmanuel was the only one who was not infected with HIV but they all joined the *koperative* together four years prior to the research.

The story of that day, for me I was with my colleagues and it was time for testing blood [for HIV] so we had gone there [to the hospital] and some were infected so the peer educators came to us... After coming from there, some found that they were infected... and she [peer educator] gave us another service because when one has just come from the hospital and he has found out that he is infected, he has to go in solitude, things like that... My colleagues, the ones we used to move together, joined and I said that let me too join the *koperative*.

The peer educator warned this group of young men before they were tested that if they were infected, they may want to go into solitude but it was better to join the *ishyirahamwe* and be together with others. Emmanuel joined the *ishyirahamwe* with his peers, even though he was not living with HIV. He spent a lot of time convincing his parents that he was not infected with HIV. They made him test several times before they finally believed him.

But the fact of the matter was that within the close-knit villages, people were monitored and approached if they were suspected to have HIV. This is further exemplified below in

Umutesi's story. If one was already suspected to have HIV in the village, then perhaps the next step would be to have a test to confirm or deny the rumors. Either way the monitoring of the population was not just apparent in the village, this monitoring took place within the *amashyirahamwe* as well (see below).

Another way people came to join the *ishyirahamwe* was by being directly recruited by the *ishyirahamwe* for a particular reason (see Umutesi's story below). In other cases, the community members, after hearing about the *ishyirahamwe* from the physician or within the village, looked for members in their community and asked them to take them to an *ishyirahamwe* meeting so that they could also join (e.g. Berchmans story in chapter 9). No matter how the members joined, there was an overarching message that people who joined the *ishyirahamwe* were doing the "right" thing and those who did not join the *ishyirahamwe* were the ones spreading the epidemic. Uwase comments on this fact, highlighting that the leaders are the ones who state that those who do not join the *ishyirahamwe* spread the epidemic.

"You even find the leaders saying that we thank those who have accepted and joined the *ishyirahamwe* and are known because others who don't join the *amashyirahamwe* and who don't accept that they are HIV positive and they don't even show it, they are the ones who are continuing to infect other people in ways that are secret and unknown."

This was a common theme in the *ishyirahamwe* members' trope about people living with HIV who do not join *amashyirahamwe*: the people who would not join the *ishyirahamwe* were those who were continuing to spread HIV. Leaders and members alike communicated this type of rhetoric, which surely encouraged people to join the *ishyirahamwe* and do the "right" thing in their own community. This type of talk coupled with the promotion of coming together then

shamed some people into joining the *ishyirahamwe* because if they did not, then they were the ones who were spreading the epidemic.

Joining an *ishyirahamwe* was not solely about coming together. Being with others was often stated as a positive benefit of the *ishyirahamwe* and sometimes even the reason members stated for joining but in reality the people living with HIV were supposed to join. This message was presented to those who tested positive for HIV at the health clinic yet members often spoke about how the *ishyirahamwe* helped to make their experience of HIV more “normal” in the context of their daily lives.

Nyiramwiza, a 56-year-old member of the Northern *Ishyirahamwe*, *Abakundanye*, found out she was living with HIV in 1998. Her initial reaction was dramatic, as it was with most people, but after coming together with others, she began to feel more “normal”.

“I felt like dying, I went into a coma...but when we are together [in the *ishyirahamwe*], we feel like we are like other people who are normal.”

But this normality she spoke of meant what in the context of Rwanda? And who are the other people to whom she strived to be like? In Nyiramwiza’s statement, when the group was together, they were like others - the normal people but then who were the pathological? The members before they were together? “Pathological”, according to Canguilhem (1989:203), “must be understood as one type of normal, as the abnormal is not what is not normal, but what constitutes another normal”. At what point do the members view their pathology as normal? Perhaps they felt like others who were not infected with HIV because those who did not have HIV were in a normal state of health. But they still had HIV. There was also talk about how HIV was like other diseases so perhaps the notion of normality changed as well. HIV was not the only illness that affected people, especially in a post-conflict setting where many people suffered from

trauma, physical and psychological, from the genocide. Alternatively, they, in the group who were people living with HIV, were like the others, in the community, because they were no longer in solitude in a culture where coming together was the spoken “norm”. Being excluded from the community had large impacts on one’s life. Perhaps the normal was being together with others. Was the group still excluded from the wider society? Likely yes. But at least they were together.

Years back before the genocide, Nyiramwiza’s husband moved to a different village for work, which was not unusual. He lived in that village and traveled home on occasion to be with his family. He found another woman in that village. When the genocide erupted in 1994, both Nyiramwiza and her husband fled the country but separately as they were not physically together when the genocide started. They ended up in different countries during the course of the genocide. After the genocide ended, they both came back to Rwanda and eventually reunited and started living together again. After some time, Nyiramwiza had heard that her husband’s “whore⁴⁷” had died of AIDS. Nyiramwiza was scared to go for testing but then she became ill and finally went for an HIV test in 1998. At that point, she found out that she was also infected with HIV. The clinic encouraged her to join the *ishyirahamwe*.

After knowing that I was HIV positive before joining the *ishyirahamwe* I was having fear in my heart, and I was filled with loss of hope, when I would feel an ache in my head, I would say, “now I am going to die.” If I felt the pain of worms in my stomach, I would say, “now I am going to die.” It became something normal. But after going to the *ishyirahamwe*, I met my colleagues and we talked about it, how it is [living with HIV]. Now I feel there is no problem because I know that it [HIV] is a disease just like any other. So that is what has changed, because anytime even a person who is not suffering from HIV can die.

⁴⁷ Sex outside of marriage was considered prostitution in Rwanda. As such, referring to the woman as a “whore” or prostitute did not mean that the woman was a commercial sex worker.

Every time Nyiramwiza felt unwell, she thought she was going to die. These feelings became her norm until she joined with others and realized that there was life after HIV. She continued to tell us about the benefits of being in the *ishyirahamwe*.

“I benefit ... coming out of solitude, I am with others and feel that there is no problem since that problem did not happen to me alone.”

Nyiramwiza’s story was another instance of how the genocide indirectly impacted her HIV status. Although she does not outright state that the genocide caused her to acquire HIV, her story entailed of a genocide that caused her family to be separated, new unions formed, and upon reuniting, HIV came alongside. There was more to Nyiramwiza’s story than her husband with his “whore.” The legacy of the genocide, for her, was HIV.

Equally important to being with others, the *amashyirahamwe* were the prime candidates for the resources therefore joining had material benefit, at least in the past. When people joined the *ishyirahamwe*, the GoR could keep track of people living with HIV through RRP+, whether they did or not was not known. Although RRP+ was considered a local NGO, it was still closely linked with MoH. On a more local level, leaders in the community could keep track of the behaviors of those living with HIV and teach people how to live positively, another facet of the *ishyirahamwe* that was often relayed as being beneficial to members (see chapter 7). However, even if a person living with HIV was not part of the *ishyirahamwe*, there was still some surveillance of their behavior from the clinic into the village.

This was not to say that there were not positive benefits of joining the *ishyirahamwe*. Members came together and helped each other with projects, became friends with other members, and even shared their personal resources with each other. For example, the Eastern *Ishyirahamwe*, *Abihanganye*, had an informal *ubudehe* program, although it was not called as

such, it was very similar to the *ubudehe* of the past, more so than the current *Ubudehe* Program. *Abihanganye* had a rotating work initiative, in addition to building their *koperative*, where the group went to one member's home each week and helped them with a project that they otherwise would not be able to accomplish in a timely manner on their own. To determine the order in which the work took place, the president wrote the number of people who wanted to participate on slips of paper and threw it into a pile. Then each member took a slip of paper from the pile and the number on the paper corresponded with the order in which they proceeded with the work. The work included a variety of tasks specific to the individual needs of the members. For example, several times we tilled member's fields so that they could cultivate seeds. Another time we made hundreds of bricks so that a member could build small houses on his property (see Figure 18 below). The *amashyirahamwe* were beneficial to the members but at the expense of being known as living with HIV within the local community.



Figure 18: Bricks made by the association for one member to build houses on the family plot (photo by Jennifer Ilo Van Nuil)

I helped to persuade a community member to join the *ishyirahamwe* in Kigali, *Abihuje*. The president, Berte, of *Abihuje* heard through her community network that there was a woman, Umutesi, who was living with HIV and having some trouble. She was not part of an *ishyirahamwe* at that time. The president heard that this woman was breastfeeding and not adhering to her ARVs so we set up a meeting to have a discussion with this woman. These behaviors were a problem not only for her health (e.g. drug resistance) but also for the health of her baby (e.g. increasing the risk of HIV transmission to her child through breastfeeding and not taking ARVs). We saw the woman walking up the hill after an *ishyirahamwe* meeting one afternoon. The president asked her if we could come visit her later that week and talk about her health. The woman said yes.

A few days later, I drove to our usual parking area on the side of the main road and the woman we were meeting was there, along with two other women and an older man in his sixties. The vice-president was also there and called Berte to come and meet us on the road. As soon as Berte arrived, we walked down the hill on the dirt path past several small shops and many little homes. We entered Umutesi's compound and were greeted by several small children. She ushered us into her home and we sat on the sofa. Berte explained to her that I was conducting research and asked if it was okay if I was there to observe the discussion. Umutesi consented. Berte took out a survey and asked her a few questions: name, age, marital status and number of children. Umutesi, who was 30 years old at the time, was married and had four children. The youngest was three years old and she was still breastfeeding him. Umutesi was taking bactrim but no ARVs, although during the interview, she told us that she had just started taking ARVs recently. The doctor gave her 15 tablets to begin her therapy. Berte asked her if she filled her medicine and the location of where she filled her ARVs. She shook her head with tears in her

eyes and said that she filled her medicine in the next town over. Berte told her that she needed to keep her appointments and fill her medication on time. She asked to see her appointment book and there were only appointments listed for the day before (September 2012)⁴⁸, one in June 2012, one in April 2012, and five listed in 2011. She should have gone to the clinic once a month and filled her medication each month. Her CD4 was recorded only three times: 474, 418, 574. For June and the previous day's appointment in September, it was left blank.

Next, Berte told her about the purpose of the *ishyirahamwe*. She told her about three other *amashyirahamwe* in the area in case she did not want to join ours, which was the one in her immediate community. Because we were in Kigali Province, there were many *amashyirahamwe* in the nearby areas. She listed the location and some of the activities on which each *ishyirahamwe* worked. She explained some of the problems that happened when people were living with HIV (e.g. isolation, depression, trouble with medication). She then asked, "How can we be friends and help each other?" At that moment, the woman's husband entered the room with his appointment card in his hand and handed it to Berte after greeting us quietly. Berte showed me his card, which was completely full of appointments. He attended his appointment every month and filled his medication regularly. He was taking 3TC⁴⁹ and two other medications. His CD4 was not listed on the card but he assured us that he was strong. He picked up one of his children and left out the front door. Berte looked at Umutesi and she started to cry. "Wihangane" (endure) Berte took her hand in hers.

Umutesi told us that she did not want to join the local *ishyirahamwe* because she did not want others in her community to know about her HIV status. Berte told her it was okay that she

⁴⁸ I think she initiated the health clinic visit because she knew we were coming to visit her. The president of the association also confirmed this suspicion.

⁴⁹ HIV medication called Lamivudine

did not join this *ishyirahamwe* but she should join with others in some place. Again Berte mentioned the three closest *amashyirahamwe* in the surrounding communities as alternatives to joining the *ishyirahamwe* in her community. Berte again stressed the many health benefits of being with others. She told her that she could come and that she would not have to say anything at the meeting, it would come slowly by slowly. I was surprised when Umutesi agreed to come to the next meeting. She had hesitated for so many years. Why now?

We offered to pick her up at her house and take her to the next meeting. She agreed and ended up attending the next meeting (as well as subsequent meetings) and introduced herself at the first meeting stating that she was living with HIV. During an interview, Umutesi admitted that her husband had been encouraging her to join the *ishyirahamwe* for some time so when we came to the house, she felt it was a good opportunity to finally join. Her husband joined the *ishyirahamwe* with her. Umutesi was diagnosed with HIV in 2004 when she was 22 years old and joined the *ishyirahamwe* at the end of 2012. She never told anyone, other than her husband, about her HIV status. Others who were living with HIV knew her status because they saw her at the HIV clinic but she still hesitated to join.

I do not think someone like Umutesi would have joined the *ishyirahamwe* without the urge from the president of the *ishyirahamwe*. She had been living for years without joining an *ishyirahamwe*. But after joining, she said that she very happy to be a member. After being in the *ishyirahamwe* for two months Umutesi told me: “It helps me because I no longer am in solitude and I no longer go far in thinking negatively and I no longer hide.” But surely she had her own way of handling life with HIV before the *ishyirahamwe*. Perhaps she did not want to be singled out in the community as a person living with HIV. Maybe by not joining for all those years, she was able to remain an active member of society who was not stigmatized or known as a person

living with HIV. She was isolated, in a sense, from others living with HIV by not joining. One of the immediate consequences of joining an *ishyirahamwe* was public disclosure of HIV status.

Not everyone wanted to join the *ishyirahamwe* and things changed even more after the *amashyirahamwe* were transforming into *koperative*. After the shift began, Felicien found, in his Master's research on *amashyirahamwe* for people living with HIV that many people in Kigali dropped out of the *amashyirahamwe* because they did not want non-HIV positive members to join and know their HIV status. There were even wealthier people living with HIV who traveled very far to see a doctor or even request after hour appointments so that people do not see them at the clinic and label them as living with HIV so disclosure of the status was a large problem for some.

Public Disclosure

People sometimes avoided joining an *ishyirahamwe* so that their HIV status was not known, just like others who attended clinic appointments after hours to avoid being known as a person living with HIV. Although there were people who were not living with HIV in the groups, there was still discrimination against the groups as a whole, even at the time of the research although members and others contested this notion initially (see chapter 6 on *akato*). Normally if one was an *ishyirahamwe* member, eventually they would have to publicly disclose their HIV status, either through the community events where community members would see that they were a group of people living with HIV or some members literally publicly disclosed their status at community meetings. This public disclosure was one strategy of reducing *akato* in the community. There were times when the peer educators approached people but they refused to come to the meetings because they wanted their HIV status to remain unknown in the community, like for example, Umutesi for all those years.

When one joined the group, they began with a brief introduction in front of the group at a meeting. Uwase was a 49-year-old member of *Humura*. She found out she was HIV positive in 2004. She joined the *ishyirahamwe* shortly after learning her HIV status. Below is the story of the day when she first joined the *ishyirahamwe*.

Yes, they had a meeting and then they said, ‘we can see there is a visitor that we don’t know, let her stand up and introduce herself and tell us how she came here.’ I stood up. The people who had brought me had told me before that I would have to stand up and say that I have a problem [of HIV] and that is why I came to join hands with you. So I stood up and said my names and that I have come to the *ishyirahamwe* of people living with HIV.

After disclosing the status to the group, it was known that at some point you would be known as a person living with HIV in the community.

Uwase continued: “...When you accept to join the *ishyirahamwe* of people living with HIV, you also accept to be known as a person who is HIV positive.”

The *amashyirahamwe* and its members were known as such in the communities. The leaders and members were individually known, the locations of work were known, and even meetings locations and times were known. Several times as we were walking to work in a field or before a meeting and people from the community would say things about us. One time we were working at a member’s home at the Eastern *Ishyirahamwe*, *Abihanganye*, and about five men from the community heard that there was a *umuzungu* (foreigner) working with the people living with HIV so they all went to the site to see if it was the case. Therefore joining and belonging to the *ishyirahamwe* inadvertently exposes one’s HIV status within the community and often brought some form of *akato* to its members.

The public disclosure went beyond joining the *ishyirahamwe*. The clinic also became a place where disclosure of HIV status was common. When people did not attend their clinic appointments, the clinics sometimes worked with *ishyirahamwe* leaders to locate the patients in

the community and remind them to go to their appointments. But some clinics went a step further to ensure that people adhered to their appointments and disclosed the names of people who did not attend their appointments at the clinic. In one local health clinic, Jean de Dieu, also a member of *Abihanganye*, informed me about the process of identifying the members who missed their appointments and the members' roles in helping other members to go to the clinic. He told me that there was a list of people who did not attend their appointments on public display at the clinic. This list was disclosed to others in the clinic, including other patients and anyone else who happened to be in the clinic waiting room at that time. The names of those who did not attend were read out loud in the waiting room so that the other patients would look for those missing patients in the community and encourage them to come for their appointment. "When we go to the health facility and they read out the names of some of our members in the *ishyirahamwe* who are not present, we go and visit them and tell them: 'why have you refused medication?' We then advise them and they go and get medication." Although this particular section of the clinic is only for those living with HIV, it still might deter people from attending a clinic in the first place: "They do dodge [going to the clinic] because there are some [people living with HIV] who don't want to be seen... Those are the people that refuse medication."

The groups were not always directly linked with the local health centers, however, the *amashyirahamwe* were known by the health centers and would call upon the *ishyirahamwe* for assistance with their patients who were not adhering to their clinic appointments. The situation created tensions for people living with HIV because those who did not want their status disclosed in the community would be exposed as living with HIV if they ever missed their appointment. Others simply avoided attending clinics in their home villages and towns. Instead they traveled, sometimes all the way into Kigali, to avoid being seen by their friends and neighbors in their

community. But traveling to another village or town was not an option for everyone. Those who could not afford to do so would be forced to either have their status known or not attend the clinic at the expense of their health. Again, public disclosure was something that was almost a given upon diagnosis of HIV, unless of course, one could afford to test and treat their HIV in private. It was possible to have an HIV test at a private clinic but it cost quite a lot of money.

Just Coming Together...

The people who do not want their statuses known were always the ones blamed for spreading HIV and also refusing medication. They were referred to as “hiding” or “dodging” the clinic when perhaps they had very good reasons for not wanting to join the *ishyirahamwe*. No one should be forced to join. It could also be the case that the people did not want others to know about their HIV status, which should also be their right. In certain instances, coming together was the best thing for people but at the same time, did they really have an option? The disclosure of HIV status also brought *akato* to those living with HIV. The *ishyirahamwe* strove to fight against *akato* yet belonging to the *ishyirahamwe* brought *akato* to its members. The story of *akato* is discussed in the next chapter.

CHAPTER 6 AKATO

Coming together to fight akato

I now come back to the story of *akato* that was introduced briefly in the introduction with the car incident. When discussing *akato* with members of the *ishyirahamwe*, I heard the same story: *akato* no longer existed for people living with HIV but it existed in Rwanda in the past. I could not truly believe that there was no longer any *akato* and it frustrated me. I could not get people to discuss the reality; they were all telling me that *akato* no longer existed. I wanted to understand why people were telling me this narrative. Perhaps because *akato* reduction was one main goals of RRP+, the members wanted to make sure I knew that they were being successful in that fight. Alternatively, the members may not want to admit that they are part of a stigmatized group. But it extended beyond the members. I also heard this same narrative in 2009 when I was in Rwanda working for FHI. My first trip to Rwanda was in 2008 and I conducted data analysis on interviews with people living with HIV. I read the transcripts, which were collected in 2006, and could feel *akato* in their stories. Yet when I spoke with people working in the healthcare community about “stigma” against people living with HIV, I was told repeatedly that there was no *akato* against people living with HIV in Rwanda. Further in 2009, I worked on a small booklet using the same narrative data to educate health providers about the lives and experiences of people living with HIV. We created several categories and I suggested stigma as a chapter. It was turned down immediately because “stigma no longer exists” so we did not need to address it in our booklet. Whatever the reason for the narrative of its denial, the event described in the introduction encouraged members to talk about *akato* in a different narrative where *akato* indeed existed.

But the story did not end with the first incident with the car. The word appeared again on the car for a second time shortly thereafter at the *ishyirahamwe* site in the East. I was parked in the sector office parking lot, which was located right off the main dirt road and someone wrote *abanyasida* (people with AIDS) in the dust on the car on the back passenger door. On the front driver door it said *umuzungu* (foreigner). I showed the president of the Eastern *Ishyirahamwe* and he grabbed some leaves and wiped it away quickly. This was only a few days after the first incident at *Humura*. That same day, there was a luncheon with people from the local health community. I was really late to the meeting but I raced to the luncheon after the fieldwork to ask my Rwandan colleagues what they thought was happening with these two incidents.

They explained the case in several ways. First, the people in the community were warning me that I was with people living with HIV. I did not think this was the case as I had been with the group for months by that time and I was known in the communities. Second, my colleagues thought that perhaps people in the community thought that I also had HIV and were demonstrating that they knew about my HIV status. This could very well be the case at *Humura* but in the East at *Abihanganye*, my driver door said *umuzungu*, not *abanyasida*. The final answer proposed was that people in the community were giving us all *akato* because I was together with an *ishyirahamwe* for people living with HIV. Again, *akato* was present in a place where *akato* supposedly did not exist. The narrative had changed: my colleagues were now admitting that *akato* was present for people living with HIV. At this point, I decided to learn about *akato* against people living with HIV, beginning first with what exactly was meant by the Kinyarwanda term *akato*.

Meaning of *akato*

The Kinyarwanda word, *akato*, was commonly used to describe a sort of “stigma” against people living with HIV. I spoke with several linguists in Rwanda and was told that the word *akato* has four main meanings: quarantine, stigma, isolation and marginalization. *Akato* was derived from the word *ubwato* (boat) and was part of a diminutive noun class⁵⁰ therefore literally means little boat. Following the linguistic rules of Kinyarwanda, I deduced that it takes on the meaning of being sent off in a small boat at sea: isolated, abandoned, and quarantined. Yet when I verified with Felicien, who has a BA in Kinyarwanda, he said that it was a totally different word from *ubwato* and it was not at all related linguistically. However, I could also say *akato* to mean little boat but the pronunciation was different creating a totally different word.

There were several instances in which the word *akato* was used. For example, the word *akato* was used in farming. When there were sick cows, for example, and the area needed to be quarantined so that other cows did not become sick, then the farmers would *akato*, or quarantine, the land to prevent other cows from grazing on the harmful land. Also when people had a communicable disease, such as tuberculosis (TB) or leprosy, and they were sent to isolation the word *akato* was also used. In both cases, people or animals had a contagious disease that was easily transmitted. As such, they were sent to *akato*. In these instances the word meant something similar to quarantine or isolation.

Another example of the meaning of the word *akato* was marginalization. For example, in the East African Community (EAC), if the community did not allow Burundi to join and become a member of the EAC, this was also *akato* but not necessarily in the same way as in the former

⁵⁰ Kinyarwanda has ten noun classes, each with singular and plural cases (though some count each individual case as one therefore some say that there are 19 classes; class 10 does not have plural). The aka- utu- class is considered class 7 in most circles.

examples. There was no reference here to disease or the need for quarantine; it was simply a way of leaving out or marginalizing groups of people or an entire country. Finally, *akato* was used in the context of HIV to describe instances of stigma. Yet the English word stigma does not fully capture *akato*. When discussing the meaning of the word *akato* with members of the *amashyirahamwe*, most described it as a form of isolation. As such, during interviews and conversations Felicien and I probed about the meaning of *akato*, the situations in which *akato* occurred, and the ways in which people living with HIV experienced *akato*. According to participants and others in the community, this word had strong meanings and feelings attached. It was not something simple, nor was it exactly what others described as stigma. There was another word for discrimination, *ivangura*, but it was used primarily for discrimination based on ethnicity, place of origin, economic situation not chronic illnesses, such as HIV, TB, and Ebola. *Akato* was the only word I discovered that was commonly used for what we describe as stigma in the context of HIV.

There were several facets to the *akato* against people living with in Rwanda. One part of *akato* was name-calling and talking about those living with HIV either behind their backs or in front of them. Another part was not sharing food or drink and/or avoiding those living with HIV.

The first part of *akato* that was described to me was name-calling. People in the community would use names to refer to people living with HIV with a variety of words, some more insulting than others. A common word included in the name-calling was *abanyasida*, which literally means people with AIDS. The word *abanyasida* has the French acronym for AIDS, SIDA, embedded into the Kinyarwanda word, therefore it literally meant people with SIDA (or AIDS). Other times people spoke about the people in the community who were sick

with AIDS [*Ngo yarwaye SIDA*]⁵¹. Both these cases were simply calling the person the disease or stating that one had the disease. *Abanyagiswaku* was another term used for people living with HIV that goes beyond the disease itself. The ending of the noun, *-igiswaku*, refers to a type of aggressive ant with visible teeth that can cut humans' skin. When adding the prefix *abanya-* it changes the noun to refer to people (e.g. *abanyarwanda* is translated in English as Rwandans). Literally the term was translated as people with these aggressive ants. *Abanyagiswaku* was a slang word used to refer to people with AIDS because AIDS was viewed as being aggressive and harmful, like the *igiswaku* ant. Worse than that, people in the community spoke about the *ishyirahamwe* members as if they were already dead (*nyakwigendera*⁵²) and even spoke about those who were living with HIV using such words right in front of them like they did not exist anymore. This talk was sometimes directed at people because they belonged to the *ishyirahamwe* but other times it was a reflection of their physical appearance (e.g. showing some form of physical illness, whether related to HIV or not). When members spoke about *akato* to me, they would discuss that *akato* against people living with HIV included being called these names. Even simply being called *abanyasida* reduced the person to a diagnosis and for them, this was a big part of *akato*.

Other diseases and illnesses carried *akato*, such as tuberculosis (*abanyagituntu*), leprosy (*umubembe*), people with mental problems from a curse (*abasazi*), infertile people (*ingumba*) and drunks (*abasinzi*), to name a few. This type of name-calling was considered *akato* with one exception. Those with mental problems that were not from a curse were not called *abasazi*.

Others who deviated from the “norm” but not based on health were called names as such but it was not considered *akato* (e.g. rich people, foreigners). However, one large exception was

⁵¹ Literally “that she is sick with SIDA”. From interview with Claudine.

⁵² Literally means “someone who has passed away” also sometimes means “moving coffin”.

in the case of genocide perpetrators. *Abagenocidaire* means genocide perpetrators in English. This was considered *akato* and sometimes the term was extended to children of perpetrators as a way to offend and shame the entire family.

Claudine who was 48 years old from the Northern *Ishyirahamwe*, *Abakundanye*, spoke about the *akato* she experienced in the past when she looked physically ill from the progression of HIV. The *akato* reduced after she started to physically look better, presumably from the ART. “They would single me out, I used to experience *akato* from people saying that I am suffering from AIDS, now it has stopped, I have cured my body now.”

In the past, Claudine’s body showed the visible effects of HIV such as wasting and people assumed that she was living with HIV and as such, talked about her as if she was living with HIV without knowing for sure. For Claudine this assumption (whether correct or not) constituted *akato*. Other participants agreed and had their own stories. Claudine took ownership of her body and health status that she, not the medicine, cured her own body and then the *akato* stopped.

When probed about what this *akato* really meant, she stated:

“Definitely they wouldn’t share.”

Beyond simply being assumed and labeled verbally as having HIV, she also noticed that people did not share food or drinks with her due to fear of contamination. After she joined the *ishyirahamwe*, she felt like *akato* was reduced both personally for her and within her village. She also spoke of government programs that were set up to fight *akato* against those living with HIV and if community members were caught giving *akato* to people living with HIV, there would be some form of punishment.

“After some time he [executive secretary of the sector] held meetings with the population and they told them that they should not give *akato* or isolate people. And that the one who will be

caught doing that will be punished.”

Akato against people living with HIV and the laws against it were just a small part of a larger dialogue of coming together as Rwandans. In this utopia, there was no *akato* against people living with HIV or differentiation based on ethnicity. The mantra was that everyone was Rwandan and if one gave someone else *akato*, they would be punished.

Because of the collective nature of society and the interdependence of Rwandan society on each other for basic needs, isolation in and of itself was a dramatic form of punishment or shaming. Being isolated from the community could mean that the very basic needs, such as food, were cut out. The economic marginalization of most families resulted in people relying on each other to survive. These small forms of coming together included swapping food to avoid purchasing at the market (e.g. my garden has tomatoes and yours has papaya so let's swap foods), *ikimina* which was the pooling together of small amounts of money by a group of people and one person received the total amount on a rotating schedule, contributions for weddings and funerals, and simply sharing resources. Beyond a program like *Ubudehe*, the members often used creative ways to sustain their lives within the community as well as within the *amashyirahamwe*. Being isolated from collective life meant a lot more than how it was often stated to me.

Members spoke about how as soon as their neighbors found out about their HIV statuses, sometimes they would not want to share food or even use the same waterspout. This isolation was not always the case but when members were isolated, it impacted their everyday life. These members joined the *ishyirahamwe* as a way of finding a less corrosive environment within the context of *akato* from the community.

The *amashyirahamwe* had resources that came from within, from their own initiatives and/or saved monies. Some *amashyirahamwe* had money set aside for people who needed food.

Members also exchanged food with each other. Though most members with whom I encountered were poor and had very little, they seemed very willing to help each other in any way they could. This behavior was common in Rwanda as a whole; it was not just within the *ishyirahamwe* that this type of shared communal behavior existed, again stressing the importance of being integrated.

Josee, a member of *Twizere* (in the West), told me about her friends in the *ishyirahamwe*:

“Ahahahaha!! We converse and laugh, if I don't have something they give it to me or I give them what I have that they don't have.”

When asked if her friends outside the *ishyirahamwe* could offer her the same support, she responded:

“They can also do it but mostly a person is rescued by those that are near.”

The *amashyirahamwe*, in fighting isolation, were fighting to remove the shame associated with living with HIV and helping members to integrate into a community so that the impact would not be so dramatic. If not within the village, they formed their own *umuryango* within the *ishyirahamwe*. Like Josee said, those who are near rescue us. And being with others who faced similar problems, like being isolated from the community, created a space for them to feel part of something and continue to benefit from the shared resources.

But Claudine, from *Abakundanye*, still thought that people stopped giving her *akato* because her body was visibly cured and she no longer looked sick. This sentiment was echoed in other interviews as well. When people began to feel and look healthier, then they felt like the *akato* from others reduced. ARVs have reduced this form of *akato* on some level because it had reduced the visible effects of HIV including physical ailments (such as skin rashes or dramatic

weight loss). The visibility of any disease causes some level of discrimination and when people begin to look like others, the fear reduces as well. Their neighbors went back to sharing.

It was still puzzling that members insisted that there was no *akato*. Considering people felt that *akato* was a strong word with strong meaning attached, perhaps knowing about the *akato* from the past was why members initially thought that there was no more *akato* from the community. The instance of the car brought up interesting stories of *akato*. Though Berchmans argued that *akato* had ended, after remembering the incident with the car, he admitted that *akato* still existed. He laughed as he remembered what happened to the car.

I even saw it written on the car, hahaha you don't remember? We saw it down there?

You don't feel something?

Even *akato* has not yet stopped! There are times you can look at someone and you can see he/she is *aguhaye akato* [giving you stigma] and when you are just looking at him/her only...You were *abanyasida* [people living with HIV], hahaha!

He wanted to know if I felt something. Did I feel *akato*? Before I could answer, he continued and gave an example of *akato* that happened to him more recently. He was at a meeting and when another person joined their table and that person left after realizing that there were people living with HIV at the table.

“Eeh, he heard what we were conversing about [HIV] and shifted! He went! You understand? It showed me the reason why he shifted, even if he didn't show it to me or by him saying it but with his actions, you can even see, it **is** *akato*...It looks like *akato* still exists but does it cause us instability like before? **We are not still unstable.**”

The progress of the NGOs and the development world in their fight against *akato* had failed and members often failed to realize it. The members did not want to admit it but after some reflection on the topic, Berchmans realized that yes, *akato* did indeed exist. *Akato* caused

people living with HIV many problems in the past but according to Berchmans it did not cause instability like before. Other members agreed and did not admit that *akato* existed until we really probed about it, using the example of the vehicle. But the *akato* I saw on the car was only part of the story. The part of *akato* that was more significant in their lives was the isolation. But that was remedied in part by the *ishyirahamwe* and part within the village. Perhaps name-calling existed but that in and of itself did not cause instability like before. A man leaving the table at a meeting or people having ignorance was different than being abandoned or isolated from the community. Even the car incident made many people laugh when I told them about it (members and non-members alike), perhaps because they were uncomfortable⁵³ about the situation but perhaps because this type of *akato* had an impact on life somewhat but not like before. They were not unstable from it at the current time.

Berchmans continued the conversation about how *akato* was not an issue like before because people who were not living with HIV joined their groups.

“*Akato* is not still a problem because as you can see people who are not infected want to be with us in the *ishyirahamwe*...in order to cooperate with us in cultivation. They are requesting it now, even those sayings they used to say that we are approaching death, no one is saying it, no one is saying that we are dying...”

Even the name-calling had stopped to some extent. Claudine told me, “We work alone and they even no longer say that we are *abanyasida*, we are people like others, they no longer say that.” For Claudine though they still worked alone as an *ishyirahamwe*, at least people in some communities were not using names to set people apart. But it was not the case in all communities; these names were still used in some areas. Genoveva from the Western

⁵³ As in other places, in Rwanda sometimes people laugh when they are uncomfortable; it doesn't always mean that they think the topic is funny.

Ishyirahamwe, Twizere, said that the people in her community still called them people who are sick with AIDS [*turi abarwayi ba SIDA*] and called themselves normal or healthy people [*ni bazima*] but “for us we don’t accept [the names] because we see our life is just like theirs.” For Claudine, normality maps onto health and she spoke of those who are sick (with HIV) versus those who are healthy but not just the absence of health in general, the absence of health due to HIV. Even the words were etched on the vehicle so the name-calling was not completely removed from the communities.

Claude, from *Humura*, stated that *akato* still existed in the community, based on the event that happened with the car:

We will have joined with them so that *akato* goes far, it [getting HIV] can also happen to them too, if they came and we combine harvest they would be developing us, but they cannot come because they are always suspicious of things that they don't know. The example I can give you is the things they wrote on the vehicle. Do you think there are no other vehicles that are normally there but why this one? Isn't it because they had seen that you come to visit us?

There was also a type of self-stigma where people isolate themselves, called *kwigunga*⁵⁴.

Members claimed that *kwigunga* existed and that the *ishyirahamwe* helped to fight against this kind of personal withdraw also. Berchmans explained:

“We are people living with HIV even *akato* keeps on following us because we isolate ourselves but when we are with others conversing - I told you someone asked me how AIDS pains me in that conversation - they feel it even before they could say when did this one come and when did he arrive in those people.”

Claude agreed:

“No, no if we gave ourselves *akato* we wouldn't be going where others are, we would always be indoors hiding.”

⁵⁴ English: To withdraw oneself, normally due to emotional hurt.

The experiences of *akato* described to me in the interviews⁵⁵ and through informal conversations were not instances of isolation like before when the *amashyirahamwe* first emerged. Though I argue that *akato* still clearly existed in Rwanda, it was not the extent to which people were being outright abandoned. However, it still made a difference in the lives of people living with HIV. Belonging to the *ishyirahamwe*, despite the resources and social support they received, also shaped how community members viewed the *ishyirahamwe* members. They were automatically assumed to have HIV and the members then experienced life differently than before the community knew about their status. The fact that people still remained in the group and tried their best to fight against *akato* in their communities brought the group closer together and made their togetherness more significant.

When RRP+ was initially formed in 2003, one of the primary goals was to reduce *akato* against people living with HIV. It was clear that *akato* was a problem that needed to be addressed so the *amashyirahamwe* were placed in charge of this task and aimed to reduce *akato* in their communities through a variety of methods, including public testimonies and education. However, these techniques to reduce *akato* overall in the community brought *akato* to members who joined the *ishyirahamwe*. The direct disclosure from public testimonies and indirect disclosure simply from being seen with *ishyirahamwe* members resulted in increased individual *akato* to members. Therefore the solution to reduce *akato* actually in practice caused increased *akato*.

⁵⁵ In the formal interview, we asked the participants a series of questions about *akato*. Before specific questions we asked first: *Did people treat you differently after they found out you were living with HIV? How?* Then we asked about the situation that happened to the car. Next we asked general questions about the word *akato* itself. *What is meant by the word akato? Does akato exist in your community? How, against whom?* We followed up with questions specifically about the *ishyirahamwe*. *How does your ishyirahamwe work to fight against akato? Against other forms of discrimination in the community?*

Claude, a 59-year-old married man, was one of the founders of *Humura*. He found out he was living with HIV in 2002. His wife did not have HIV and at the time of the research they had six children. In 2002, he was a local leader in a local government position. Claude took his leadership role within the community and used it to fight against *akato* by giving his own testimony about how he was living with HIV. He also used his own testimony as a way to gain members in the *ishyirahamwe*. However, Claude was respected in the community because he had a leadership role. He was also more well off financially than other members. We went to Claude's home to conduct interviews. He had a large compound with livestock. He also kept bees and had a small honey business. For him, being known as living with HIV, despite the *akato* he received, it was okay.

“To look for members, this is how it was, we were like three people who had started [the *ishyirahamwe*]. Aaah and they would say, ‘*Abanyasida!*’ Did you see what they said on Jennifer’s vehicle the day before yesterday [*Abanyasida*]...we would experience *akato* when we would sit as we had accepted our status.”

Claude experienced *akato* because he and the others were together in a publicly known group that was for people living with HIV. By starting the group, it meant, to them, that they accepted their HIV status but also resulted in people in the community knowing that they were living with HIV. This resulted in *akato*. For Claude, this was not a big problem; the *akato* was being called *abanyasida*. For others perhaps this would have caused more distress. For someone who was already economically marginalized to add on more *akato* from having HIV would have much more impact. Claude, as a leader in the community, wanted others in the community to understand and realize what it meant to have HIV.

After I became the head of the cluster I would hold meetings and tell the community members, ‘Do you know who *abanyasida* is?’ For me I agree that I

have HIV and I explained to them how I am a model farmer and how I keep bees but I would first explain to them about my problem of HIV, so as they were still giving us *akato*, people would come [to the *ishyirahamwe*] but fearing and hiding. So for the *ishyirahamwe* to be strong it was very difficult for us.

For Claude, it was no problem to be known as living with HIV. He had a leadership role in the community and had income from his own projects. Even if people in the community isolated him from accessing resources, he had his own ways to survive. Other people wanted to remain hidden because people living with HIV were not treated the same as those who were not. An equally puzzling case was when others joined the group for people living with HIV who were not infected with HIV. Why would people take on this identity if they were not living with HIV? Why would they want to bring unnecessary *akato* to themselves? Or was their story completely different? There were several HIV negative members in the *amashyirahamwe* and I describe a few of their stories below.

The non-HIV positive members

Joining an *ishyirahamwe*, for whatever personal reason, disclosed the HIV status of members to the community and often brought *akato* to the members of the group. However, not everyone in an *ishyirahamwe* was living with HIV. Since the emergence of the initial *amashyirahamwe*, there was a rule that members had to be either infected with HIV or affected by HIV in some way. For example, if someone in their family was living with HIV, they could join on that family member's behalf. In the Northern *ishyirahamwe*, before registering within their *ishyirahamwe*, the potential members had to show proof of their HIV status, either their own if they were infected or their child (or someone else) if they were there as an affected member. To prove their status, they had to show a card from the health clinic stating that they were infected with HIV. At the time of the research, the rule through RRP+ was that 80% of the members in each group had to be living with HIV. Most *amashyirahamwe* had some members

who were not living with HIV. It was puzzling that people who were not living with HIV joined the group, potentially bringing *akato* into their lives. I spoke to several members who did not have HIV but were active members of the *amashyirahamwe*.

In the past, when resources were provided to members, sometimes people would join the *ishyirahamwe* to gain access to these resources. Members would even join multiple *amashyirahamwe* to obtain the resources from multiple sources. RRP+ was set up, in part, to combat this from happening. In the rare instance, members would outright lie about their HIV status, stating that they were living with HIV as a way to gain access to the resources that were offered through the *amashyirahamwe* for people living with HIV. The members of *Humura* told me about a previous leader of their *ishyirahamwe* who pretended to have HIV to gain access to resources. He even went for medication every month and attended clinic appointments at the local HIV clinic. He made his way up to being president of the *ishyirahamwe* until one day the healthcare facility demanded a CD4 level check. His results showed that he was indeed not infected with HIV. He ran off to Uganda with the remainder of the resources and was never seen again. There was another instance where a small clinic was offering 10,000 frw to anyone who tested positive for HIV to help them with basic needs such as food and clean water. The clinic decided to not demand proof of HIV status when the people collected their money; they simply had to show the paper that indicated that they had been tested at the clinic. This paper did not include the test result. When people in the community heard about this offer, many people went for testing and no matter what their status, they claimed to be HIV positive to obtain the 10,000 frw. These two cases are very different. A man taking on the identity of a person living with HIV day after day was very different from people pretending to have tested positive for HIV one time. Though in both cases, resources were the motive behind the deception.

In a context where the majority of people are living in poverty it was no wonder that people fought for scarce resources and even lied about something like their HIV status. The resources that were provided to members created some level of jealousy in the community. If not jealousy, then certainly an attitude of why them and not us?

In other cases, family members of infected people joined the group on that person's behalf. Epiphanie was a 58-year-old HIV negative member of *Humura*. She first joined the *ishyirahamwe* in 2005 after being approached by Berchmans, the president of the *ishyirahamwe* at the time. Epiphanie's daughter was a member of the *ishyirahamwe*, as well as her granddaughter. Both were living with HIV. Epiphanie's daughter was raped and infected with HIV during the genocide in 1994 and her granddaughter was infected at birth in 1997. In 2005, Epiphanie's daughter died leaving her grandchild an orphan. Berchmans went to Epiphanie's house after her daughter died to see if she wanted to join the *ishyirahamwe* on behalf of her granddaughter. When her mother died, she was too young to be in the *ishyirahamwe* without a guardian so Berchmans requested that Epiphanie fulfill this role. Epiphanie joined immediately without hesitation. The group invited her to come to the next meeting with her granddaughter. They attended the meeting and she has been an active member ever since.

Her granddaughter died in April 2012. Epiphanie did not know what to do about staying in the *ishyirahamwe* after her granddaughter died. She thought it would not look okay in the community if she remained a member without having an infected person to represent. She questioned what people in her community would think if she remained in the group without having HIV.

“After the child died, I stopped going there and said that if I continue it will not look well but Berchmans told me that we worked well together, that I never gave them *akato*, and that I was

good to them and that I should come back and stay in the *ishyirahamwe*.”

Even her son encouraged her to quit the *ishyirahamwe* because she was not living with HIV.

This made her feel bad and she really faced a challenge.

“The members said, ‘We will not let go of you.’”

So she stayed with them since that time and the members continued to be supportive to her.

“When I lost that child, that is when I saw that we are together, they visited me so much, they supported me, and they were near me, if they had not been with me, I would not be with them now, I would not be with them, you can see that they have trust in me.”

At the end of an interview with Epiphanie, I asked her if she had any questions or additional comments and she asked if we (I was with Felicien) agreed with her decision to remain a member of the *ishyirahamwe* despite the death of her grandchild. Epiphanie was not shy about her HIV status and she informed me that most of the community members knew her story.

The genocide destroyed families but not just during the genocide. The aftermath also disrupted families: deaths, prison, those who fled, some returned, also families continued to deteriorate from HIV as in Epiphanie’s story. For Epiphanie, the *ishyirahamwe* members supported her when her granddaughter passed away. In this case, Epiphanie was viewed as another member of the group regardless of her HIV status. They helped each other during rough times. People often spoke about the *ishyirahamwe* as their family, “*umuryango wacu*.” Perhaps this was exactly what Epiphanie needed when she lost her daughter from HIV and then later lost her granddaughter. The *ishyirahamwe* picked up when the family unit was deteriorating.

Another member, Chantal, a 47 year old widow who was HIV negative joined the Kigali

Ishyirahamwe, *Abihuje*, but told community members that she was living with HIV. She joined the *ishyirahamwe* because her 11-year-old niece was living with HIV and she wanted to obtain some resources for her. The *ishyirahamwe* leaders suspected that she was living with HIV but she already knew her status. She went for testing again to show the *ishyirahamwe* leaders her negative status. When she learned that the *ishyirahamwe* was giving out a small amount of SOSOMA, which was a combination of soya, sorghum, and maize flour often fed to children as porridge to members. When Chantal heard about this, she wanted to join the *ishyirahamwe* to access the resources. She joined on behalf of her niece.

The *ishyirahamwe* members knew that she was not living with HIV but they all accepted her into the group as a caretaker for the niece. After she joined, people started to talk about her in the community and suspected that she also was living with HIV. Instead of fight the rumors, Chantal decided to tell the neighbors that she was also living with HIV, as a way to sensitize them to go for testing.

So for me I would teach them [neighbors] and tell them that I am also having it [HIV] and when we got to know each other well, I told them that I do not have it [HIV] because I wanted them to have the strength to go there [to be tested] because they [*ishyirahamwe* leaders] were suspecting that they had HIV. So the good thing is that you should not be suspected of having it and you too start to suspect yourself yet you don't have it, when they would go for testing they would even find that they don't have it, indeed they were not having it.

Chantal likely wanted to help the others in the village and sensitize them to go for testing. She told me time and time again that this was her motivation for telling others she was infected with HIV. However, there was also some protective reason for admitting that she had HIV instead of state that her niece had HIV. She told her niece not to tell anyone about her HIV status for fear of *akato*:

They would rebuke her, that is why I told her that if you say it [that you have HIV] to the children in the neighborhood that you play with they will be rebuking

you, "Go! You have HIV." ... They will give you *akato* and you will have caused it. You are not sick but you have the Virus that causes AIDS, so if you tell people, the children that you play with will give you *akato* and not play with you. I keep on teaching her that, by all means she doesn't tell them, you can see the children they play with her, there is no problem. *Akato* is a problem that is in the country...

Instead of tell the neighbors that it was her niece living with HIV, she said that she was the one with HIV and the neighbors spread rumors about her. Anytime she was sick, they all gossiped that she was dying of HIV, "the wings are spreading," HIV has come to life and spread its wings. Her friend told her about the gossip at a local meeting and it hurt her: "I hurt but I laughed while feeling pain." She confronted the person who started the gossip but did not deny to her that she had HIV. Chantal remained strong in her lie but for what?

The case of Chantal was peculiar. Perhaps she did not want her niece to experience *akato* as she did and therefore maintained her lie. She took on the *akato* herself to save her niece from dealing with the neighbors. Yet she told the members the truth after she joined the *amashyirahamwe*. They did not mind that she was a member. Chantal's story points to just how divided the village can be and how quickly people in the villages spread rumors about others. Epiphanie was not known in her community as living with HIV, likely because the community already knew about her daughter and granddaughter. There might also be some sort of difference because Epiphanie's daughter was infected with HIV during the genocide. Epiphanie told me on one occasion that others in her village were jealous when her daughter received resources from AVEGA, the association for widows of genocide and those who were infected with HIV during genocide.

More recently people started to join the *amashyirahamwe* for reasons beyond accessing resources (as these resources have declined greatly) for themselves or for family members. At *Twizere*, which was a fully functioning *koperative* in the West, there were several members who

were not living with HIV. When the groups became official *koperative*, they could no longer restrict who joined, that is they had to accept everyone into the group, regardless of HIV status. Emmanuel, a 23-year-old HIV negative member of *Twizere* agreed that some people do not join the *ishyirahamwe* because they do not want their statuses known in the community. He even joined the *ishyirahamwe* as a way to reduce *akato* in the community; he was HIV-negative. When he told his parents that he joined the *ishyirahamwe*, they were convinced that he had HIV despite him telling them repeatedly that he was not living with HIV. His parents made him go for testing several times to prove to them his negative status. For his parents, belonging to an *ishyirahamwe* meant that one had HIV. This was the case before and the impression of older generations. However, the younger generations found something different in the *amashyirahamwe*: the potential for income. Before Emmanuel joined the *ishyirahamwe*, he went for HIV testing with a group of his friends; they all joined the *ishyirahamwe* together, primarily for the income-generating activities, regardless of their HIV statuses. The *ishyirahamwe* took on multiple meanings and people had multiple motivations for joining and remaining in the *ishyirahamwe*. A more recent motivation was the *koperative* income generating activities.

There were younger members in the other groups as well but *Twizere* had much higher number of younger members than the other four *amashyirahamwe*. The younger generation saw HIV through a different lens than those ten or twenty years older. As they were coming into their sexual adulthood, HIV was a health threat but not like it was before ARVs were widely available. They also saw the opportunity in the *koperative*. The *ishyirahamwe* took on different meanings for this younger generation. Emmanuel's parents even saw the group as something very different than him. He just wanted to make some money. He did not mind if other members had HIV or not. He saw the opportunity. This same generation was born right before or right

after the genocide therefore the genocide was an oral history from their families, not an experience. This changed the outlook of this younger group in many ways.

There were others who joined the *ishyirahamwe*, just in case they acquired HIV in the future. Maria was a 57-year-old woman living with her husband, five of her own children and four orphans. Maria told me that she had never been tested for HIV yet she was a member of the *ishyirahamwe*. I interviewed Maria on a crisp Saturday morning at *Twizere*. The wind blew through the small space between the door and the torn *katenge*⁵⁶ cloth that was used to create some privacy for our interview. She was a member of the *ishyirahamwe* but she was not very active in any activities in the past months. She told me that she had been very sick. The sun glistened on the side of Maria's face making her kind deep brown eyes sparkle as she quietly spoke. When the wind blew the cloth slightly, there was enough light to see my papers. We were in a small space in a building in the middle of the village so the voices of people wandering through the market and the loud music filling the square made it difficult to hear her responses.

Maria became a member of the *ishyirahamwe* three years ago when the president approached her and told her that he wanted people living with HIV to be together. She was very sick at the time but officially joined the *ishyirahamwe* as a caregiver, one who helps those living with HIV because she had not yet been tested for HIV. Maria lived in a different village, there were no other members from her village in this *ishyirahamwe*. The reason she traveled to a different village was so that people in her own community did not start gossiping that she also had HIV. She told her family about the *ishyirahamwe* but she did not tell her neighbors because "they too do not tell me what they do, haha". Maria wanted to go for testing after she joined the group but her son was drowned in a river and died. She had not been well since her son died so

⁵⁶ Local cloth

she avoided going for testing. She said that she would go for testing in the “upcoming week”. Felicien thought that she perhaps had HIV but did not want to tell us but this was just his opinion.

Though she did not know her status, she was still sick and being with others who were “sick” energized her and prevented her from being lonely: “We started this *ishyirahamwe* so that all the people who are sick should not stay home in solitude.”

Further, she informed us, “because I was having bad health I thought that maybe I was also in a bad situation [living with HIV]. Then I decided to go to the *ishyirahamwe*, maybe I would go for testing too, so that I can stay with others.”

Yet there were still some negative attitudes in the community, according to Maria: “they [community members] say that those are the people who are HIV positive, they handled themselves badly, they are suffering from HIV...they handled themselves badly and got infected.”

Even after she goes for testing regardless of the result, she will not leave her colleagues. “No I can’t leave, I don’t know the time I will be in bad health, no one knows a bad day. I will continue to be with my colleagues, no one know the day that we will be in bad health so it is to continue to be with my colleagues, no problem.”

Maria wanted to remain with others who are sick so that if (when?) she got sick, she would already be with others who were sick. She also benefited from the material resources when she first joined the group but these resources were no longer available.

In all the instances, the HIV negative members gained something from belonging to the groups, mostly material resources for themselves or family members. However, over time, the *ishyirahamwe* became more than a way to access resources. Though some people left the

ishyirahamwe, many remained with the group. Epiphanie remained with her colleagues after her granddaughter died. Both Chantal and Emmanuel remained with the groups and worked in the community to reduce *akato*. But why? There were so many other groups in the community to join, why join the people living with HIV?

Conclusion

The use of programs that encouraged Rwandans to come together was certainly part of a larger national project of reconciliation. The promotion of “home grown solutions” helped Rwandans to own their projects and feel like they were a part of a solution. This mantra of coming together also encouraged all Rwandans to embrace their “shared” history. It was not easy to come together with the memories of genocide in their minds. Additionally, coming together resulted in being exposed in the community into a potentially stigmatized social position. But yet it was almost required to join so there was little choice. Members were pressured to join from clinics, peer educators, and if they did not join, they were recruited in other ways. If they did not join, they were isolated, not just personally but also from the resources. If they were known in the community as living with HIV, they may also experience isolation from neighbors resulting in reduced access to shared resources.

Then the disclosure from joining resulted in *akato* because now you are known in your village as living with HIV. You have someone like Umutesi who never joined but when she joined, she was known in community and started receiving *akato*. Now she has to rely on the group to fight that *akato*. Or you have a member who was known as living with HIV in the community and was experiencing *akato*. Joining provided some protection against that *akato* but also with impacts.

To come together is good but it is not without costs. Some of these costs are described in the next chapter where I discuss the moral economy of the HIV support groups. Beyond public disclosure, members were expected to act in certain ways in the community. The *amashyirahamwe* were active in ensuring that their members were behaving in a way that was consistent with the government recommendations, namely the Living Positively Campaign, among other health recommendations.

CHAPTER 7 MORAL ECONOMY OF GROUPS

Introduction

People joined the *ishyirahamwe* for a variety of individual reasons but many did not have a choice. They were forced to join to gain access to resources that they otherwise could not obtain. Joining resulted in disclosure in the village and the threat of *akato*. The *akato* from the village reinforced their joining and the members became more dependent on the *ishyirahamwe*. It provided a place that was less toxic than the wider village in which they lived. In addition, the *ishyirahamwe* provided access to resources and other benefits. However, there were certain expectations to which members were required to adhere including components of the Living Positively Campaign. Some of these expectations went against their own values. If a member could not adhere to the expectations, they were kicked out of the *ishyirahamwe*, back into the margins of society. Living with HIV resulted in being isolated from the community and joining provided some protection against that isolation. If one could not change their life to match the expectations set forth in the *ishyirahamwe*, then they were further marginalized from their community, more so than before joining.

In this chapter, I examine the expectations that were required as part of the membership in the *ishyirahamwe*. There was a reciprocal relationship between the members and the *ishyirahamwe*. Even after the *amashyirahamwe* stopped giving out resources, the members were still expected to keep their end of the bargain. There was an enormous emphasis on surveillance of members' behaviors and the *amashyirahamwe* were a way to enhance social control of people living with HIV.

In the first meeting I attended with *Abihanganye* (in the East) the president, Michael, gave an educational talk to the members at the small sector office where the group regularly met.

There were 28 members (17 women and 11 males) attending that morning. Michael read from a small book he received from RRP+ that was written to guide *ishyirahamwe* leaders in educating the members on various topics. The overarching message on this day was about how to live positively with HIV. He started the session by stating to the members that it was their own responsibility to stop HIV transmission in the community.

To do so, you must create a more positive image in the community [of yourself]. If you all portray positive behaviors in the community, then more people in the community would go for testing and learn their status. The epidemic will not stop if people do not know their statuses.

Further, it is not required that people living with HIV never have sex again because we all have sexual desires but we need to make sure we use condoms and think about the consequences of infecting other people.

Michael was at least realistic about sex and the sexual desires of people living with HIV. In many other *amashyirahamwe*, the mantra was something along these lines: “Abstain but if you can’t abstain, then use a condom.” In this *ishyirahamwe*, the focus was instead on the consequences of infecting other people with HIV placing the responsibility of containing the epidemic with the individual members. The mantra was that the individual was responsible for the collective health of the community. Not only was it bad for you and your sexual partners but also the sexual behavior of members had consequences on the community as a whole. In this sense, he stressed that the members have an obligation to both their partners and community.

He continued to discuss the consequences that would occur if more and more people were infected with HIV.

“When more people are infected, the demand for ARVs and health services will increase. Remember that ARVs are very expensive, almost as much as a nice piece of land.”

At that moment in Rwanda, most people who needed ARVs received it free of charge but this was also during a time when many of the *ishyirahamwe* members had seen funding and/or

resources from other NGOs reduced or eliminated completely. Most members told me stories about past resources they received through the *ishyirahamwe* and the fact that these resources were slowly diminishing.

“Also, if you don’t use condoms, your HIV levels will increase because there are many strains of HIV that can infect and re infect you. These bad behaviors will also reduce your CD4 count. If you have a CD4 [level] of 600 but have bad behavior, your CD4 might decrease to 300 after the bad behavior. Therefore your bad behavior is bad for the whole community.”

Michael used very moral wording to discuss how to live positively. He referred to unprotected sex as a “bad behavior” and that behavior could have a direct impact on the members’ health. The advice to use a condom during sex was good advice for people living with HIV, however, the problem with this educational stance was that it conflicted with the members’ social norms about having a family, specifically having children. If all unprotected sex was a bad behavior, then members had to deal with the reality that not only could they not have unprotected sex but they also could not have a family in the future. The *amashyirahamwe* never outright stated that members should not have children but the implicit message was there. I come back to this in the pages that follow. He goes on using the same morally charged words and threatens that the government will take away their support (e.g. ARV) if they are bad.

We must be thankful to RRP+ and to the government that we have access to ARV therapy. If the government sees us misbehaving, they will not be happy and they will become discouraged to continue being the advocates for us, for ARVs, and other services. If their current efforts do not contribute to solve the problem of slowing HIV transmission, they will be forced to stop all efforts. So, if the current HIV prevalence is 3% and it increases to 5%, the government will think that the number increases even with ARVs, what will the government do? What will happen?

Member: We will die.

The room went silent for a few moments. The members were staring at the front of the room with very serious looks on their faces. We will die. They will die.

But what was death? What did it mean that they will die? The members were already sensitized to stop having sex so they now had sexual death. They were encouraged to not have more children so they had legacy death, especially if they never had children before they were infected with HIV. They may have encountered some social death after their HIV diagnosis, either by isolating themselves or by being isolated within the community. Were they not already dead in many aspects? This comes back to the question posed in the introduction, “What is an adequate life?” Does living in this moral order really bring more life than death?

Michael ended his educational talk by using the government’s response to the bad behavior as a way to scare the members into better behavior.

Finally he broke the silence.

“Yes. I have condoms at my house if anyone needs them at any time. If HIV is only in us, when we die, there will be no more HIV.”

This proclamation was a strong one indeed. Michael wanted the members to take ownership of stopping the HIV epidemic, a huge task. He also threatened them with the notion that their medication might be taken away if people did not do their part in stopping the epidemic. At their death, HIV should stop. They could and should be responsible for stopping the HIV epidemic in Rwanda. Although the members were experiencing several types of death while living, upon their ultimate death, they would take HIV with them, which would be their legacy. If they could not leave behind children, then at least they would have a different kind of legacy.

ARVs, rumors, and behavior

Although RRP+ and the individual *amashyirahamwe* did not help directly with gaining access to ARVs, the leaders became advocates for their member *amashyirahamwe* for the provision of medication. In Rwanda, people no longer had to belong to an *ishyirahamwe* to obtain medication, although in the past, it was a condition for gaining access to ARV. Because treatment was widely available in Rwanda at the time of the research, people living with HIV, depending on their CD4 count, pregnancy status, and co-infections, among other factors could access ARV treatment through the health clinic free of charge (MOH and RBC 2013). Sometimes people had problems accessing the medication but it was usually due to stock problems that affected the country as a whole. If there was a stock problem, the clinic pharmacy provided two weeks of medication instead of a full month so the access was not an issue, it was the frequency that the person had to return for more medication. The *ishyirahamwe* provided education through the living positively campaigns on adherence to medication but there was no direct link to medication.

The ARV rumors and worries circulated the communities. The rumors were mostly about how the international and governmental support for ARVs would be reduced and possibly eliminated. But members worried about the medication access. Although there were certain expectations from the government regarding access to healthcare and ARVs, in the case of people living with HIV, the rumors that the care could be halted was a very scary thought for many of the members.

At that point in time, there was no plan for the ARV support to be reduced. I heard rumors from members in the South (*Humura*), East (*Abihanganye*), and in Kigali (*Abihuje*). In one instance, a man who was living with HIV was so distraught with the idea that he may no

longer have free access to ARVs, he ended up in Indera Mental Hospital⁵⁷. The rumor started when a few *ishyirahamwe* members from *Abihuje* went to the hospital and found that the medication was gone at that time. They went back and reported to everyone in the village that there was no more HIV medication. The man went to investigate the situation himself and the nurses told him that soon the medication would have to be purchased by the individual but they would help him find a way to survive. They told him that the funding that granted those living with HIV free medication would soon end. This news caused him so much distress that he “went mad”, had a seizure at the local market, and was taken to Indera Mental Hospital.

Michael, the president of *Abihanganye*, as documented in the vignette at the beginning of this chapter, also mentioned the possibility of losing access to ARVs briefly. However, in his story, he claimed that the medication access would be reduced directly because of the behaviors of the *ishyirahamwe* members. At least in the first rumor, the medication had stopped because of funding not related to any individual behavior.

Claude from *Humura* worried about losing the medication access and highlighted how ARVs helped him build his CD4 count from 181 to 1200.

“We would ask them if the medication was going to lack. And it is bad to take drugs badly, for me I started medication with a CD4 count of 181...I did not have energy but now I have [a CD4 of] 1200. But we all said that once this medication lacks, we will all be in danger.”

Others heard that they had to begin paying for their medication but they did not yet know the amount or that “the time will come when it will be hard [to access medication] for one who is not in the *ishyirahamwe*...It is said by those who lead us, they said that it will be hard for the one

⁵⁷ Indera Mental Hospital was the only psychiatric hospital in Rwanda.

who is not in the *ishyirahamwe* to get medication because he will not be in the known number.” Uwase from *Humura* made the above comment.

Even though people living with HIV were no longer required to join the *amashyirahamwe* to gain access to ARVs, the leaders stressed that belonging to the *ishyirahamwe* would increase their chances of accessing medication if there was a change in the funding of ARVs. At first glance, this type of talk sounded like another way to get members to remain in the *ishyirahamwe* and live positively. But thinking about it from a funding perspective, the numbers were sometimes useful to secure funding and increased numbers showed more need (c.f. Nguyen 2004).

Berchmans, a leader of *Humura* agreed that if access to medication became a problem in Rwanda, those who were in the *amashyirahamwe* would have a better chance at accessing the medication, another motivation to remain in the *ishyirahamwe*. He also spoke about the peace in the country of Rwanda and how nothing can break the ways, pointing to the continued worry about the stability of not only the medication but also the country as a whole. In this instance, the remnants of the genocide were on the surface.

...when we get the chance and our medication continues and sustainable peace continues in our country because nothing can come to our country to break the ways, what I want is our *ishyirahamwe* that we formed, it would be stronger in a way that is visible, and if the medication stops then the umbrella group [RRP+] should be our spokesperson, so that even if it [ARV] stops we become like exemplary to other people so that they [donors] may come to us in big numbers. Because if you can see in the future it may happen that the medication stops, even it may be possible that the ARVs become less and they say: “Where are the people in RRP+? They are the ones whom we are only going to give medication because they are the ones who have made their status known.”

More recently, the clinic linked the person living with HIV to the *ishyirahamwe* when they first tested positive instead of the other way around like it was in the past where the *ishyirahamwe* became a link to ARVs, like in West Africa (Nguyen 2010). Berchmans even

mirrored the reality that occurred in West Africa where those who disclosed their status were the ones to receive the medication in the above segment (Nguyen 2010). Yet at the current time, often members were already on ARVs when they joined the *ishyirahamwe*. Access to ARVs was no longer a big challenge so the clinic could refer potential members to the *ishyirahamwe* for other support, not access to ARVs. Only one member told me that she joined the *ishyirahamwe* for medication access but this was Maria, from *Twizere*, who told me that she was not living with HIV. She had not gone for testing yet but thought that if she had HIV, then by belonging to the *ishyirahamwe*, she would be able to access the medication, if she ever wound up needing it. Overall, the leaders and members worried that the ARV support would eventually be reduced but belonging to the *ishyirahamwe* would increase their chance of the future reduced support.

Michael threatened members into living positively, stating that the government would take away their benefits if they misbehaved. This type of talk and performance about behavior within the *amashyirahamwe* presented very fine moral lines about how to behave, how to live with HIV, and created a sense of surveillance of individuals' behaviors. Although there were many benefits of joining the *ishyirahamwe* and joining was expected for people living with HIV, members were expected to act in a certain way and some of these behaviors did not reflect the way of life in Rwanda. For example, Rwandan women were expected to have multiple children but in the *ishyirahamwe*, one should abstain from sex altogether. Although total fertility in Rwanda has decreased from 6.1 to 4.6 from 2005 to 2010, the total fertility rate was still at 4.6 (MOH 2012). In the past, pregnant women were kicked out of the *ishyirahamwe*, even though with proper prevention of mother to child transmission (PMTCT) couples were able to have children with a low chance of transmission to their babies. Rwanda had a strong PMTCT program but having children was not necessarily encouraged and often was discouraged,

although not stated in any formal policy: “It [the *ishyirahamwe*] helps us, those who have husbands, not to have children, to give birth to children when you have HIV it is not good, that is what the doctor told us ...first, you are killing your life and second of all you will have done bad for the child because it is born with HIV.” Mama Sasha, a 48-year-old mother of nine⁵⁸ commented. However, people living with HIV were having children and it was possible with the advances in medication as well as the strong PMTCT program.

People were expected to participate in the *ishyirahamwe* but when they failed, they were kicked out. I returned to all *amashyirahamwe* about one year after the data collection period ended to provide preliminary results. At *Abihuje* in Kigali, they had kicked out two members for not living positively. If members could not live positively, then the consequences were bad for the whole community but even worse for the people living with HIV. Not only were those who were kicked out of the *ishyirahamwe* known in their community as living with HIV but upon being kicked out of the *ishyirahamwe*, they were also known as being bad citizens. Imagine the marginalization faced by those members.

To assist in and control the education provided at meetings, RRP+ developed educational booklets for the *ishyirahamwe* leaders to use at the meetings. In each *ishyirahamwe*, there were educational sessions at each *ishyirahamwe* meeting (i.e. not at the *koperative* activity meetings, if this work was done separately) much like the vignette presented at the start of this chapter. Educational topics included discordant couples, medication adherence, eating healthy, learning to cook healthier, the importance of attending doctor appointments, hygiene and issues related to safe sex (i.e. abstain but if not, use condom). One of the main topics was sex. Sex was often discussed using morally charged words: one should not have sex at all but if one’s body fails,

⁵⁸ She has eight natural children and cares for one orphan.

then he or she should use a condom. Genoveva told me about having “unnecessary sex” and how it can kill you but if you cannot abstain, then use a condom. For her, all sex was “unnecessary”.

“If I had indulged in unnecessary sex, I would be dead,” Genoveva from *Twizere* stated during an interview.

She continued, “or when your body fails, use a condom.”

This type of moral dialogue was reiterated by members in the interviews, in informal discussions, and during educational sessions. The members were expected to live positively but if they (or their bodies) failed, then the plan B was to use condoms.

Having sex was considered a failure of the body for the people living with HIV but for others, a perfectly normal behavior. Again the *ishyirahamwe* norms strayed away from the social norms of Rwanda. Religiously, sex before marriage was considered “bad” in Rwanda but many brides were pregnant at the wedding ceremonies. People joked that it was a way to know if the future couple were capable of producing children. Fertility was something that was valued greatly in Rwandan society. Before I had my baby, I was uncomfortably interrogated countless times about why I did not have children. Beyond children, female sexual pleasure was something that was valued in Rwandan society. For example, women practiced labia elongation as a way to increase sexual pleasure but also build social capital (Larsen 2010). After being diagnosed with HIV, the women were no longer allowed to be sexual beings and they should not have children. If they had desire, then their bodies failed. The same applied for men.

Genoveva was also a peer educator and she explained that members get into trouble with the *ishyirahamwe* if they “misbehave” meaning having unprotected sex and/or getting pregnant. According to Genoveva, there were steps that she took, as a peer educator, when there was a report that someone was engaging in “bad” behavior. First, the peer educator would hear about

the member's behavior through informal community networks such as other *ishyirahamwe* members, family members of the *ishyirahamwe* member, and/or other neighbors and leaders in the village. The peer educator would go to the member to "sensitize" him or her about the behavior and the consequences. If the peer educator's efforts did not change their behavior immediately, then a close friend of the member, either someone living with HIV or not, was consulted to help. If the friend did not or would not help, then normally they let it go and let the person deal with the problem on his/her own. If a member did not change his or her behavior, then they became known as causing trouble in the village. These people were often not welcomed back at the *ishyirahamwe* meetings. According to Genoveva, "people don't fall into bad behaviors for too long."

It is no real surprise that people do not fall into "bad behaviors for too long." Having the *ishyirahamwe* watching your behavior was one thing but then to involve your friends and family added another level of surveillance. If one does not change their behavior, then they are kicked out of the *ishyirahamwe* and left in the margins rumored to be a troublemaker. Then these people became known as the people living with HIV who were not in the *amashyirahamwe* spreading HIV and causing trouble in the village. Claudine from *Abakundanye* told Felicien and me a story about her neighbor who was living with HIV, had three children, and was not adhering to her medication.

For example, there is my neighbor, she is HIV positive; she went to the health center after giving birth. There is a person who was in charge of babies after delivery, there is a nurse who lives near by and the other nurses had told her that there is a person who is [name] and she lives in [town], so she came to me at home and asked me to show her [name]. I said that she lives there come and I will show you so I went and called her and found that she was not home. The next morning the nurse came back again. So what the neighbor did is that there was flour that they used to give for children, she went to get it when she had gone to resume the program of medication.

Claudine's neighbor went to the clinic but only for the support of flour and at this time, she was also given medication. The clinic staff sensitized those living with HIV to recruit others whom they suspected to be living with HIV to gain access to the support. Claudine took it upon herself to try to recruit her neighbor into the *ishyirahamwe* but first the nurse disclosed the neighbor's HIV status to Claudine.

She came to us [the *ishyirahamwe*] but previously they used to give us *mituweli* [national health insurance] at the health center and they had told us that we should tell people that we suspect to be HIV positive to come for *mituweli*, so I went and told her but she ignored me, so I became silent, so when I heard that it had happened to her and the nurse came and took her to the health center and then we met there, they made the program for her but the husband left her and then there was a second child.

Claudine took it upon herself to try to convince her to take medication.

And this child was of another man, when it was time they told her to stop breast-feeding and she refused. She continued to breast feed the baby saying that she has no means, I would go to her and tell her, "Come and we go to the health center so that you go to [nurse] and get the medication just like others do, do you see any problem on us [those taking medication]?"

She said, "No, for me I will start taking medication when I am about to die."

When the [first] baby grew she gave birth to another [second baby], after a month I don't know whether she killed it or what but the baby died, they even imprisoned her, we did not know the circumstances in which the baby died, we didn't even bury the baby, aren't you listening to that? She gave birth twice yet she is HIV positive, now she is pregnant for the third time, now doesn't she infect those people [her sexual partners] and she has refused to go for medication, so that is the example I can give you.

Claudine's story of her neighbor showed how stories about those who were misbehaving were told and the negative attitudes that members had toward people who did not outright live positively. The woman was certainly not welcome at the *ishyirahamwe* but became another story of those who were infecting other people and "misbehaving" and an example of how not to live one's life.

Zigon (2007) provided two examples where he used his theory of moral breakdown. One example demonstrated the moral breakdown of the group and the second of the individual. I will briefly summarize the example of the group and then discuss the moral breakdown in the Rwandan. Zigon (2007) discussed the work of Joel Robbins in Papua New Guinea. In this case, the Urapmin faced moral breakdown because there was a conflict between the new Christian culture and the traditional Urapmin culture. Specifically, personal will was viewed as positive in one and negative in the other and as such, there was a society-wide moral breakdown. The ways in which the individuals dealt with this was to completely abandon the traditional view of the will through confession and moral self-reflection (Zigon 2007).

A similar situation occurred in the HIV associations. There were expectations regarding behaviors in the *amashyirahamwe* that did not match with the expectations of society more generally. This was the moral breakdown within the *ishyirahamwe*. The behaviors were surrounding kinship and sexuality, as mentioned above. But how did members experience this moral breakdown? Being part of the group and listening to the morally charged health messages meeting after meeting certainly promoted the newly expected behavior. Unfortunately I do not have individual reflection on this topic from members. Instead I have how the group functioned together to achieve the larger goals. One such practice was the surveillance of each other's sexual (and other) behavior. Claudine's story of her neighbor was one clear example of how the members and community health workers watched each other and tried to help each other out of "bad" behavior. Another practice was to threaten access to medical care. If the members were behaving poorly, then they would risk losing access to ARVs for the whole. It was almost as if the members were forced to abandon their past views and if they could not, they were simply

removed. But would this not also create a society where people avoided HIV testing until after they had children?

Education: Beyond safer sex

The education went beyond safer sex and family planning and the education was not always of such harsh nature. Leaders from the government (at various levels) and RRP+ leaders became involved in the education at times. Normally these leaders were not involved in the care of people living with HIV, only the educational aspects that took place during the meetings. At *Humura*, I attended a meeting where the RRP+ district representative came to the meeting and stressed the importance of living positively including eating well, sleeping, laughing, living together, cooking and drinking enough milk. They reinforced the messages provided in the booklets produced by RRP+.

The education also sometimes included hands on learning and the involvement of the wider community. At *Humura*, lessons were organized where members learned, with the help of a local NGO, how to cook nutritiously. The *ishyirahamwe* members divided into three groups of ten and they cooked for each other once a month. The lessons were conducted in individual members' homes on a rotating basis. Caritas funded the education with the goal of improving people living with HIV's nutritional status yet the lessons could be useful for anyone in the community. The staff from Caritas attended the lessons and first watched how the members cooked and then as a group helped each other to learn how to cook more nutritiously. After cooking, the members all enjoyed the food together. Epiphanie, from *Humura*, explained that once a year, they even have a celebration with the local leaders and community members.

“We make it a celebration! And invite the executive secretaries and all the people! They come and we feed them!”

They cooked sweet potatoes, cassava, beans, and meat. They also learned how to make juices (e.g. from carrots) and milk from soya. In addition to cooking lessons, they also had lessons on growing different vegetables and fruits, as well as better methods to cultivate.

Epiphanie invited Felicien and me to her home when she would host the next lesson: “We eat, we all eat, even our leader eats! We share, even our leaders from Kigali come to visit this!” She even brought us to her home after the interview so we could see the location of her home.

The kitchen gardens provided members with education about eating well but also a chance to share food and drink with friends and family. Members spoke about how in the past one form of discrimination they faced from the community was that people feared to share food and water with people living with HIV. The act of sharing and eating food together indicated, to the members, that at least people could share food with them. In addition, more globally kitchen gardens were one way to reduce the level of poverty in the community on a small scale. It was true that people living with HIV needed good nutrition, especially when taking ARVs. At the same time, the rest of Rwandan society also benefited from the kitchen garden education. The parties expanded to include leaders outside the *ishyirahamwe* and even other community members. The kitchen gardens were an example of integrating the community more widely. When the *amashyirahamwe* first emerged, the members came together with each other to pull themselves out of isolation from the rest of the community. They created a community of their own. But as time went on, the *amashyirahamwe* began to reintegrate people back into their lives. This was further exemplified with the *koperative* movement, although this was an initiative of the GoR.

Conclusion

There was a mismatch between some of the *ishyirahamwe* norms and norms about sexuality and having children. The *ishyirahamwe* norms were instilled through education promoted by the GoR through RRP+. The education that was relayed to the *ishyirahamwe* members was filled with morally charged language. Bad behavior resulted in a threat of the loss of healthcare access, namely ARV. People living with HIV joined the *ishyirahamwe* to do the right thing according to their physicians, disclosed their status in the community, and underwent surveillance of their behavior within the village. Further they were forced to change their values and norms about sexuality and childbirth. If they did not, they failed, their bodies failed, and they were kicked to the margins outside of the village, outside of the *ishyirahamwe*. The ways in which the leaders and members (e.g. remember Claudine's story about her neighbor) spoke about HIV and the behavioral expectations resulted in a very different kind of every day life and a very different kind of sociality.

In the next chapter, I discuss the latest development in the *amashyirahamwe* for people living with HIV: the shift to become more self-reliant and form income-generating *koperative*. Many of the members with whom I spoke talked about the *ishyirahamwe* and *koperative* as two very distinct entities: *amashyirahamwe* always needed financial support, *koperative* created their own financial support, *amashyirahamwe* members were passive, *koperative* members were active, to name a few. Yet the changes on the local level were not always so apparent.

CHAPTER 8 *KWIGIRA* (SELF-RELIANCE)

Introduction

“If the *ishyirahamwe* can't develop you, then what would be its importance?”

-- Chantal, 49 year old HIV negative member of *Abihuje*, the Kigali *Ishyirahamwe*

In this chapter, I describe the *koperative* movement in more detail. The *koperative* movement was more than simply a transition from *ishyirahamwe* to *koperative*. It was a struggle for most of the *amashyirahamwe* not only because of the paperwork and finance involved but also because it entailed a shift in attitude from being “beneficiaries” to “active actors.” For many years, people joined the *amashyirahamwe* for people living with HIV because they needed extra assistance due to the physical and emotional problems they faced from having HIV. Over time, the external resources decreased and the GoR urged all groups of this type to become fully functional income generating *koperative*. The emphasis was still on coming together but now with a twist: people were supposed to come together to be self-reliant, or *kwigira* in Kinyarwanda. The message went deeper; self-reliance was the theme of the 2013 Genocide Commemoration often stated as “*Duharanira kwigira*” or in English, striving for self-reliance. During the 2013 Genocide Commemoration, the message of self-reliance was plastered on the billboards and on the documents related to the commemoration.

The theme of self-reliance was also incorporated into government documents. I was hired as a consultant to edit government documents plans and proposals for some of the larger government programs. Each program was introduced with a paragraph about how Rwandans were relying on “home grown” solutions so that Rwanda could be self-reliant and less dependent on donor funding. These strategies fit within the GoR’s overall poverty reduction and development plans.

On the local level within the *amashyirahamwe*, the message from the government was that if the groups did not transform into *koperative* they would not be supported anymore. However, the majority of the *amashyirahamwe* were not financially supported anyway yet they all still strove to become active *koperative*. Beyond financial resources, the *amashyirahamwe* still relied on the government for their healthcare needs. Recall from the previous chapter the strength of the rumors about losing access to ARVs. The *amashyirahamwe* were still reliant on the government for their care and medicine and as such, the *amashyirahamwe* tried their best to adhere to the government's new rules about *koperative*.

The overall goal of the change from *ishyirahamwe* to *koperative* was to build independent, self-sufficient *amashyirahamwe* that were not dependent on NGOs or government support. This was the same exact message that was relayed in the policy documents. According to Felicien, the *ishyirahamwe* members, like other Rwandans, should be productive members of Rwandan society. Because of the advances in ART and the widespread availability of ART for those living with HIV, people were healthier than before. The members were fully capable of becoming self-reliant, like all Rwandans. After all “we are all Rwandans.”

From simple beneficiaries to active actors

Felicien and I were going to visit *Abihanganye*, the Eastern *Ishyirahamwe* for the first introduction visit. Felicien was driving rapidly down the main road to the *ishyirahamwe* in the Eastern Province. The road to the East was relatively straight, as compared with the main road to other areas of the country. Every few minutes, he pointed at something and told me the word in Kinyarwanda. *Inka, abana, bisi nziza* (English: cow, children, nice bus). I repeated and if it was a word I did not know, I added it to my notebook. It was our first trip to the field together and my first visit to an *ishyirahamwe*. Because I did not have access to a car at the beginning of the

fieldwork, Felicien offered to drive me to the field sites in his personal car. I gave him money for fuel and a little extra for wear and tear. After turning off the main road, we traveled past lush banana field after banana field, down a bumpy dirt road. Every time a car would approach us from the front, Felicien quickly rolled up his window to avoid particles of the red dust cloud from entering the car. If I did not roll mine up quickly enough, he would yell at me in Kinyarwanda. After the car had passed, we rolled the window back down again because it was hot in the car. By the time we reached the location of the *ishyirahamwe* meeting, the car was full of dust, inside and out, regardless of our efforts to roll the window up and down every time a vehicle passed us.

I had no idea what to expect at this meeting but I was under the impression that we were going to the *ishyirahamwe* to introduce ourselves at the beginning of a regularly scheduled meeting. We were almost one hour late for the meeting so when we arrived the meeting had already started. We were late because the district representative of RRP+ wanted to come with us to the *ishyirahamwe* to introduce us. We first drove to pick him up in the district center and then headed back to the *ishyirahamwe*. As we pulled into the sector office where the meeting was held, a man dressed in khaki trousers and a button down shirt walked out the door to greet us. It was Michael, the president of this particular *ishyirahamwe*. He told us that the meeting had started but he would pause the educational session so that we could come and introduce the research project to the *ishyirahamwe* members.

Michael ushered us into the meeting and sat us in the front of the room at a large wooden table on wooden chairs. He introduced us to the members and we gave our introduction speech and then stayed for the meeting. I was very surprised about what happened at the meeting because I had a completely different view about what would occur during an *ishyirahamwe*

meeting. In my mind, I thought there would be some educational lessons and then group discussion about HIV and how it impacted the people's lives⁵⁹. Instead, there was a small lesson on condom use and then the rest of the time was spent doing accounting: *ikimena*, loan repayment, and loan disbursement. These were the ways in which HIV impacted people's lives: financially.

Beyond coming together as an *ishyirahamwe*, now the *amashyirahamwe* were supposed to combat poverty and help improve people's lives in general. These small accounting activities were the bulk of the meetings because poverty was readily apparent in members' lives. The meetings went beyond facts about HIV and how to live positively, although this was still present in the meetings and all members were expected to adhere to the rules of this health campaign. The majority of the time in the meetings, the *ishyirahamwe* members tried to financially improve their lives together as a group.

As we drove back toward the main road, I told Felicien about support groups for people living with HIV in the USA and how different this group was in comparison. I was especially surprised about the focus on finance and accounting. He told me that if we had visited the groups five years ago the members would have asked us for money but now they were striving to be a self-reliant group. I asked him why. Felicien told me that the *amashyirahamwe* changed a lot in the last five years: the members went from being "simple beneficiaries" to "active actors" in the community, partially because of the push to become a *koperative*. Felicien repeated the rationale for *koperative* that was stated over and over by leaders from the local level in the village up to

⁵⁹ This idea demonstrated my own western bias about what it means to be in a support group. As part of a past job (2005-2008), I worked with people living with HIV who were involved in support groups in Detroit, Michigan. My perception of groups was shaped by this experience. We ate food, had an educational lesson, and then a small amount of socializing. It was 1-2 hours once a month. I initiated and managed one group in the community, Motivational Mondays, during this time also.

leaders in the national government. The *amashyirahamwe*, as with other groups of people, were supposed to come together locally, become self-reliant, and solve their own financial problems.

The main emphasis at this particular meeting was finance and I later found out that this emphasis was common throughout the groups in the country. The meetings were mostly about accounting. At *Abihanganye*, during one meeting each member received a bankbook so that they could keep track of the money they had saved within the *ishyirahamwe*. The goal was to teach members to be responsible with money by keeping track of lending and borrowing plus saving money for the *koperative* activities. Everything had to be documented and this process took up the majority of the meeting time.

One question that remained with me since the first drive with Felicien to *Abihanganye* was: how did the members transform from passive gatherers of free resources to active actors in the community and what did it mean to be an active actor in the community? The local clinics urged people living with HIV to join the *ishyirahamwe* and live positively. The local leaders urged the *amashyirahamwe* to turn into *koperative* to become economically sufficient. The members were supposed to be sexually responsible and stop the HIV epidemic and also become economically responsible and dig themselves out of poverty. In this chapter I explore this question, the transformation process, and how the transformation impacted the experience within the *ishyirahamwe*.

The *Koperative* laws

In the 2009-2012 Rwanda National Strategic Plan on HIV and AIDS,⁶⁰ it outlined recommendations to help reduce the socio-economic impact of HIV through generation of income and creation of *koperative*:

Income generation. The review recommends the focus on production activities that respond to the market needs and on cooperatives' capacity building to identify and assess market opportunities; and to develop businesses. Funding and access to credit for viable IGAs needs to be increased but only alongside the promotion of better market analysis and linkages and business planning. Credit guarantee schemes, as well as other capitalization approaches should be considered. Increased capacity on project design and management, leadership, financial management and cooperative organization are prerequisites for effective economic programs.

Cooperatives. There is a need to clarify the regulation on formation of cooperatives in order that it responds to the vulnerable people's needs and to support partners in their organizational capacity building and improvement of their business performances. Skills in identifying and evaluating market opportunities need to be developed in cooperatives. (MOH and GoR 2009)

When I first arrived in the field, the change to *koperative* had already been going on and it seemed like there were *koperative* everywhere. My colleagues and I even joked about how everything in Rwanda was turning into a *koperative*⁶¹. In July 2009, in an article written by a journalist for the New Times⁶², it was noted that there were already 4,442 cooperatives that were legally registered in Rwanda (Babijja 2009). The *koperative* in Rwanda also had an umbrella agency called Rwanda Cooperative Agency (RCA). All cooperatives were supposed to be registered with RCA, similar to how all *amashyirahamwe* were registered with RRP+. The RCA defined a cooperative as “an autonomous association of persons united voluntarily to meet their common economic, social, and cultural needs and aspirations through a jointly-owned and

⁶⁰ The Rwanda National Strategic Plan on HIV and AIDS was written in collaboration with the Rwanda Ministry of Health, CNLS, Clinton Foundation and UN agencies.

⁶¹ We even started our own unofficial cooperative called JennifeRWA.

⁶² The New Times is a local Rwandan newspaper published in print and online in English.

democratically controlled enterprise, according to internationally recognized cooperative values and principles” (RGB 2014a). Not all farmers, for example, were required to be a registered cooperative, however, the government encouraged formal registration. In theory, all cooperatives were the same and were governed by the same rules as defined by RCA. The difference between the *amashyirahamwe* for people living with HIV and other cooperatives was simply that the *amashyirahamwe* were initially organized into groups based on HIV status while other cooperatives were created based on a business strategy.

The sacrifice of the *ishyirahamwe*

“Working for the *ishyirahamwe* we can call it volunteering, it’s like a sacrifice only. But in the *koperative* we follow the profits, you see that harvest of grains, if we harvest it...I will get like 5,000 frw from it...but in the *ishyirahamwe* instead of getting something we give out...That is why the government established strong motives to join *koperative*.” Berchmans (*Humura*)

Felicien and I discussed in our first two meetings how the transformation to *koperative* was problematic for *amashyirahamwe* and their members. The discussions stemmed from my curiosity and confusion about how this transformation could work. Even the leaders of RRP+ were confused as to how to handle this situation. The local leaders wanted their sectors to have income generating projects, including the HIV *amashyirahamwe*, because the district leaders were being urged by the province to develop their districts and create more income for their communities, as well as encourage self-reliance among their citizens. As such, the leaders were encouraging the entire community, including members of all *amashyirahamwe* (not just HIV related) to develop official *koperative*. Even the larger entities related to HIV, such as CNLS, encouraged the *amashyirahamwe* to transform into *koperative* because *koperative* had the

potential to receive more funding than *amashyirahamwe* because of their legal status and more formal paperwork process.

The income generating activities were present in most of the *amashyirahamwe* even before the push to become koperative. One major reason groups, like *Humura*, attempted to create income-generating projects was that there was a reduction of external funding. In the past, there was a great deal of funding from external sources to fund the *amashyirahamwe* activities and/or provide basic resources for the members. Members in the *amashyirahamwe* spoke about how in the past there was a lot of support: ranging from payment of school fees/material for children to receiving livestock and food support. This encouraged many people to join the *ishyirahamwe*. There were people who joined more than one *ishyirahamwe* to get the support from more than one place although this practice stopped after the emergence of RRP+. RRP+ required that all members' names and identification numbers were documented and submitted to the main office so that they could keep records of all members. Anyone who was involved in more than one *ishyirahamwe* was told to remain a member of only one *ishyirahamwe* and this was enforced by RRP+. The membership rules at that time likely had to do with the scarce amount of resources that were available. The resources had to be spread out more evenly across groups.

It was not surprising that when the majority of the funding ended, some members of the *amashyirahamwe* left, especially those whose main goal of belonging was the financial support and/or access to resources. The majority of the *amashyirahamwe* received little to no external funding at the time of the research. This was one of the reasons that the local governments encouraged the *amashyirahamwe* to transform into *koperative* to fill the income/resource gap. Another rationale for transforming into *koperative* was because under Rwandan law, if a group is

generating income, they cannot be an association; they must be a cooperative or registered business. As such, when it became apparent that the groups were generating income, they were approached by local officials and told that they must change their legal status and become a *koperative* and start paying taxes on the income. The overall drive to create a self-reliant Rwanda started at the national government level and entered into all facets of life. Over time, Rwanda would pull itself out of poverty, come together and solve the nation's problems without external assistance. One way to achieve this was to take the already organized *amashyirahamwe* and force them to become *koperative*.

The local groups had to change and think of an income-generating project that was attainable for their members. This was much easier said than done. The government envisioned the *ishyirahamwe* members as able-bodied capable of initiating and working on projects. The public health message was along the lines of HIV was an ordinary disease, like other diseases like diabetes or high blood pressure. People living with HIV were no longer dying; they could live a long and fruitful life. It was true. People living with HIV were living longer healthier lives with ARVs. Yet taking ARVs often brought challenges. It required food and people were supposed to be healthy and relax. The time and energy spent starting and working on an income generating project while at the same time trying to find the money to buy nutritious food (or any food for that matter) for yourself and your family could be exhausting for anyone, regardless of their HIV status. Under this government rhetoric, Rwandans were expected to be healthy hard working people and build their *koperative* groups.

And the members wanted to become a *koperative* even if it exhausted their energy doing the activities. They wanted to live the life that the government envisioned: working in a *koperative* and being self-reliant. But how could they be completely self-reliant when they relied

on the government for their healthcare? The thought of losing their medicine, as described, caused major problems in the communities of people living with HIV. And the members kept trying.

Despite the fact that the government agencies at all levels urged the push to *koperative*, employees and members working within RRP+ thought the transformation from *ishyirahamwe* to *koperative* would cause more problems than it solved. The main issue that was posed by RRP+ leaders was regarding the social support provided by the *amashyirahamwe*. They felt that the social aspect would be lost if the *amashyirahamwe* turned into *koperative*. Felicien, in his Master's thesis, found that the majority of people joined *amashyirahamwe* for people living with HIV for two main reasons: psychosocial support and material support. Because many of the *amashyirahamwe* lost their external material support, one remaining motivation for people to join and remain in the *ishyirahamwe* was for the social support, the very thing that leaders thought would be lost if all *amashyirahamwe* transformed into *koperative* (Rusagara 2010). Another issue the leaders of RRP+ were very concerned about was that in a *koperative*, anyone could join. They feared that people living with HIV would leave the *koperative* because others in the community would join and "know their secrets". This did not occur immediately. At the time of the research only 72%⁶³ of members were living with HIV. By June 2013, 83% of members were living with HIV. Over the course of one and a half years, the percentage of people living with HIV in the *amashyirahamwe/koperative* actually increased, not decreased. The leaders from RRP+ feared that by being a *koperative*, more and more HIV negative members would join and then they would not meet the RRP+ requirement. This did not prove to be the case although the transformation was still in its infancy. There was still some hesitation from community members

⁶³ The numbers are from December 2011.

to join the *amashyirahamwe*. Recall the *akato* faced by Emmanuel from his parents when he joined the *koperative* or Chantal who joined the Kigali group on behalf of her niece and lied about her HIV status.

Koperative were not always immediately successful, in fact they often failed: I met a woman who ran a local NGO with the goal of helping vulnerable women (e.g. single mothers, commercial sex workers) by helping them start *koperative* and generate income of their own. Her first project was to start a *koperative* for single mothers who were sex workers in Kigali. She identified 16 women who were involved in commercial sex work. She rented a house for them, bought them some goats, and gave them some money to start up a *koperative* so they could leave commercial sex work and earn their own income. She did not provide the women any guidance in forming the *koperative* but instead gave them the autonomy to decide their business activities and the ways in which they would run their *koperative* on their own. She went back less than two months later to check on the women and all the women had left the house with the goats and money. She said that if she had done the same thing in a rural area, this never would have happened because in the village there was nowhere to run. The women would have tried to begin something but it did not mean that the project would not have failed in two months. This caused the woman who started the project so much aggravation that she closed her NGO. There were blatant problems, such as a lack of organization and a business plan, with the planning of this *koperative* but the reliance on *koperative* to solve all problems was apparent. Forming a *koperative* was not always the answer to the problems. Failure of projects was also common in the *amashyirahamwe* for people living with HIV, as described below.

At *Humura*, Berchmans explained the transition from *ishyirahamwe* to *koperative* and the complications that arose from it. He began by discussing the many sponsors they had in the

beginning who gave them resources to begin *koperative* and the struggles they had trying to transform the *ishyirahamwe* into an income-generating *koperative*. Later they had to start projects that would bring income to their groups.

In 2005 we had sponsors...they sponsored 40 chickens, they gave us 40 hoes, we were 40 members...We had a loss from the chickens, people were even not taking care of them...then in 2008 we started to sew baskets, do you know the revolution [*inkubiri*⁶⁴] of baskets? We brought a teacher, we added money, we were giving a salary every month, when the money finished, we stopped it...In 2009, the revolution [*inkubiri*] of *koperative* arrived, we contributed also, we searched for a lawyer who will help us to make laws, he ate our money, 140,000 frw, then when we went to submit, they said the law changed.

The laws kept changing and because they tried several projects that all failed, they finally decided to cultivate.

“Let’s see what can bring us together because we have failed to sew baskets, we have also failed to raise chickens, let’s see what we can do to bring us together so that we do not become weak again. We formed a *koperative*, all of us who cultivate there, we are in a *koperative*.”

But in reality, they were not a registered *koperative* yet. They wanted to be a *koperative* because they were told to transform into a *koperative*. They had tried several projects along the way that failed. Finally, they decided to cultivate, a project that they could easily do without much assistance from trainings and with little capital. In the quote by Berchmans at the beginning of this section, he stated that for the *ishyirahamwe* you give but in the *koperative* you receive. The *ishyirahamwe* was like a sacrifice or a burden but with the *koperative* there were gains. Yet the group never gave up and continued to try to become a *koperative*. They had still not succeeded a year after the fieldwork ended but they kept trying. Part of becoming a *koperative* was the massive amount of paperwork that had to be filled out. *Humura* had only filed the sector paperwork. Even if the gains were not financial at that time, Berchmans and his

⁶⁴ *Inkubiri* translates as doing something together in a group

struggles to form a *koperative* gave him a project to achieve. He was proud of their accomplishments as a *koperative*. He stated, “*Zitukwamo nkuru*” meaning the burden or blame is for the elders or that the blame always goes back to the leadership. He was the leader of the *ishyirahamwe* so he was to blame for the failings of the *koperative* activities. Yet he kept striving to build his *koperative* because it gave him a sense of purpose. *Koperative* were different than the *amashyirahamwe*, at least in the community. When others in the village saw the group earning an income from their projects, they were viewed in a more positive light than before. Now the *amashyirahamwe* were working for their own income, not accepting resources (although if resources came along, the members certainly would not refuse it). At the same time, they remained an *ishyirahamwe* because there was still value in the *ishyirahamwe* as well.

Widespread sensitization to the *amashyirahamwe* regarding becoming a *koperative* began in the communities in 2008. First, the local leaders encouraged people in the villages to form *koperative*, including the *amashyirahamwe* for people living with HIV. Because the government used performance-based evaluation, *imihigo*⁶⁵, the future job security of the local leaders was tied to the goals and performance of the sector (Logie, et al. 2008; RGB 2014b). If one goal was to transform *amashyirahamwe* into *koperative*, then the sector leaders needed to strive to meet this goal or they risked losing their jobs. The *koperative* movement was a national policy that was implemented through the lowest governmental level, within the same level of the individual *amashyirahamwe*. RRP+ assisted the *ishyirahamwe* leaders to transform their *amashyirahamwe* into *koperative*, as well as strove to keep the *ishyirahamwe* aspects (e.g. social support), the very foundation upon which the groups were established and maintained.

⁶⁵ *Imihigo* is a performance based evaluation system used in local government, another home grown solution.

***Ishyirahamwe* specific⁶⁶**

At the end of 2011, of all the *amashyirahamwe* for people living with HIV at that time (n=1,400), 503 have not yet started the legal process to become a *koperative*, 510 were in the process of becoming a *koperative*, and only 387 were fully registered *koperative*. In June of 2013, there were only 382 fully registered *koperative* out of the 1604 *amashyirahamwe* for people living with HIV. 425 were in the process of becoming a *koperative* and the remaining 797 *amashyirahamwe* had not yet started the process (see Figures 19 and 20 below). Based on these figures, over the year and a half that had passed, some *koperative* failed, others were started, and others were still in the process or moved in between these different categories. It is a bit peculiar that the number of *amashyirahamwe* that had not started the process increased greatly from 2011 to 2013 from 503 to 797. RRP+ did not have more detailed records about the individual *amashyirahamwe* so it was difficult to come to answer sound conclusions about the shift to *koperative*. However, many of the *amashyirahamwe* still participated in income generating activities even though they were not formally registered with RCA.

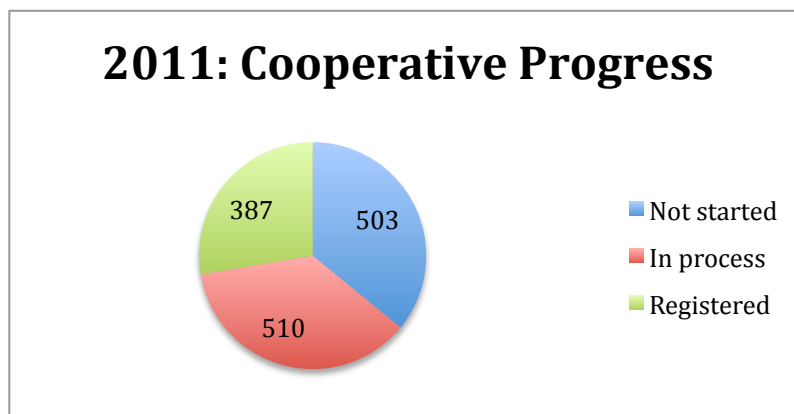


Figure 19: The status of the shift to *koperative* in 2011. The total number of *amashyirahamwe* at that time was 1400.

⁶⁶ All this information provided by RRP+

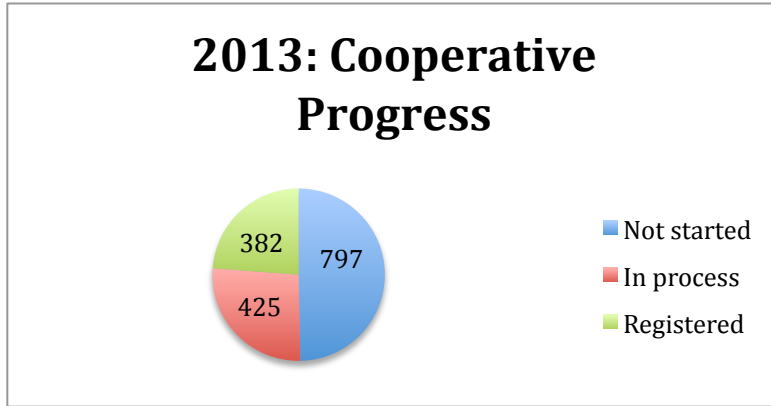


Figure 20: The status of the shift to *koperative* in 2013. The total number of *amashyirahamwe* at that time was 1604.

The transformation from *ishyirahamwe* to *koperative* formally began in 2008. Before 2008, many, if not most, *amashyirahamwe* participated in income generating activities but they were not registered *koperative*; they were still *amashyirahamwe* working under RRP+. After 2008, *koperative* began to be created from the existing *amashyirahamwe* for people living with HIV although the groups still technically remained under the umbrella of RRP+. After registration with RCA, they were bound to the rules and regulations of not only RCA but also RRP+. Some of the activities of the RRP+ *amashyirahamwe* with *koperative* activities included: carpentry, agriculture, breeding, commercial activities, sewing, weaving baskets, savings and credit, pottery, making bricks, and jewelry.

To get an idea of the transformation, I include some details about the five *amashyirahamwe*. The struggles of *Humura* are described above. In the *amashyirahamwe* with which I worked, only two were fully registered *koperative* (North and West) and the others were in the process of becoming *koperative* although this meant different things to the groups. For example in the East, *Abihanganye* was in the process of saving the money that was required to initiate their project. In their minds, they were in the process of becoming a *koperative*. Strictly

speaking, these *amashyirahamwe* were considered, by RRP+, to not have started the process. The members hoped to initiate a chicken project in the future. The monthly member contribution to save money for this project was 150 FRW per month⁶⁷ in the past but the project contribution was increased right before my research began to 850 FRW per month. The members in the group were extremely poor and only ten members contributed this amount regularly making it difficult to save enough money to initiate the project. The group, at the time of the first meeting I attended, had 165,000 FRW saved to begin the project but they needed a total of 4 million FRW to start the chicken project. It would take them a long time to raise the capital to begin but at every meeting, those who were able contributed their shares.

The group in the North, *Abakundanye*, raised pigs, worked on an agricultural project, and opened a small boutique that sold cakes and tea. This group considered themselves to be a functional *koperative* and all the members had paid the capital. Each person contributed 4000 FRW in two distinct parts: one part was money and the other was a certain level of participation in work activities. The pigs lived in a small barn close to the location of the meetings. Each member brought food to feed the pigs and it seemed like the project was going well. However, when I went back to discuss the preliminary results with this *ishyirahamwe*, they told me that the pig project had finished. Someone had stolen some of the pigs and they were not able to raise more money to keep the project going.

The Western *Ishyirahamwe*, *Twizere*, had received their registration as a *koperative* in April 2012 but they started the *koperative* process four years earlier in 2008. The *ishyirahamwe* received training from RRP+ on how to become a *koperative* in 2008 and the group managed both *ishyirahamwe* and *koperative* activities simultaneously. This group had primarily

⁶⁷ 1 USD = approximately 650 FRW (*amafaranga*) at time of data collection

agricultural projects; one project consisted of group agricultural research on maize crops and use of fertilizer. There was a section of their crop where they used a chemical fertilizer, a section with an organic fertilizer, a section with both chemical and organic fertilizer, and a section with no intervention. They were trying to maximize their crops at the minimal fertilizer cost. The contribution was 5000 FRW and 40 members had paid in full while 50 were in the process of paying. The additional 30 members had not yet paid anything for the *koperative* activities.

The Kigali group, *Abihuje*, was not a fully registered *koperative* but they had many small projects including raising goats, growing mushrooms, and selling products at the market. Their projects were failing also. The goats had miscarriages and then they could not afford to pay the person they hired to look after the goats. They had to sell the goats, even though they had built a large goat house. When the research ended, they decided that they would rent out the goat house to try to make some money. They also grew mushrooms and built a small house to grow mushrooms in. The mushrooms were sold at the main market in Kigali.

Local *koperative*

One rule of *koperative* was that to join, each member must pay the required amount of shares. From an outsider perspective, it would seem problematic as many people who originally joined the *amashyirahamwe* were poor and lacked resources. Could they afford to pay yet another contribution? Poverty was one reason that they joined the group in the first place. Yet the *amashyirahamwe* and the members also had longstanding ways to exchange resources and access financial resources (e.g. *ikimina*). There were cases where some *amashyirahamwe* had members who could not pay the shares; therefore they were technically only part of the *ishyirahamwe*, not the *koperative*. For example, the members of the Eastern *Ishyirahamwe* had saved only 165,000 FRW (of four million) toward their *koperative* but they could not officially begin their *koperative*

until they had the total amount. Yet it is quite amazing that ten members raised 165,000 FRW toward their *koperative* amount. Several of the *amashyirahamwe* started the *koperative* work informally until they settled their paperwork with all the levels of government (e.g. raising goats and selling mushrooms in Kigali and cultivation at Humura).

One benefit of having shares instead of just a contribution was that in the *koperative* system, when one dies their children inherit their portion of the *koperative* but in the *ishyirahamwe*, “we immediately remove him from the book” Berchmans explained. Though it might be difficult to raise the money to start the *koperative*, the members have a long-term investment that can be passed to their children, assuming that they were able to pay the full contribution amount. This system left out the poorest families who were unable to contribute the shares leaving them without any investment for their families.

The members spoke about the issues that newly diagnosed people face in regards to joining and paying shares. When someone was first diagnosed with HIV, the last thing they were thinking about was paying a large contribution for *koperative* activities. At *Humura*, they used the following strategy to recruit newly infected members into their group.

“When someone reveals that he is infected, he doesn’t think well, there are few who take it in their mind, you can’t mobilize him to join a *koperative* and give a contribution of 5,000 frw, he can’t understand. We first bring him and we show him and let him join the *ishyirahamwe*, when he becomes stable and sees how the *koperative* is important, he says let me join others, and he accepts to contribute because the virus is that thing that causes poverty” (Berchmans)

Some *amashyirahamwe* really tried to be both, although this was impossible by definition. One benefit of trying to be both an *ishyirahamwe* and a *koperative* was regarding immediate social support that was necessary for those newly infected with HIV. It is not likely

that a person who is newly infected would want to immediately join a *koperative*. They first needed the social support aspects of the *ishyirahamwe* as well as material support at times. Berchmans commented: “But there is another good thing, in the *ishyirahamwe*, the person who was new and very ill, we use the contribution to buy sugar and porridge for that person.” The *ishyirahamwe* then still acted to provide social support and provide the little resources that they could while at the same time having extra *koperative* activities on the side. After the newly diagnosed person had come to terms with living with HIV, they could join the other activities.

Further the social support aspects were more valuable to people newly diagnosed with HIV so this was something that had to be maintained. At a meeting discussing some promotional posters for people living with HIV, a RRP+ member made a suggestion that a word on the poster *amashyirahamwe* should be changed to *koperative* because officially the *amashyirahamwe* were supposed to be transforming into *koperative*. This was the official stance of RRP+. Others disagreed and stated that they wanted to keep the word *ishyirahamwe* because they wanted to promote the social support aspects, not the *koperative* aspects. The word *amashyirahamwe* implied something very different than *koperative*. To come together, *gushyira hamwe*, had a different meaning than joining a *koperative*. The word, *koperative*, was a Kinyarwanda word that was created with French and/or English influence. This word did not exist before. For newly diagnosed individuals, the *ishyirahamwe* aspects were more important than the *koperative* aspects. The word *amashyirahamwe* was kept on the poster but could the social really be kept in *koperative*?

The leaders of RRP+ were very concerned with the transition to *koperative* yet the impact on the individual members was actually quite minimal. Some members felt that the shift from *koperative* to *ishyirahamwe* was a change in the term only, similar to how I thought the

terminology had changed from *gahunda* to *amashyirahamwe* to *koperative*. For example, Claudine from the *Abakundanye* explained to me that the *ishyirahamwe* no longer existed it was now a *koperative*.

“*Koperative* is the one in front, it is no longer an *ishyirahamwe*, we used to put ourselves together in *amashyirahamwe* and then the word came from the sector that it is now not an *ishyirahamwe*, it is a *koperative*.”

For her, the shift to *koperative* was a result of the leaders coming from Kigali in 2002 telling them that they must become a *koperative*. After this point, she confirmed that the group was a *koperative*. However, nothing changed in the way the group was organized or in the activities:

“Nothing changed, we kept working the same way.”

The shift to *koperative* for some of the members was simply a change in the terminology but nothing else, in their minds, changed. They had been doing the same things, added a few more projects, generated a bit more income, but nothing more than this change in nomenclature. This attitude said a lot about the transition. Those who did not notice a difference continued to live the same way, worked the same within the *ishyirahamwe*, and expected nothing more.

Other members knew the differences between the *ishyirahamwe* and *koperative* but the impact was not too different. For example, Umutesi from *Abihuje* stated the difference:

“The *ishyirahamwe* is to come together and the *koperative* is to create self employment, that is how I feel about it.”

In addition to development, according to Mama Sasha from the *Twizere*, the *koperative* also encouraged self-reliance now that external support had reduced. These members were reiterating the goals of the *koperative* movement. The goal was to create a new Rwanda where all members,

even those who were living with HIV would reduce the burden of poverty within their own groups.

People were, however, concerned that people who were not living with HIV could join their *amashyirahamwe*. In *Abakundanye*, Nyiramwiza explained that in the past when they were an *ishyirahamwe* group only, they did not allow HIV negative members but now they welcomed them into the *koperative* though not one HIV negative person has joined the group.

“When we were an *ishyirahamwe*, we were not allowing them [HIV negative members] but now that we are a *koperative*, the doors are open, anyone who comes would be welcome...it is necessary because a *koperative* has no boundaries...but not even one [HIV negative person] has joined.”

Mama Sasha thought that an advantage of having HIV negative members in the *ishyirahamwe/koperative* was to reduce akato in the community: “that [having HIV negative members] is also good because they don’t say that it is bad to meet with us.”

When community members saw others joining the group who were not living with HIV, they would see that there is no problem joining with them. Others felt that HIV negative members would be advantageous for the group because the members who were sick might need help from those who were not sick, especially when the work involved manual labor in fields and in the community yet no one joined the groups, with the exception of the *Twizere*. The difference with this *ishyirahamwe* was that this *ishyirahamwe* was a fully functioning *koperative* generating income and people in the village noticed this and some joined.

But Claudine had a different idea:

“No he or she cannot come, they would listen to our words! No, that way she would be listening to our words!”

Even Jean de Dieu agreed with Claudine: “Our *koperative* is for people living with HIV, it is not for people who are not living with HIV, so you can see that there is no way that we can allow them. They will come to listen to our secrets...to listen to our words or laugh at us.”

Grace from the *Abakundaye* stated that they heard from the local leaders that they now must allow people who were not living with HIV to join and they were all disappointed but “luckily they [HIV negative people] also never came”. In Kigali, Umutesi discussed how it would be a bad thing to allow HIV negative members into the group for two main reasons: the HIV negative members would obtain irrelevant education because they do not have HIV and they would see the HIV positive members and potentially talk about them in the community.

The members had mixed feelings about whether or not it was a good idea for those not living with HIV to join. Yet most agreed that:

“There is no social in *koperative*.”

The social was one of the remaining advantages of the *amashyirahamwe* for members. The social aspect of coming together because of a similar problem or because they were somehow the same (i.e. living with HIV) was still there even within the *koperative*. However, now the problem to solve was changing. When the *amashyirahamwe* were first formed, the problem was that people were dying of HIV and needed a form of support but later the issue to solve was how to become self-reliant, economically responsible citizens.

CHAPTER 9 CASE STUDY: BERCHMANS

“Ibuye ryagaragaye ntiriba rikishe isuka ni ukuvuga ko ubu nta kwanduza abandi biturimo twe.”

[The stone that has been seen will not harm the hoe since the person digging will dodge that stone.]

I met Berchmans the first day I visited *Humura*, the *ishyirahamwe* in the Southern Province. The *ishyirahamwe* met for meetings at a local government office but it was a weekend so the offices were closed. Berchmans led a group of people down the road to where Felicien and I were waiting for our introduction meeting. He was wearing black trousers, black rubber boots, and a white collared shirt and was carrying a hoe over his shoulder. He greeted Felicien and me with a huge smile and then he informed us that he was the current president of that *ishyirahamwe*. Felicien knew him from his previous work with RRP+. Other *ishyirahamwe* members followed behind him and each greeted me one at a time holding both arms to my arms and stating a greeting. The group had just come from working in their field to attend the meeting that Felicien and I arranged to introduce the research to the group. A few members found some chairs and wooden benches from the neighboring houses and the meeting began outside behind the offices. I tried to sit on the ledge of the building with the other members and they pushed me off, pointing to the bench in the front. Berchmans introduced Felicien and me to the group and we gave our routine introduction speeches. First I presented my introduction speech stating my name and the basics of the research project. Then Felicien filled in the details of the project including when and how the research would take place. He, as normal, showed the group all the approvals I had received to conduct research in their district and village.

As Felicien was speaking, one woman walked in late and wanted me to reintroduce myself so I gave the small speech a second time. Felicien ended by giving the opportunity for questions. A woman had a question; she was speaking in Kinyarwanda quickly and her tone sounded harsh. I could not understand what she was asking but Felicien translated for me. Her message was not harsh at all; she said that it was very good when the community members see people visiting the *amashyirahamwe* for people living with HIV. She was very happy to meet me and she hoped I would come to her home and meet her children. I told her yes, I would visit her. Then she responded that I should come back again and again. I agreed. The president was concerned that my research results would not reach the community. I told him that I would at least come back to present preliminary results before I left Rwanda, which I did in late 2013. The final question was a comment and it was regarding how the members felt honored that their *ishyirahamwe* was chosen out of all of the *amashyirahamwe* in Rwanda. She said that there was no way they could refuse participation in this research.

Again pointing to this idea that a refusal to participate in research would be unlikely. The leaders gave me permission so the members accepted. This reminded me of how many of the members came to join the *ishyirahamwe*. The doctor told them that it was the right thing to do and they did it.

I always felt very welcome with the *Humura* members, whether together cultivating in the field or engaging within the community, they always wanted to introduce me to other people in their local communities. There was a sense of pride to have a regular visitor among them and they readily explained my involvement with their group when we walked from place to place.

I spent many days with *Humura*: in the field working together; at member's home enjoying meals together, in addition to the regular *ishyirahamwe* meetings and activities.

Berchmans was always present coordinating my arrival and departure times and locations to meet. Each time I went to the field, he would greet me on the road and rush me back to the field where the members were working. He was very tall and took giant steps across the cornfield. He gracefully glided over the ditches in the field. I had to almost run to keep up with him and normally I fell, once or twice a day, into the watery ditch on our brisk walk to find the others. He always came back and gave me a hand after I fell into the ditch.

I share Berchmans' story to conclude because his story painted a picture of many of the themes and concepts I shared throughout the dissertation. He had been involved with the *ishyirahamwe* for people living with HIV since 2004 when he first found out his HIV status. His story provided a strong indication of how the *ishyirahamwe* formed his experiences by giving him social support and creating a community for him within his village. His story also showed what testing and treatment were like for those living far outside Kigali in the villages. He spoke to the discrimination against people living with HIV during the early years of the epidemic and the struggles that members had within their own communities. Berchmans joined the *ishyirahamwe* in 2004 but he remembered how the country responded during early 2000s to those living with HIV, not long after the first *amashyirahamwe* emerged.

“I went to be tested because I was seriously ill. It was those days when people were saying that I was bewitched.”

Berchmans first joined the *ishyirahamwe* when he was 46 years old. He joined shortly after he was diagnosed with HIV that same year. Testing for HIV was not easy at this time because there was not a local site near his house that conducted testing for HIV. He had to travel

to Kigali by bus⁶⁸ to be tested. In those days, if one had unexplained illnesses that could not be cured with local or Western medicine, others in the community would often say that the person was bewitched as a way to explain the unknown illness. During the times after the genocide, there were also suspicions related to the genocide circulating the communities.

Berchmans decided to go for testing in Kigali because he had heard about HIV and wanted to learn his status. He was also very sick and probably suspected that he had HIV. His wife was also living with HIV and may have tested before. Both Berchmans and his wife knew about the *ishyirahamwe* before from other community members.

After a positive result, the doctor requested that he stay in Kigali for two weeks to start treatment but he had no place to stay in Kigali so the doctor gave him a transfer to a clinic that was closer to his home. Access to ARVs was still limited to those living outside Kigali so the doctor preferred that he stay in Kigali for treatment as he was very sick. Unfortunately Berchmans did not have the extra funds to stay in Kigali so he had to go back to his village and this was when his wife went to the local *ishyirahamwe*.

If Berchmans had extra money, he would have stayed in the town. The poverty that many members faced made their healthcare experience very different than the wealthier individuals who could more easily access medication from Europe or through other connections. When he went to the local clinic in the village area for treatment, they made him test again even though he told the clinic that he had HIV. They referred him to the *ishyirahamwe* but he actually knew about it from a neighbor before he tested. He was really sick at that time.

⁶⁸ At the time of the research in 2012, it would take me about 40 minutes to drive to the town off the main road in my own vehicle. In 2004, the main road was not nicely paved like it is today and he likely traveled from his home, located off the main road.

“The strength of my body didn’t exist, I had to use a walking stick...my wife was still strong. She is the one who managed to go [to the *ishyirahamwe*] and I was registered...Even I didn’t contribute [for the contribution] myself because I had no property...”

At that time the *ishyirahamwe* required a one-time contribution of 2500 FRW⁶⁹. Berchmans did not have this amount of money but he went to the *ishyirahamwe* meeting anyway to introduce himself. This was very different than how the new *koperative* were to operate. If one did not have the shares, they could not join the *koperative*. The *amashyirahamwe* proved to be a bit more flexible in this respect.

“The first day I came they gave out a speech, the one who was the president at that time said, ‘Here we have visitors.’ They were in a meeting, we entered...we used to do meetings on Tuesdays; on Tuesday that is when my wife went there. I told you my wife is the one who registered me. I tried and I also went there myself. After reaching there they said, ‘Here we have visitors.’ You would stand up and introduce your name, where you live and what brought you [to the *ishyirahamwe*]...They would say, ‘How did you come?’

Berchmans chuckled remembering his first time at the *ishyirahamwe*.

“Why are you coming here? What do you want?”

The other members wanted new members to be explicit about their HIV status. Berchmans explained that sometimes people would go to the *ishyirahamwe* meetings simply to see who was living with HIV in their village or to work with them without fully understanding the makeup of the group.

⁶⁹ Around \$5.60. The exchange rate in 2004 was about 442.99 frw for 1 usd (https://en.wikipedia.org/wiki/Tables_of_historical_exchange_rates_to_the_United_States_dollar accessed 17 October 2015.)

As such, when visitors arrived at the meeting, they had to state their name and their business with the *ishyirahamwe*, meaning that they had to disclose that they were living with HIV. The disclosure at the meetings was a sort of protective function for the *amashyirahamwe* to make sure that people were there for the right reasons and not to spy on the group. Other groups spoke about this disclosure at their first meeting. *Abakundanye* had more protection in place and required proof of HIV status before joining the *ishyirahamwe*.

“I tried to tell them that I went to be tested [in Kigali] ... and I found out that I was living with the infection. We were saying ‘I am sick’ [*nararwaye*]. Back then ‘living with infection’ - that saying has changed. There were many sayings to describe that you are infected.”

Berchmans explained to the *ishyirahamwe* members, “My wife and I, we come to cooperate with you.’ And they said, ‘Who directed you here?’ I said, ‘No one directed me, I knew this *ishyirahamwe*.’

But Berchmans also knew a neighbor who was a member. For some reason he decided not to tell the group. Perhaps he did not want the others in the group to know he was acquainted with her.

“But there was a lady who was a member...She asked me if I went for a test? And I told her that I was tested, she said, ‘how is it?’

‘I found that I am infected.’

She said, ‘Why don't you join the *ishyirahamwe*?’

“She is the who told me that they meet on Tuesday. She told me even the [amount of the contribution] and I went and I joined them.”

“She told me, ‘Also you must give 100 FRW⁷⁰ every week when you attend here, will you be able to afford it?’

And I said, ‘I will try, I don't know.’ They immediately wrote me in the book, and every Tuesday we went there when we were not sick.”

At this time, the *amashyirahamwe* were known in the community and Berchmans thought that joining the *ishyirahamwe* was the next step after a positive HIV diagnosis. He joined when he was really sick. The *ishyirahamwe* grew and continued to help people who were dying of AIDS. Berchmans’ experience with HIV changed. He transformed from a sick person to a person helping others who were sick but this was the case for many people as ARVs were not widely available at that time. The group not only spent time with those who were sick but they also helped the sick members access resources such as soap, food supplies, among other small material items. These became some of the benefits of joining the *ishyirahamwe*. The poverty levels in Rwanda can be dramatic. Any little bit helped but first one had to know his or her HIV status. It was a trade off.

They were getting sick in their homes and becoming very ill, we would go to be tested at the last minute. It was being a hero, people then died and were finished, to go and get tested was a great thing. Then we [*ishyirahamwe* members] could go buy sugar and porridge, we could find for them soap, the volunteers could come around them because those who recognized [that they were living with HIV] before were strong...the *ishyirahamwe* could help, neighbors used to come where they [those living with HIV] were gathered and say, ‘See those who are dead [*nyakwigendera*] and give us *akato*.’

Here, by *akato*, Berchmans was talking about isolation. The neighbors would avoid people living with HIV. They also talked about them in a negative way, even right in front of the group and/or individuals, as if they were already dead and could not hear them. The *akato* was a huge problem for people living with HIV during the late 90s and early 2000s, according to members.

⁷⁰ Around \$0.16. The exchange rate on July 2, 2012 was 596 frw for 1 usd (<http://www.oanda.com/currency/historical-rates/> accessed 31 December 2014.)

Berchmans remembered when he first joined the *ishyirahamwe*, the group only held regular meetings; there were no work activities as in present times. It was a time to come together and be comfortable with others who had similar problems. Members were also sick more often during this time.

“But joining the *ishyirahamwe*, the reason it was good by then, I am telling you, you could rest! When we were in a meeting there is a time we could [have the meeting] and we finished at two pm or at three pm and then we would go back home.”

When Berchmans first joined the *ishyirahamwe*, although he was sick, he was still capable of offering his math skills to the group.

When I reached the *ishyirahamwe*, I told you that even if I was very ill my brain was still working, I was someone who knew mathematics very well. After reaching there I helped them in mathematics and everything that was taking place. I was not an accountant or a treasurer but they made me a close supervisor. They said even if he is sick, he tries mathematics, after reaching there I became a supervisor but after the committee changed, I became the vice president.

Although Berchmans was ill, the *ishyirahamwe* gave him a chance to be a productive member of the group. At first he simply helped with finances but after a while, he moved up in the *ishyirahamwe* and held other more formal positions, eventually becoming the president of the *ishyirahamwe*, the position he held during the time of my research. He was also the president of a local *koperative* group at the time of the research. This group gave Berchmans the chance to feel like an able bodied human, despite the HIV diagnosis and counter to what people in the community were saying.

Berchmans did not hide his status in the community even though the community avoided people living with HIV. He immediately told his children, then his one living parent, then his relatives, and finally his neighbors. Some of the neighbors treated him differently after learning

about his positive HIV status but eventually the neighbors came back around and went back to sharing food and other household supplies.

“First, after telling ... my neighbors [my HIV status] there are some who stopped coming to my house but nowadays...we share salt and everything.”

Berchmans credited the *ishyirahamwe* as a sole reason for reduction of *akato* in the community: “Even *akato*, we say if there were no *amashyirahamwe*, *akato* could be still existing.”

In Berchmans’ mind, the *ishyirahamwe* was the key player in *akato* reduction. In this story, he admitted that *akato* did not exist at present. For him, his neighbors started sharing with him again. The sharing brought people out of isolation. For people living with HIV part of the isolation was being isolated from these informal economic networks. Sharing even salt was a huge transition.

Within the first year of testing positive, Berchmans also took his five children for testing several times because he had some doubts about the results and wanted to make sure that he knew the status of all his children. Berchmans and his wife cared for seven children of which five were their naturally born children. He finally stopped testing them when they became old enough to acquire HIV on their own (i.e. they had reached sexual maturity). His responsibility for his children’s HIV status had ended and luckily none of them were infected.

“The result showed they were not infected...I have tested them five times now. I now stopped because now they are at the ages where maybe they are the ones to bring it for themselves.”

When *Humura* first started, the group met in a room that was provided by the sector. They had their meeting and gave their weekly contribution to help pay for basic office supplies

and for the little material support the *ishyirahamwe* offered the very sick members. Berchmans even referred to these times as a battle.

“But it was a battle of *amashyirahamwe*.”

A battle to get new members despite *akato*, a battle to find ARVs, a battle against *akato*, a personal battle to not lose hope and a battle to reintegrate into a divided community.

Berchmans played an active role in encouraging people to stop losing hope, to visit the doctor, and to engage in better hygiene practices.

He continued:

By then people with AIDS were looking bad. You could see them, it was because of being hopeless and lonely, those forum meetings there at the sector [is where] they could say what are they lacking. When they have *mituweli*⁷¹, I could tell them if someone has showered and goes to the hospital, even the doctor advises [good] hygiene in order to look perfect. Then he/she managed to get that soap...Slowly by slowly we accepted ourselves, we were not even cultivating because we were very weak...after understanding that medication is good, we started to plan [to cultivate].

About one year after Berchmans joined the *ishyirahamwe*, in 2005, ARVs became more widely available in Rwanda. When Berchmans started ARVs, his overall strength increased. He also stated that ARV access was another help to reduce *akato* in the community because the medication helped people living with HIV to become physically and more importantly, visibly healthier.

In 2005, that's when I started to take ARVs. That is to say I started to become a person. I looked perfect, that medication helps you to regain your picture. I started to eat. As days passed they [neighbors] saw me going with a hoe to dig. That is to say that my children that they limited to come [before], they allowed them. They [neighbors] came, we shared food and nothing happened.

Finally the neighbors saw his physical appearance change and he no longer looked sick. The neighbors began to accept him and his children, who were all HIV negative. Nothing happened

⁷¹ Community based insurance scheme

to the neighbors, they realized that people living with HIV were not the walking dead and they should not be feared. Yet the fear and *akato* against people living with HIV still remained.

He continued about the importance of the *ishyirahamwe* in fighting *akato*:

That's why the *ishyirahamwe* has a reason of being important. We [people living with HIV] came together. We fought against *akato* as much as you can. We fought for it because being together made people see that we are still alive. The answer is not dying like they were saying that we are soon dying. They [neighbors] saw one year or two years passing, we used to have an *ishyirahamwe* called [name]. It was working here, only in three sectors. We had 105 members in 2007. In 2006 I said, 'We could end a year with out losing a person!' That did not surprise us. Even people are saying that we are approaching death but up to this time we cannot fail to do projects.

People in the community saw the people living with HIV as just that, living. The *akato* stemmed partially from the fear of death but Berchmans thought that by coming together, they had reduced *akato*. The *amashyirahamwe* gave people a way to live a more normal life, not the sick life associated with *akato*. Yet their lives were different than others outside the *ishyirahamwe*. They had to live bound by the rules of the *ishyirahamwe*. Their peers, their leaders, and their healthcare providers monitored their personal behavior. All dreams of having "normal" sexual relationships were altered.

Although Berchmans felt like he was becoming "a person" again through the ARV use and was not being stigmatized by his neighbors and within the community, he still remained strong within the *ishyirahamwe*. The ARV use increased his appetite therefore he gained the weight that was originally lost when he became sick. The ARV use also cured visible opportunistic infections, such as skin lesions. For him, being a person meant looking physically healthy, without visible proof of illness and a healthy weight. The *ishyirahamwe* had many benefits for Berchmans including:

Being with others, that's what I was thinking would be very important to me because I told you when we go and do a meeting, we can breathe and accept

ourselves. That is to say, if you are at home and you don't go where others are, you could feel a problem being a burden to only you and you feel that pain, you are the one having it only and even loneliness comes and depresses you. When you go and join others you find someone is there, the good thing of *amashyirahamwe* in these days, there are some who used to give us *akato* but at this time we are together.

Going to the meetings produced an alternative personhood for Berchmans. Even if he felt like a person again from using ARVs, he still looked to the *ishyirahamwe* for a personhood that involved being with others. Even the acceptance of their HIV status was not completed until they were in the *ishyirahamwe*. This feature was relayed time and time again. Beyond simply being with others, members helped each other when they needed things related to HIV, like their medication. For Berchmans, it would not be easy for someone who did not have HIV to go to the hospital and pick up medication for HIV. However, members could easily go to the clinic and retrieve medications for other members. Pragmatically it made more sense for members to retrieve medication from the clinic. They knew the clinic, with whom to speak. But also family members may have refused to go for fear of *akato*.

“The important thing is our lives, when I have a problem of not having someone to send to get medication at the hospital, I consult those people we have the same problem, I have never sent someone who doesn't have the same problem to the hospital, maybe he can't even go there...but these people they are like my secretaries I tell them all my problems.”

In addition, Berchmans gained physical strength and overall health, certainly partially from ARV use. He held the position of president in both the *ishyirahamwe* and *koperative* and often attended RRP+ sponsored trainings on living positively that he relays back to the *ishyirahamwe* members. The meetings also provided him a chance to meet other people in the community and gain new perspectives.

There is knowledge about AIDS, there were trainings about accounting, trainings about livestock, about human rights, we passed through those trainings. When you get out and get those trainings and you get to know people, there are some people that I didn't know but now I know them because we meet in the meetings or trainings. You can see it in our *ishyirahamwe*, when someone reaches where others are, you change even in your thinking. If I can tell you the problem we have is HIV, that is to say when you isolate yourself and keep it [HIV] in yourself, it can stay in you.

He continued.

“You think positively, you think well because you can't be hopeless you don't like to be someone who says, ‘I am hopeless.’ That is to say when you go where others are, you change. Even what I was talking about, in trainings, when you get trained you get to know things.”

There is no loss, but for me I say this many times that no one can tamper with me... but those other people there, they are the ones who are causing all these problems that we are having in our Rwanda, because for me I see them in places where we meet, in bars where they do things because for them, people do not accept they have HIV since they are not in *amashyirahamwe* and yet they have something they are hiding with and that person also has his own way of thinking, *akato* has been shown and it is like the saying where they say that the stone which has been seen will not harm the hoe since the person digging will dodge that stone, so that is to say that for us in the *amashyirahamwe* we can't infect other people because for us we have been known.

Berchmans story illustrates the impact of HIV *akato* that existed in Rwanda. The families in Rwanda, either by choice or simply due to lack of resources, left those living with HIV in the hands of the *ishyirahamwe*. The *ishyirahamwe* helped them financially, materially and emotionally but at the same time the member had another set of expectations under which they had to live.

In addition, the *ishyirahamwe* also created a sense of productivity for Berchmans. He used his skills and contributed to the *ishyirahamwe* activities. He also was able to attend meetings and trainings to increase his skills and knowledge and help the community. Berchmans even became the president of a nearby *koperative*. All these new activities for Berchmans helped

him to create a new meaning for life. He was now working and this was something that was important as life and work give meaning and purpose beyond being sick.

CHAPTER 10 DISCUSSION AND CONCLUSION

The stories and observations I included in this dissertation demonstrate the complexities surrounding the *amashyirahamwe* for people living with HIV in Rwanda: the complexities within the *ishyirahamwe*, within the community, and within members' lives. There are several aspects of the research that I want to consider to conclude the dissertation including the following topics: coming together (practice and rhetoric); inclusion, exclusion, and vulnerability; global inequalities, local realities. One topic I want to stress first is the problems with trying to study *the* culture of Rwanda. Throughout this research I uncovered many different instances where the complexities of identifying one Rwandan culture was problematic. There were so many different players intersecting and interacting in Rwandan history. Not only did these players become part of the ever-changing cultures of Rwanda, if you will, but some of these players also influenced the modern day *amashyirahamwe* for people living with HIV. Even though some of this broad complexity did not come out on the ground in the field, this was the overarching and extremely complicated context in which the *amashyirahamwe* functioned.

I discussed the *abiru* in chapter two and how the dynastic histories were kept through an oral tradition. This practice acknowledged a certain history so already diminishing the diverse cultures among Rwandans and the areas they conquered. Colonization also added the influences of first, Germany, and second Belgium. The subtle ways that language was used on the identity cards to instill notions of ethnicity is an example of how colonization impacted Rwanda. Not to mention the myriad religious influences throughout time, even before missionaries first arrived in Rwanda. Over time, a huge handful of religious groups took over the religions of Rwanda. Then there were the returning refugees coming from Uganda, Tanzania, Congo, Burundi,

Europe, North America, and many other places. All the returnees had taken on new languages and cultures during their time away from their own country.

There were also many influences from international players in the past decades. Rwanda was an interesting context because many countries had some interest in Rwanda: European countries, China, United States, Canada. Because there were both French and English speaking segments of the population, the countries with an interest were diverse.

In summary, before making my concluding remarks I want to strongly relay the complex social context in which the *amashyirahamwe* existed. Additionally, throughout this dissertation, I emphasized some of the historical aspects of Rwanda, although obviously not exhaustive, as a way to show that an understanding of HIV in Rwanda is reliant on understanding the context of Rwanda through space and time. Methodologically and following Didier Fassin's work in understanding HIV in the context of South Africa (Fassin 2007), I tried to incorporate various aspects of Rwandan history that impacted how HIV was intervened upon and experienced by members. That said, I now come to the theme of coming together, the "Rwandan tradition" that guided many of the current government programs.

The Practice of Coming Together

An overarching theme of the dissertation was on coming together, both as practice and as a rhetoric strategy. In practice, people came together. People living with HIV came together in HIV *amashyirahamwe* and people came together within the local villages for poverty reduction through the *Ubudehe* Program, to name two examples. There were many other examples of people coming together in Rwanda that were mentioned in this dissertation (e.g. *umuganda*) and many instances that were not discussed here.

Members from the *amashyirahamwe* spoke about how they “just” came together. That was it. It was very matter of fact, almost common sense and obvious to the members. When I asked members why they joined the group, the primary response was to be together with others or to come together. But to me, an outsider, the whole idea of coming together was complex, especially in a post-genocide context. Who came together? And equally importantly and perhaps slightly more interesting, who did not come together? I address the latter below. To state that coming together was natural, that people just came together, no questions asked, added a layer of complexity to the issue of coming together. I never heard from any members that coming together was not easy but some people did not join the *amashyirahamwe* in their own community. There were not *amashyirahamwe* in every village but normally people joined the *ishyirahamwe* that was closest to their home. Remember Maria from *Twizere* who joined the *ishyirahamwe* a few villages from her own village? Maria said that she did not want people in her community to know that she was part of this group. Perhaps her reasoning went deeper than simply being known as living with HIV or being seen with the group. Perhaps she did not want to join the group in her village because of unresolved conflicts from the genocide.

During the genocide, community members participated in genocide with their neighbors or against their neighbors. The violence was very personal. The fact that the people living with HIV came together naturally into these groups was not so simple as “just” coming together. The ways in which members spoke about coming together also presented a picture of the reality in which they lived. For them, it was supposed to be natural to come together. This was the rhetoric that was used to make people believe precisely this point. But coming together had consequences for the members who joined. Although Maria was not known as a person living with HIV in her

own community and she informed us that she in fact was not living with HIV, she was known in other communities as living with HIV.

The first *amashyirahamwe* emerged in response to an immediate need for those living with HIV when they had little support from family and neighbors. Members recalled those times stating that they were isolated and faced *akato* because of HIV. But this was the same time when the trust and unity of the entire country had deteriorated after the genocide. Locally neighbors tried to come to grips with what happened. Their neighbors killed their families and now they had to live together with the same people. They were supposed to pick up the pieces and build a united neighborhood, a united country. The first informal *amashyirahamwe* emerged shortly after the genocide after a new government had taken over the country and reconciliation was at the top of the agenda. However, the country at this time was still trying to knit society back together, a society that was torn apart for the years leading up to the genocide. Then add to the landscape HIV. Imagine being a person living with HIV in this context. Perhaps the neighbor living with HIV was the one who raped your daughter who now also has HIV. Suspicions ran high; rumors spread through the villages. The HIV epidemic in Rwanda was enhanced by the genocide and the violence that led up to it. To make matters worse, the entire infrastructure in the country was destroyed including the public health infrastructure that had done a decent job at containing the HIV epidemic before the genocide. This was the context under which the first *amashyirahamwe* emerged.

But perhaps because there were so many problems in the communities from the genocide, the disclosure of HIV status was not as big of an issue? The identities “perpetrator” and “victim” had entered the Rwandan landscape after the genocide so what was the impact of adding “person living with HIV” to the list of new identities? What was worse: being labeled “abanyasida” or a

“perpetrator” in a community with mostly victims or vice versa (i.e. being a victim in a community full of perpetrators). This is not meant to diminish the consequences of having the identity of a person living with HIV in Rwanda. I do not want that to be the take away message. Instead I want to demonstrate the complexities in this social world where HIV and recent ethnic conflict collide. There was also a difference if one was living with HIV as a victim of the genocide. There were other groups for the victims of genocide living with HIV, such as AVEGA. Were these people looked at differently than those who contracted HIV by “misbehaving”? Surely there were differences within this complex terrain.

Another practice of coming together often resulted in material resources, especially at the beginning of the HIV epidemic in Rwanda. Marsland (2012) conducted research in Tanzania in 2009 with informal groups for people living with HIV and found that the disclosure of HIV status for members who joined a group, incidentally also called *Humura*, had some material value to the person disclosing. The material support helped them to pay their way in a poverty ridden context (Marsland 2012). Pragmatically, from the members’ perspectives in Rwanda, there were practical benefits to coming together in *amashyirahamwe*, similar to those in Tanzania. Before, certainly there was a material value to disclosure, especially when the resources from NGOs were abundant in Rwanda. Recall Berchmans comment about how “they” told the people living with HIV to come together and after they, the people living with HIV, were together, the groups accessed benefits from the GoR and other donors together as a group. The main difference from Marsland’s work was that in the new “model” *amashyirahamwe*, that is, those that successfully became a *koperative* group, there was not a material value of disclosure of HIV status as such. Now the material value of joining an *ishyirahamwe* was being part of the *koperative*; disclosure of status, if one followed the rules of *koperative*, was no longer

a requirement to join as the *koperative* groups were not for any specific group of people. However, as we saw, many of the *amashyirahamwe* continued to work the same way even after they became a *koperative*.

When the people living with HIV came together, it sometimes caused strains on other relationships in the community, often due to the resources that some people received and others did not. For example, neighbors were jealous that the people living with HIV received resources and due to their negative HIV status, they were not eligible for these benefits. If one behaved “well” then they were not rewarded with benefits. This was partially stopped with the *Ubudehe* Program when all the monies were put into one sum for distribution. That is, people living with HIV could not obtain funding from the government just because they were living with HIV.

The jealousy in the community reminded me of a conversation I had with Felicien about how the GoR wanted control of the funds that were allocated to Rwanda. I asked him to explain the rationale. He gave me an example of a program that offered ARVs free of charge to prisoners. At one time, the prisoners, many of whom were genocide perpetrators, were receiving ARVs and those in the general population, including genocide survivors and rape victims, had limited access. This situation did not only cause jealousy but far worse, outright anger. The survivors and others living with HIV were outraged and demanded that the program stop. But the funding was such that it was supposed to go to the prisons. The GoR then made some changes as to how the future funds were to be allocated. Other forms of support enhanced the tensions in the community about resources as well. For example, AVEGA, briefly mentioned above and in the sample section, only allocated their resources to genocide survivors, many of who were infected with HIV but not other people in other groups such as the *amashyirahamwe* that fall under RRP+. This is elaborated below.

There was a downside to coming together. The same rhetoric that brought people together for good also brought people together for bad. As mentioned, the regime of Habyarimana also used the rhetoric of coming together and also the rhetoric that the coming together was part of Rwanda's pre-colonial history (Desrosiers 2014). How could people really accept that coming together was good or part of Rwanda's history when just years before the previous regime used the same rhetoric? Looked what happened when people came together. April 7 - July 4, 1994 - need I say more? Even worse, some of the "home-grown" solutions were used as places to identify the remaining neighbors that needed to be killed during the genocide. *Umuganda*, in this case, was the local community works day where people came together to build the community but during the genocide it was used as a way to identify Tutsi to kill (Twagilimana 2007). Coming together to murder your neighbors. If you were not with them, you were against them. *Gushyirahamwe ni byiza*. (To come together is good.) How could this be? This tension was the problem of coming together. This unstated tension was eerily present in the background of the associations. It was inscribed, to follow Fassin's (2007) thinking, on the bodies of Rwandans who witnessed the horror of coming together or who came together to commit genocide. Surely these memories impacted their everyday existence. So "just" coming together was a huge myth.

The Rhetoric of Coming Together

The theme of coming together was one that was used to encourage Rwandans to reconcile. The GoR spoke about how Rwandan "culture" emphasized coming together and how this was an important part of their culture, the culture before colonization. This mantra was presented alongside a history of Rwanda where ethnic divide was created during colonialism. The current GoR stressed that practices of coming together were part of Rwandan pre-colonial history, a part of their culture and values that were lost after colonialism. The emphasis was to

come together and solve problems locally with each other because this was how Rwandans worked in past times. As mentioned in chapter five, the recent *Ubudehe* Program was rationalized in this way, as well as the *amashyirahamwe* for people living with HIV and many other programs. But the *Ubudehe* Program of from the past was very different than the current program. This aspect of the work fit in with Hobsbaum's work on the invention of tradition meaning "a set of practices, normally governed by overtly or tacitly accepted rules and of a ritual or symbolic nature, which seek to inculcate certain vales and norms of behaviour by repetition, which automatically implies continuity with the past" (Hobsbawm 2012:1). The value of mutual assistance and the norm of coming together were both emphasized by the GoR in a way that demonstrated that this was the pre-colonial way of thinking and doing, a way that should be naturally adopted.

The invention of tradition was not something novel; there were many examples of societies doing this through space and time. The thing that was surprising was that in the Rwandan case, people came together after genocide. Coming together in a post-conflict society regardless of whether or not it was a norm of the past was a complicated matter. This mantra of coming together was even a part of Rwanda's larger reconciliation project to unite Rwandans. This, in part, reinforced the motivation to join the groups for people living with HIV, among other governmental programs and development initiatives.

The other very interesting point about this rhetoric was the performance surrounding these ideas and the strategies used to relay the desired message. It went beyond inventing the tradition. The use of language was not only very important but also very strategic. In addition to the "home grown solutions," the language used to talk about the individual members' expectations about how to live with HIV was another solid example of how ideas were

performed. The ways in which the leaders of the *amashyirahamwe* used words helped to mold the identities of the members in very specific ways. It was a performance, one that convinced people to behave in a certain way. The performance was scripted by RRP+. The leaders presented the educational information from small booklets provided by the leaders. The leaders often went for trainings on how and what to present to the members. Although for different end goals, it was kind of like the days when people living with HIV learned how to give their testimonies. Nguyen (2010) presented a case from his work in West Africa where people learned how to articulate their HIV testimony. They specifically learned how to provide the type of testimony that would present them as a good candidate for ARV treatment. The goal there was to access limited life saving medication. In Rwanda, the goal was to model the people living with HIV to be “good” citizens living with HIV. The discourse that was used was strategic, if not manipulative at times.

Inclusion, exclusion, and vulnerability

Beyond “just” coming together, there were individual consequences of coming together, in the *ishyirahamwe*. Belonging exposed the member to the community as being a person living with HIV or bringing the conversation outside the realm of HIV, the *Ubudehe* Program, where one’s vulnerability was assessed and exposed to the community. Here, I want to stress the importance of social networks, using the *Ubudehe* Program example. As one can imagine, if one’s social network included leaders of the village, then perhaps this could help the vulnerability assessment. It was normal for community members to dispute their own assessment number or that of their own neighbors. If one had better connections, perhaps they would receive the *Ubudehe* funding more rapidly than those who did not have the connections. It reminded me of work done by Susan Reynolds White and others in neighboring Uganda. Whyte et al (2013)

studied AIDS care in Uganda and the importance of social networks and connections as a way to access care emphasizing how these people living with HIV were “socially embedded seekers of health, not passive recipients of donor beneficence” Whyte, et al. 2013:147. They termed this type of health seeking behavior and the ways in which people used their relationships circles “therapeutic clientship” (Whyte, et al. 2013). Petryna (2002) also discussed how claimants used their social networks to negotiate a “better” claim category to obtain better benefits from the state.

All of the strategies to gain more resources for better or worse vulnerability assessments demonstrated a clear capability, one that would move that person outside of being the most vulnerable. Those who were most vulnerable were the ones who could not negotiate their vulnerability in the first place or perhaps even come to the meeting. These were also the people living with HIV who did not attend the meetings or who could not adhere to the rules and regulations of the *ishyirahamwe*.

There was a lot at stake in not belonging to a group like the *ishyirahamwe* for people living with HIV. In Rwanda, those who did not join the group were known in the community as the ones who were spreading the HIV epidemic. As mentioned previously, those who were in the *amashyirahamwe* were the ones doing the “right” thing. Although this did not necessarily apply to the wealthier segments of the Rwandan population, this was the case for the majority of those living with HIV. Contesting the belonging often resulted in that person entering an even more vulnerable position. Those who did not join the group and whose HIV statuses were known in the community were considered outsiders. But joining the group also caused members to become outsiders within the community but at least they were with each other. Who, then, was vulnerable?

Other studies have demonstrated how people contest their belonging to society in general or on a smaller scale the family and the ways in which belonging or not resulted in vulnerability. For example, Nguyen's (2007, 2010) notion of therapeutic citizenship demonstrates this idea. Those who belonged to the group became part of the pool of those who were selected for the limited ARVs that were available at that time in Western Africa. Those who were able to not only join the group but also articulate their testimony benefited greatly because they were the ones who ended up accessing the life saving medication. Those who were excluded from the group because they could not speak about their HIV story, were left without ARVs to die.

In another case, Biehl's (2005) work on zones of social abandonment clearly shows how some people become excluded from their very own social life. Biehl tell the story of Catarina, a resident of Vita, a zone of social abandonment but also a place where families dropped off sick family members to essentially die. Vita transformed into an asylum for these excluded people where "the abandoned waited *with* death" (2005:1, emphasis original).

If we examine other cases, we can see that the isolation and marginalization of the members from the community was not the same as others described. For example, Biehl (2005) described "biocommunities" as the groups that were formed out of the people who ended up at Vita. These individuals had been completely abandoned by their families and had nowhere else to go. They formed this community together. The members from the *amashyirahamwe* were marginalized from their communities but it was certainly not as extreme as those left at Vita. The members still lived in their communities with their families; they still participated in other community events, such as meetings, the *Ubudehe* Programs, and *umuganda*. They just added on the *ishyirahamwe* where they could be with others who were "like them". This is a completely different type of exclusion but still exclusion nonetheless. The inclusion of being part of the

group caused some form of exclusion due to the public disclosure of HIV and the *akato* that existed in the community. However, the *akato* “did not cause instability” like before, to use Berchmans’ words.

Those who contested their membership in the *ishyirahamwe* and those who could not take on the subjectivities demanded by the *ishyirahamwe* were a different story. These are the people who faced the most marginalization. The ones who really need the most assistance were the ones to be cast out of the group, just like those who could fight for a better vulnerability assessment were the ones to receive the help but those who did not even have the capability to negotiate were left without assistance.

If we look at exclusion from an even broader level, at the beginning of the HIV epidemic, the whole continent of Africa was excluded from ARV access yet encompassed some of the hardest hit areas. Crane (2013) outlines the argument about how the “North” argued that African HIV patients would not be able to adhere to medication. The opposite was the case, however, the continent was excluded from the care. Other arguments were also documented to refrain from providing medication, such as HIV subtype (Crane 2013). This brings me nicely to my next point about global inequalities and research agendas.

Global inequalities, local realities

The inequalities went deeper than a few extra resources for people living with HIV within villages in Rwanda although those extra resources made a difference in the lives of the individuals. What about all the other diseases left out of research circles or proposal calls? Take cancer for example. Julie Livingston (2012) wrote an excellent account of cancer care and treatment in Botswana. Part of her discussion focused on precisely this point - why was all the money going to HIV treatment and research and not cancer (Livingston 2012). Contrast this to

work by Crane (2013) who wrote about a hospital and laboratory in Uganda and their amazing growth including infrastructure, staff, and knowledge due to the overwhelming amounts of funding that came in for HIV research.

Why were there thousands of groups organized for people living with HIV but not one cancer support group organized in Rwanda? Even in my own work, the focus was on people living with HIV but what about other diseases from which people were dying? Has my research also focused entirely on AIDS because of its “exceptionalism”? Studies surrounding HIV were more easily funded or so the story went but there was also a lot being said about HIV. Would the story have been the same if I had studied another type of group, for example a genocide survivor group? Would the story of belonging and exclusion been the same? The case of the *Ubudehe* Program made it clear that there were other vulnerable community members who were excluded from the program because of their inability to actively participate and others were active in the process and became known as the most vulnerable but were in fact not. Certainly if I had done the project several years previous or immediately after the genocide, there would not have been the cohort of the younger generation for whom the genocide was only an oral tradition.

The moral order for people living with HIV in Rwanda

There were many players that impacted the ways in which the *amashyirahamwe* were molded in order to create a moral order for those living with HIV. The GoR and its strategies of reconciliation and poverty reduction broadly impacted the *amashyirahamwe* as noted above. The ways in which HIV was referred in communication and the moral language used to talk about the expectations of members impacted how HIV was intervened upon in this context. The living positively advice given by leaders of the *amashyirahamwe* although directly from RRP+ scripted

booklets, had additions from the leader and even threatened members into good behavior but even if people did not agree with the advice on how to live, people still joined the groups.

Joining the *ishyirahamwe* was not a choice for many members. Those who needed resources joined the *ishyirahamwe* and in a context of severe poverty, people maneuvered their way through different channels to support their families. The majority of the benefits about which members spoke (these were mostly from external NGOs in the past) were material benefits including pigs, flour, maize, food, soap et cetera. The *ishyirahamwe* became an economic resource for people beyond the resources provided from NGOs. Even after the NGO resources were reduced, people still remained active in the *amashyirahamwe* although some people left the groups. If a person was isolated from their community because of HIV, they could join the *ishyirahamwe* to form a community of their own and build up economic networks that were lost due to *akato* and marginalization from the community from their positive HIV status. There were many ways the *amashyirahamwe* formed the same channels of resources that were found in the village, such as trading foods and borrowing from neighboring households.

There was also social support. This support helped members to find a sense of personhood collectively. In other words, an emergent form of sociality came out of meetings together as a group for people living with HIV, while individual subjectivities were reshaped within from the moral messages provided to the group.

Many members were told to join the *ishyirahamwe* from their healthcare provider after receiving a positive diagnosis. And many, but not all, listened. There were also messages from community leaders that those who were not in the *ishyirahamwe* were the ones who were spreading HIV. Add to that the stories about ARV funding and fear about losing the benefits in the future, unless one remained a member of the *amashyirahamwe*. It made sense in the context

of Rwanda for some people to join or remain in the *ishyirahamwe* at the expense of being known as living with HIV and potentially facing *akato* from the village. There was very little choice about the matter, in many instances.

Although the stance from many people with whom I spoke, including *ishyirahamwe* members and leaders outside the *ishyirahamwe*, was that there was no *akato* in Rwanda. Part of this message was that no one should be discriminated against, which was part of a larger sentiment of reconciliation. “We are all Rwandans.” One of the goals of RRP+ was to eliminate *akato* so people argued that it no longer existed. But members faced *akato* together and it was no longer such a problem to them. Yes, they were still called names but the isolation at the core of *akato* was reduced in two ways from the *ishyirahamwe*: people formed their own community networks to replace those social bonds and networks of exchange and secondly, as time went on, people became less fearful of HIV and stopped isolation on some level. The *amashyirahamwe* were together and faced the *akato* collectively and showed their peers that they were living well with HIV.

Membership in the *ishyirahamwe* also brought a set of new social norms for the people living with HIV, often conflicting norms to that of Rwandans. The *ishyirahamwe* norms came from international public health policies, government policies on reconciliation, and *ishyirahamwe* leaders education from RRP+. People had no choice but to follow these new norms at the fear of being expelled from the *ishyirahamwe* and being known as a troublemaker in the community.

From a government perspective, it was easier to keep track of people if they were grouped in *amashyirahamwe*. The surveillance in Rwanda went beyond community surveillance of association members. I went for a five-week home leave in August of 2015. I had been living

in Rwanda for 3 years and 8 months by that time. My dad called me on a USA cell phone and told me something that was supposed to remain confidential. I told him quickly, “Perhaps we should discuss this later. I am on my way home.” He continued to tell me about the situation. I again told him that we should not talk about this on the phone. Then I realized that I was in USA where my call possibly was being monitored but likely not. From those few years in Rwanda, it became normal that my calls could be monitored and likely were.

The reality of having one’s life under constant surveillance was more than phone calls for the people living with HIV, especially outside of Kigali. People watched each other and reported behaviors to the leaders: the leaders of the village, the *ishyirahamwe*, the police, to whomever it made the most sense. There were networks of people who became the eyes of the village. In a post-genocide context, perhaps this was the best way to make sure genocide did not occur again. But these networks impacted the lives of those living with HIV, as any bad behavior resulted in further marginalization.

The *amashyirahamwe* were also constantly changing with the times. This was very apparent with the push to become *koperative*, which encouraged self-reliance through coming together but with a different common factor. Now the connective tissue was not limited to only those living with HIV but also based on those who wanted to become economically responsible. Locally, leaders often found a sense of pride in their *koperative* endeavors. They were creating a *koperative*, it was not singled out like the *ishyirahamwe* for people living with HIV. Anyone could join. Plus as a new government push, the *amashyirahamwe* for people living with HIV were at the forefront of creating their own *koperative*. They became active members of Rwandan society, even though they had HIV, just like others. Their groups were no longer excluded. They too were supposed to be productive and help build the country of Rwanda. The *koperative* efforts

were not always successful, many failed, and although some members did not even notice a change, the members were working together.

The *amashyirahamwe* created new social relationships and emergent forms of personhood based on the HIV status. The *amashyirahamwe* in Rwanda were very different than the activist groups described by Petryna (2002) and HIV activist groups in South Africa, for example (Robins 2006; Robins 2008). They were also very different from the original HIV activists in USA that essentially changed the course of HIV research and treatment by forming alliances with the scientific community (Epstein 1996). In these cases, the activists were very involved in claiming rights from the state. But the context in Rwanda was completely different, again pointing to the sheer importance of context in understanding an epidemic. The *ishyirahamwe* members did not demand much of anything from the state, if anything the state demanded much more from them. They were expected to live in very specific and “moral” ways and not engage in “bad” behavior. If they did, their right to medication, for example, would be taken away. The groups sometimes formed relationships with a broader community, but certainly not with experts, and not as a way to gain their basic rights. The *amashyirahamwe* formed relationships with NGOs to gain access to some resources and education but it was always in the hands of the NGO. The groups were relatively passive in the process.

The members did, however, come to terms with their new identity (a person living with HIV) together in the group and the members were reliant on the state for healthcare and medication access. The members were not like the biological citizens described by Petryna (2002) and they were not like the therapeutic citizens described by Nguyen (2010). There was no emphasis on being selected for ARV therapy as the majority of Rwandans had access. The members disclosed their status in the group and in the community but not as a way to attract

donors. In some sense, the members were triaged for resources. During the time when the *amashyirahamwe* were receiving material resources from NGOs, one had to join the *ishyirahamwe* to access the benefits. This type of resource allocation left out the most marginalized, as they were likely not members of a group in the first place. Part of the rationale for the *Ubudehe* Program was to make the economically marginalized exposed so that they could receive assistance yet the process exposed some people as being in abject poverty and they never received help, only the label. Whether the community based process of categorizing was effective or not is not the point. The point is that in an effort to be fair and adhere to the rules and regulations, the people who most often needed extra help were the ones cast in the margins. The *ishyirahamwe* members who were “bad” or “misbehaving” could have used some help but instead they were expelled from the group and their community. Those who were economically vulnerable and not able to join the *koperative* were the ones who needed the financial help the most. Although the groups were changing to be more inclusive (i.e. no longer based on HIV status), there was still major exclusion but now for those who were economically vulnerable, which, I assume, would exclude even more people. There were groups that had transformed into *koperative* and not all previous members could join the *koperative* section because they did not have the required shares.

Fluid subjectivities

There was something different in the Rwandan case from the other literature. To conclude, I take a step back and try to understand the broader implications of inequalities, responses to epidemics, and the ways in which communities form and react to new situations that arise in their daily lives. These present differences could be explained by the difference in the timeline of the epidemic in other research. Perhaps as epidemics change, different subjectivities

emerge. Nguyen (2007, 2010) conducted his research in West Africa during a time when ARVs were extremely limited. Perhaps during the early stages of epidemics, the response remains more individually focused on survival to obtain the medicine. Global health communities often facilitate the early response so the focus on the individual is not too surprising. The groups in Rwanda existed at this point but with a different purpose: to facilitate medication. As ARVs became more accessible and HIV under more control, the demands changed. The group, especially in a collective society, became the focus as more demands were made on people within such groups: to live positively and so on. The groups then became a way to organize and monitor people, as well as control the epidemic. At this point, there were still influences from NGOs as these institutions provided many of the resources.

Now as HIV was becoming known as a chronic illness, in Rwanda we see the emergence of a new sociality: the *koperative*. The groups were supposed to transform into income generating *koperative* but the key to this new form was that anyone could join the group; it was not bound by HIV status. The group became even more of a basis for support but not from outside sources such as NGOs or the government. Now the groups were supposed to be self-reliant and encompass their own development, more of a neoliberal model of development. Over time, it will be interesting to see how the socialities and subjectivities change as new diseases and illnesses pass through society.

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ABSTRACT**ABANYASIDA: EMERGENT SUBJECTIVITIES AND SOCIALITIES IN RWANDAN ASSOCIATIONS FOR PEOPLE LIVING WITH HIV**

by

JENNIFER ILO VAN NUIL**December 2015****Advisor:** Dr. Andrea Sankar**Major:** Anthropology**Degree:** Doctor of Philosophy

This dissertation is concerned with the HIV epidemic in Rwanda, specifically related to the support associations for people living with HIV. In it, I examine the reshaped individual subjectivities that emerged within the group, the emergent socialities that came to life, and the influences of the governmental and nongovernmental institutions in the wider Rwandan context. The study design combined three main features – historical research and key informant interviews on the historical forms and practices of coming together in Rwanda, ethnography on the daily activities of five specific associations and ethnographic research on the ways in which the associations shaped the experiences of HIV for its members and maintained the guidance of the shifting local and national policies. The dissertation research took place from January 2012 until December 2012, with additional field visits in November of 2013.

Findings explore the complex social setting of Rwandan HIV associations in a post-genocide context alongside national and international health policies and programs. The associations emerged under the guise of a government mandate of coming together to solve local problems. The idea of coming together is unpacked and the rhetoric of coming together scrutinized. Coming together in the HIV support group led to both intentional and inadvertent

disclosure of HIV status in the community, often leading to *akato* (Rwanda's version of something like stigma). Findings also delve into the ways in which members of the groups maneuvered their way through different channels to support their families. The groups provided a space to create new networks after networks were broken due to the *akato* from HIV disclosure.

Subjectivities were reshaped by the group mandates that required members to live within a moral order that often conflicted with the existing moral code. The ways in which association members, as well as those who elected not to join the group, were excluded and made vulnerable are examined. New changes to create income-generating groups are explored as new policies urged self-reliant citizens. In conclusion, the idea of fluid subjectivities is explored as a way to explain how people and governments respond to health epidemics.

AUTOBIOGRAPHICAL STATEMENT

Jennifer Ilo Van Nuil graduated from Wayne State University's Department of Anthropology doctoral program in December 2015. Mrs. Van Nuil worked at the Institute of Gerontology as well as the Department of Anthropology during her anthropological training. She received her M.A. in Anthropology from Wayne State University in 2008 and her B.A. in Marketing from Michigan State University in 2001. Since 2008, Mrs. Van Nuil has worked in Rwanda on several health related research projects. She worked with FHI360 on a secondary HIV prevention project in Rwanda during the summers of 2008 and 2009. Mrs. Van Nuil worked for three years at Rinda Ubuzima, a local Rwandan NGO focused on studies related to family planning, women's reproductive health, and new HIV prevention technologies. She has led several social science capacity building projects in Rwanda with more planned for the future. Mrs. Van Nuil has co-authored publications in Tropical Medicine and International Health, PLOS ONE, and the Journal of Aging Studies. Her most recent presentation was at the Institute of Tropical Medicine's annual colloquium in 2014, The Human Factor: Social Sciences in Global Health Research, where she presented on issues related to informed consent in clinical trials.