

**“I’m Positive. So What?” HIV Illness Narratives from Zimbabwe and the  
United States**

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To respect the privacy of my participants, their actual names and the names of my research sites have been replaced with pseudonyms within this text. This practice does not compromise the integrity of the stories shared.

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**CHAPTER 1**  
**INTRODUCTION**

### **Abstract**

Storytelling is potentially an important resource for HIV-positive individuals as they grapple with the changes HIV brings to their lives and seek ways to make meaning of their experiences. Illness narratives in particular create the opportunity for healing by facilitating a recasting of illness within a person's understood moral and social order; through the story's adaptability to alternative endings; and by placing "the human drama of illness" in the foreground (Mattingly and Garro 2000:8).

Using fieldwork and open-ended interviews from America and Zimbabwe, I illustrate the multidimensionality of illness narratives and their value in helping to understand the experience of living with HIV. Experiences with and conceptualizations of stigma and discrimination, community and religion emerge as main themes throughout my participants' narratives. Their stories reflect an active negotiation between themselves, their social worlds and their HIV status. I also problematize the notion that storytelling is inherently therapeutic and the implications this has for those associated with the epidemic.

My participants' stories clearly illustrate that HIV does not exist only within the biomedical sphere. I therefore have drawn upon the diverse fields of anthropology, epidemiology, history, medical ethics and narratology. Approaching the epidemic comprehensively allows practitioners, support group leaders and others associated with HIV to more capably respond to the needs of HIV-positive individuals. Analysis of illness narratives emerges as a key resource in this process.

## **Introduction**

HIV is a complex entity, existing in the medical realm of disease as well as in the cultural realm of fluid systems of meaning. As individuals grapple with the changes HIV brings to their lives, they seek ways to make meaning of their experiences. In interviews with HIV-positive individuals from Zimbabwe and the American Northeast, I have used narrative expression as a tool to explore the meaning-making process around HIV. Some of my participants articulate their illness experience largely through bodily idioms and physical isolation enforced by stigma. For others, the experience is more conceptual, affecting their understandings of themselves, God, their relationships with community members, family, friends and religious institutions. My thesis seeks to illustrate how HIV is differentially constructed by individuals from various social, economic, religious, and ethnic backgrounds. They draw on their different positionalities as tools and sometimes hindrances as they maneuver through the narrative process. Their articulations are part of an active, dialogic negotiation between themselves, their social worlds and their HIV status.

The need to narrate the strange experience of illness is part of the very human need to be understood by others, even if communication is confined to the margins (Mattingly 1998). In sharing and discussing the stories of HIV-positive individuals within the frameworks of medical anthropology and narratology, I seek to bring attention to the need to tell stories. I am concerned with how stories are more than just the form anthropological data frequently arrives in. How are people “doing things” with stories and why? How and why does narrative serve to illuminate aspects of illness that might not otherwise be recognized?

Narrative analysis has become powerful in studies of illness and healing

because it offers a basic form through which to make sense of experience. Though no tight formal model of a story exists (nor should it, as this would eliminate the difference in stories), narratives throughout culture and history offer us “dramatic” forays into social life, providing form to feeling through the relational act of telling a story (Mattingly and Garro 2000:11). Narratives are event and experienced-centered; they are concerned with human interaction, describing not only what someone does in this world, but also what the world does to that individual. Finally, narratives do not merely refer to past experience, but create experiences between their tellers and listeners (Mattingly 1998). At their broadest, telling stories allows narrators to communicate what is significant in their lives, how things matter to them. I am particularly interested in the ways in which illness fits into these larger narratives.

Storytelling, with its inter-relational and dynamic qualities, is often an important tool for negotiation between interpretive frameworks. My approach to narrative frameworks is strongly grounded in Loring Danforth's approach to religion, which “attempts to deal with the problem of human suffering by placing it in meaningful contexts in which it can be expressed, understood and either eased or endured” (1989:51). Approaching illness narratives within this interpretive “meaning-centered” approach opens up the analysis of illness experiences beyond the traditionally narrow biomedical perspective to other social and cultural systems. Doing so positions participants' narratives within a framework that views disease as a physiological pathology with symptoms that have biological referents, and illness as the interpretation particular cultures place on undesirable states with the body as a symbolic vehicle (Danforth 1989:51).

Illness therefore, is a culturally constructed response to disease, though the distinctions between illness and disease are often difficult to make. However, in the

distinctions lies the process of healing as a separate and distinct phenomenon from curing, commonly thought of as the removal and address of physiological ailments. The process of healing deals with illness as a cultural condition. Illness and its symptoms are seen as powerful symbols that use the body as a vehicle to express something about the social situation and psychological condition of those who are ill (Danforth 1989).

Such a realization has important implications for understanding sickness and the therapeutic process associated with it. Treating sickness, which involves both disease and illness, cannot be reduced to curing disease, though this is important. Treating sickness must also involve the healing of illness, which is inherently an interpretive process (Danforth 1989). To be effective as a tool for addressing illness, interpretation must occur within a set of culturally understood and accepted ways of making sense of experience. Such a process, through which individuals are given a symbolic framework, makes their disease and illness diagnosis more concrete, comprehensible and manageable. Stories, as the articulation of this interpretive process can therefore be “healing” to the extent that they help people shift interpretive frameworks, from those that are distressing and negative to those that are affirming and positive.

Many of my participants interpret their HIV diagnosis and the changes it has introduced to their lives through a Christian framework. Though they do not participate in religious healing rituals of the type Danforth describes among the Kostilides of Northern Greece, my participants develop and use religious frameworks which reformulate their interpretation of their HIV status such that they are ritually moved from a state of illness to a state of health (Danforth 1989). In this way, their frameworks and modes of interpretation facilitate change in attitudes towards



themselves, their suffering and their social world. Though they cannot be cured, they may be healed. This process is particularly important for HIV-positive individuals who may be able to draw upon these culturally specific and personalized frameworks for continued healing throughout their lives. Analyzing these frameworks, religious as well as secular, and the contexts in which they are created, enacted and challenged, illustrates the complexities surrounding my participants' narratives.

Cheryl Mattingly powerfully argues that narrative carries important functions beyond providing a form of talk; “it also serves as an aesthetic and moral form underlying clinical action” (1998:2). She argues that healers and patients not only tell stories, but often create stories through their interactions. This effort at story-making, what Mattingly terms *therapeutic emplotment*, is “integral to the healing power of narrative” (1998:2). Therapeutic emplotment

offers one way to examine the social construction (and reconstruction) of illness and healing as a fluid, shifting process influenced not only by large structural conditions and cultural meanings but also by the exigencies of the concrete situation (1998:20).

The act of articulating one's story to another individual becomes therapeutic in the construction of a social relationship, in the formulation and reformulation of experience, and the opportunity to create alternative endings (Mattingly 1998). I have sought to co-construct narratives with my participants and analyze the results.

Arthur Frank makes a distinction between stories and narratives, emphasizing a story's inter-relational dynamic. Frank argues that people tell stories to help understand themselves, their social world and the extraordinary and ordinary of everyday life (2010:14). To do so, people draw upon narratives, which act as templates with culturally specific tropes and plotlines which are accessed as people formulate their stories. Frank further distinguishes between stories and narratives by

using medical historian Anne Harrington's definition of *stories* as "living, local, and specific," referring to "immediate, concrete events" (Frank 2010:24). *Narratives*, on the other hand, are the resources from which people construct the stories they tell and understand the stories they hear. These definitions create a macroscopic and microscopic level to the process of storytelling that emphasizes not only the frameworks individuals draw upon but also the relationships between teller and listener. The distinctions between story and narrative are important for recognizing the interplay between one's personal tale and the larger social context within which one is situated.

Anthropologists have long recognized that understanding the author's position is an important aspect in interpreting text. Lila Abu-Lughod, among others, has called attention to the importance of reflecting upon one's fieldwork process and social location within one's research community and community at large. She reflects upon how she represents others and which elements of her personal background and belief system influence who she spoke with, how they interacted and the type of relationship they had (1999: xvi). This reflexive process is critical to positioning the anthropologist and his or her research claims. For this reason, this chapter includes a reflection upon my relationships with my participants and the implications this may have for the stories they shared, as well as an explanation for my involvement in this project. Considering the consequences of my research methods is also an important dimension of my positionality during interviews. I have therefore included an outline of salient specifics of my Zimbabwean and American research sites as well as the technicalities of my data analysis. Finally, I will share the major tenets of my project and my reasons for focusing on these specific aspects of my participants' narratives.

## **The Story of the Stories**

This project grew from my desire to listen. When I first went to Zimbabwe in 2009 to volunteer with Nyeredzi Inopenya<sup>1</sup>, an organization that offers psychosocial support to HIV-positive youth, I was overwhelmed by my inexperience. It was humbling and frightening to listen to a six-year old child describe her parents' deaths and what she understood about HIV, a virus she had had since birth. I became entranced listening to youth share their stories at support group meetings, often held in unmarked buildings for fear of stigma. Throughout my time at Nyeredzi Inopenya, various people prodded me, some more intensely than others, to share my story, to tell my tale. What could I say to these youth, who had experienced so much hardship, suffering and trauma at a third of my age? I was humbled into listening, to learning how these youth with smiles on their faces recounted their trials. My guilt turned to frustration and anger as I realized the limited opportunities they had for open expression. Though they joined together once a month for activities and counseling with Nyeredzi Inopenya, they were largely isolated and closeted about their HIV status. Their double lives astonished me; in their ability to move seamlessly between stories, they resembled undercover agents.

As I listened to their narratives of shame and confusion, mixed with joy and relief, I began to listen intently. I began to hear the layers of negotiation between family, friends and strangers, between different conceptualizations of the self, and an active struggle with God, natural forces and biomedical intervention. I began to understand that the act of narration, from the very moment one is welcomed to share

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<sup>1</sup>Nyeredzi Inopenya is a pseudonym. In Shona, the native language of my Zimbabwean participants, it means a bright star. This appropriately reflects the aspirations of the youth and staff at the organization. The names of all participants, clinicians, staff members and organizations have been changed to protect the confidentiality of my participants.

a story to the close of the tale, is in and of itself a healing act. Joanne Trautman Banks reminds us that narrative is fundamental to our bodies, minds, communities and souls at organic, symbolic and social levels (2002:219). It offers a profound opportunity to engage with others, to assign and debate the meaning associated with life experiences, and to maneuver reality creatively (Brody 2003; Banks 2002; Charon and Montello 2002). Storytelling and listening engage both the teller and story recipient in an expressive and transformative process that informs who we are. A form of deep human contact, storytelling and listening offered me the opportunity to learn about myself as I learned about others.

Listening to stories from HIV-positive youth during the summer of 2009 struck me as an invaluable opportunity to widen the discourse around HIV beyond a biomedical lens. I quickly became determined to illustrate the many dimensions and complexities of an HIV illness experience. I wanted to complement the stories I heard in Zimbabwe with other stories, not to establish direct comparisons but to broaden my lens. I therefore spoke with HIV-positive individuals from a clinic in the American Northeast. The stories I heard from these men and women expanded my understanding of illness narratives. They illustrate that HIV may not even be mentioned when one is discussing the changes opportunistic infections have made to one's life. HIV is not necessarily a part of their every waking thought.

When I returned to Zimbabwe in 2010 with the support of the Mount Holyoke College McCulloch Center Global Studies Summer Fellowship, I wanted to create the therapeutic space for sharing stories that my American participants had so powerfully desired. The stories that inform this thesis are not merely the stories of my participants' experience living with HIV. They are stories of our relationship, the

product of a synthetic building of questions and answers, tangents and tales.

### **American Site Specifics**

Data for this project were collected through open-ended interviews and participant-observation at two sites. The first site is a heavily Hispanic, low-income clinic in the American Northeast that has a team of specialists dedicated to treating HIV-positive clients. I shadowed the team throughout January 2010 during their appointments with clients, was included in team meetings and met with the clinic director several times for informal discussions. These experiences provided me with working knowledge of the community, the needs of the clients and which of these the clinic works to meet. It also gave me an understanding of client-clinician interactions, how the clients view the practitioners and vice versa. Finally, I learned how both groups viewed healing, illness and the American medical system. The Mount Holyoke College IRB approved these interactions in December 2009.

I was introduced to clients in the United States after the medical professional I was shadowing, either a doctor or nurse practitioner, privately explained who I was and my research interest. The clients were also given either an English or Spanish written explanation of my background and my research goal. If they agreed, I was led into the room while the medical professional excused him or herself. I introduced myself and explained my interest in learning about their life story. As I am interested in how HIV impacts their entire life story, I explicitly did not say, "I want to learn about your experience with HIV," as this might have elicited a particular type of story, one that may have been narrower than their experience with HIV. I believe my purposeful phrasing of this inquiry strongly influenced client's willingness to meet

with me and the type of tale they shared. Issues of confidentiality and participation were clearly discussed before further arrangements were made. Due to the community's tumultuous experience with authorities such as immigrant officers and the police, I obtained verbal rather than written consent.

I met with four individuals for open-ended interviews outside of the clinic. This was done both because the clinic did not have a room we could use for any uninterrupted amount of time as well as to offer the participant a more comfortable environment. Three meetings were held in the participants' homes, with one taking place in a public library. Interviews occurred in two 1-3 hour sessions, all of which were recorded. Notes were taken with permission of the participant. Although I had a list of questions and topics I was interested in, I let the participants lead the conversations to more accurately understand the important aspects of their life.

### **Zimbabwean Site Specifics**

In Zimbabwe, I volunteered with Nyeredzi Inopenya, a non-governmental organization working with HIV-positive youth while living with a staff member for eight weeks during the summer of 2010. Their name, Shona for “a star that shines bright,” was created by some of the first youth members, who aspired to become bright stars even with their HIV-positive status. The commitment to positive living reflected in the name illustrates its centrality in Nyeredzi Inopenya's ideology.

I had volunteered with the organization for four weeks the summer before; many of the participants already knew me and were overjoyed at my return. In 2009, I had created a sewing project called Stitch Your Vision which used creativity to channel youths' fears and dreams into a denim square. In 2010, in addition to the

interviews, I expanded the project, conducting workshops with over 160 children and training a team to continue the program after I returned to the States. The manual I wrote to accompany the workshops has been incorporated into the organization's model for psychosocial support and was selected as "best practice" at the December 2010 Zimbabwean National AIDS Conference. I also taught machine sewing lessons, assisted with budget and program strategy and facilitated a business skills training program for out-of-school youth.

A few of the interviews I did were conducted in pairs or groups, with the majority conducted alone. There were two reasons for the multi-person interviews. Firstly, several individuals wished to speak with me, but felt more comfortable speaking with a friend present. This perhaps illustrates the degree to which stories may be communal or in the very least, gain certain dimensions from group collaboration. During the paired interviews, participants would trade stories back and forth and branch off into new directions based on each others' responses. Exploring the complexities of narrative as a group phenomenon both in its telling and listening would shed light on the interpersonal dimensions of therapeutic storytelling. It would also present a critique to Western academic assumptions about the individuality of narrative (Wikan 2000).

The second reason for group interviews was logistical. I conducted my interviews in Nyeredzi Inopenya's backyard, as the weather was pleasant and we could avoid the activity of the building. When youth would come up the walkway, they would see us in the yard and want to join. Often, they were intercepted by a staff member who would call from the window that we should not be distributed. When this did not happen, I would quickly ask the participant if he or she wanted to keep

talking if the other youth joined us. The response was usually yes; interviews continued as various youth popped in and out of the conversations. These group interviews certainly had an impact on the narratives; I can only guess about whether participants felt more or less comfortable sharing their stories in this way. What did become clear was that participating in the interviews became a kind of badge of honor and stories, particularly among the male youth, became noticeably exaggerated. I have therefore focused on the interviews that seem the least inflated and occurred before the news of the interviews widely spread. In a thesis that purports to let people tell their own stories, my exclusion of these seemingly exaggerated tales points to a flaw in my methodology.

While in Zimbabwe, I privileged certain stories over others, discarding the stories of several young male adolescents based on other stories I heard about them that stood in contrast to my interviews. I therefore naively concluded that the stories I heard in the interviews were false or at least inflated. This judgment illustrates my own biases in hearing and expecting certain types of stories.

By disregarding these males' stories, I have missed an analytic opportunity to reflect upon the role of oratory exaggeration in the construction of young masculinity. A staff member had applauded my decision not to speak with several youth she expected would "tell me tales; you'll never get the truth." I now realize the degree to which I held the stories I heard in my interviews to be the Truth in an unmitigated form rather than a truth, situationally and relationally constituted (Walley 1997). The truth of the story should have stood on its own; it was true in its construction of my participants' thoughts and emotions in the time and place in which they were shared. Furthermore, in disregarding certain tales, I have missed an opportunity to look at the



different manifestations of therapeutic narratives. If stories are therapeutic, then made-up or exaggerated stories may also serve a meaningful healing purpose. Returning to these tales would be an important area of reevaluation of how narratives perform healing.

In both sites I talked with individuals recommended by the staff; their notions of “who has a good story” certainly factored into which individuals they chose. Though I repeatedly told them I did not want a certain type of story, or a certain age of participant, I clearly did not even heed my own concerns. I therefore do not have a random group of HIV-positive individuals, but a hand-picked group of participants viewed as “interesting” in the staff’s opinion.

This “hand-picking” may have been informed by favored constructions and expressions of self. Carl Elliott (2003), in discussing America’s relationship to pharmaceuticals for “diseases of the self” like anxiety disorders, shyness and depression, points out an American cultural construction and admiration of outgoing, bold and adventurous selves. Elliott’s inquiry into the types of selves Americans encourage themselves and others to have, implicates the selection of participants by Nyeredzi Inopenya and the American clinic, as well as my choice of stories to include in this thesis, as anything but neutral. I now realize that I had decided in advance which types of stories I thought were true, important and legitimate. Such a selection process is strongly derived from cultural norms and expectations of self expression (Elliott 2003). For example, the tales I and Nyeredzi Inopenya classified as exaggerated were not narratives we wanted to endorse. This begs the question, what kind of self am I endorsing or creating in this thesis? How is this reflective of my social location and assumptions? How might looking past these cultural tendencies be

meaningful ethnographically? Answering these questions is part of situating myself within the context of my project and its parameters as cultural phenomenon.

### **Who am I to Whom?**

I play a much larger role in these narratives than I first understood. In approaching narratives as an active and dynamic construction, my social and cultural positionings form a crucial dimension of my interviews. I am not just attached to the microphone or frantically jotting pen. The stories I heard are in certain respects contingent on me, as a particular individual, asking the questions at the time and place I asked them. These stories are therefore not unmediated, raw tales of life experience, but mutually shared and constructed narratives.

The details of my person, education, ethnicity, and nationality were not lost on my participants. Some of my participants made this explicit, describing the various stories they would have told me had I been someone else or had we met another way. From what I gathered from their implied meaning and discussions with staff both in Zimbabwe and the United States, this mainly concerned my kind heart, my willingness to listen and the fact that I am white. The existence of these different stories and the activity between teller and listener challenges the notion of narratives as concrete entities. Stories must therefore be situated not only in their social, political, religious and historical contexts but also in the storytelling situation.

My relationship with my American participants was heavily influenced by their conceptualization of the clinic and their unwavering love of the staff. Although I tried to separate myself physically (by not wearing a lab coat and holding interviews outside of the clinic) and mentally (by describing myself as a college student), I was

solidly positioned by participants as an extension of the clinic. This was illustrated by verbally connecting me with clinic actions and staff attitudes about health, particularly adherence to medication. I was initially nervous about this connection but soon realized its benefits. The willingness of participants to meet with me, a complete stranger, to discuss personal matters, was facilitated by their trust and confidence in their clinicians.

It was clear to me that participants had a special relationship with clinicians. Clinic staff were dedicated to caring for the entire client, not simply their biomedical symptoms. This commitment to comprehensive healing undoubtedly influenced the clinic's decision to advertise my project. In fact, when I first met with the clinical team, they agreed that my interviews would have therapeutic value and expressed relief that I would be absorbing this responsibility. These sentiments manifested themselves during my interviews when participants mentioned that their primary reason for agreeing to speak with me was their clinician's suggestion that it would be a good chance for them to share thoughts they don't always have time to cover in the appointment slots. The clinicians also made known their frustration with the current billing situation and seemingly unfettered rule of insurance companies in the American medical system, both of which constrain their ability to provide holistic care and offer important services such as home visits.

The responsibility I was given to provide talking “therapy<sup>2</sup>” to my American participants made me uncomfortable and had important implications for my research.

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<sup>2</sup>I should distinguish between the “therapy” the clinicians were referring to by giving participants a safe place to talk about troubling experiences, and Danforth's therapeutic language associated with religious interpretive frameworks. Though both uses of the word highlight narrative's transformative and healing qualities, Danforth's terminology is perhaps more theoretical than the clinicians implied. I often sensed the clinicians' relief that I would be absorbing their patients' burdens, if only temporarily.

Participants may have shared particular stories in hopes of getting advice, comfort and support from me that they may have not otherwise told if they approached the interview solely to share information. My role in facilitating self-reflection and self-negotiation was perhaps stronger than would have otherwise been the case. Further, had participants not held the clinicians in such high esteem, their stories may have remained superficial. In fact, participants often referred to clinicians as “family,” and shared that they agreed to speak with me to impress their doctors; they “didn’t want to let the team down.” Acknowledging the high level of trust and respect that was translated onto me through my association with the clinic, I reminded participants about the voluntary nature of our interviews and that they should never feel pressured to share anything with me. However, I think this largely went unheard; at times I felt a line had been crossed between my interview and a counseling session. On those occasions, I told them to share these stories with their clinicians or to seek the additional help of therapists or hotlines. I brought details of these resources to our follow-up interviews. I have often contemplated the type of stories I would have heard had I met these individuals another way; undoubtedly our relationship would have been more cordial and the interviews shorter.

In Zimbabwe, I was perceived as a young white female American who had returned out of the goodness of her heart to continue a sewing project and further help the organization. I was held in high esteem for my dedication to Nyeredzi Inopenya by both youth and staff. In actuality, I felt more like a staff member than a researcher. I played an important role in staff meetings, assisted with strategic planning and budgeting and helped lead support group meetings.

I had close relationships with several of my participants. We spent time

together chatting and playing games in addition to the interviews. My energy and dedication to helping the organization was known throughout the community and there was always great excitement when I traveled to different sections of town. Some of this excitement was acknowledged to be due to the honor of having a white friend visit. In fact, this was often the source of some tension as youth competed for my time; the length of my interviews did not go unnoticed. I lived with a friend and organization staff member and her family throughout my stay. My Shona skills, particularly my writing abilities, were a great source of pride for myself and everyone associated with me. In new situations, individuals usually made a point to show me off to their friends. I accompanied my friend to church, on family visits, and daily errands, which gave me a fuller perspective of Zimbabwean life. I also spent hours talking with my friend's parents about life during Independence to gain a more complete sense of Zimbabwean past and present history.

Despite my efforts to blend in with my language skills, habits, and patterns of dress, my whiteness was always foremost in people's minds. One participant remarked that he felt uncomfortable sharing the details of his suffering with a white person; "it wasn't decent and maybe I'll get in trouble somehow." The remnants of colonialism remain strong among adults and youth; the notion that it was not proper to discuss the reality of life in Zimbabwe with a white individual seemed largely rooted in a fear that one should not share the result of the damage whites inflicted upon black Zimbabweans. I found that when I asked for clarifying details or more description about certain components of an individual's story, they would quickly summarize "it was just how things were," without offering more.

Though my white skin seemed to limit certain types of conversations, my nationality distinguished me from white Zimbabweans. Especially as an American

during Barack Obama's presidency, I was separated from the former colonizers and even invited to partake in jokes about white Zimbabweans. More often, however, I was placed in a liminal state. The white privilege I held was at times glaringly obvious and quite uncomfortable; though I was barely older than the youth I interviewed and a volunteer, I was often looked to for major decisions on grant-writing or activity planning. This higher status was immediately countered by my position as a “little niece” in Shona family hierarchy; because I spoke Shona and was living and working with Shonas, I had been placed into the kinship system without knowing the rules. This led to inevitable faux pas as I unknowingly overstepped boundaries or greeted people incorrectly. Usually my mistakes were met with nothing more serious than laughter.

Finally, returning to Nyeredzi Inopenya for a second time demonstrated to the staff and youth that I was committed to helping them, that I was “not just another flimsy white.”<sup>3</sup> This earned me their trust and support as I stumbled through culturally new situations. I heard stories and components of stories I would not have heard had I not demonstrated my commitment to the organization. That said, sharing stories on such personal and difficult topics as the death of relatives, stigma, growing up ill and a fear of dying, requires a level of trust I only just started to demonstrate. The counselors at the organization shared that the stories they first hear from youth are often complete fabrications, and that the truth unfolds or is discovered as their relationship builds. Such insight illustrates the importance of social relationships to the storytelling event.

In Zimbabwe I was told stories as a white, American young woman returning

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<sup>3</sup>Though I cannot be sure which “flimsy whites” my participants are referring to, they often mentioned various aid programs, which collapsed when the organizers, almost exclusively white Americans or British, returned home.

to help Nyeredzi Inopenya, a volunteer who was eager to learn Shona and a fellow youth determined to alleviate HIV/AIDS stigma. In the American Northeast, I heard stories as an extension of trusted clinic staff, as a college student ready to learn from and respect people who felt they had been cast away.

The stories I tell, through my selection and thus validation, of specific vignettes, also reflect my cultural assumptions and social location as a young woman, a conservative Jew and an American. I have capitalized God, Being and Earth, indicating the value I assign to these metaphysical entities. I seem to have favored, or at least have been more comfortable, with stories that have a beginning, middle and end. I also operate within a Western biomedical paradigm; I have tacitly singled out biomedical approaches from illness narratives rather than considering them as only one type of illness experience. Finally, I view narrative as therapeutic. Interrogating “talk therapy” as an object of cultural analysis would strengthen my thesis by placing ethnographic distance between my social location and the stories I analyze.

### **Recognizing Stories as truth not Truth**

As I seek to understand these stories, I have considered the context within which they exist as well as the interpretative nature of storytelling and listening. Christine Walley (1997) accurately describes the theoretical value of narrative in anthropology. She illustrates through a discussion of the fieldwork she did on clitoridectomy in 1988 among the Kikhome in western Kenya that the stories anthropologists, or anyone, hear are a result of a specific relationship between teller and listener. Furthermore, they are contingent upon the social context of the narrative account, public and cultural opinions about the topic being discussed (such as female

genital operations) and the social position of the individual sharing the story.

Walley problematizes her desire and the desire of dominant anthropological discourse to search for “authentic” voices. Her critical analysis of the importance anthropologists, journalists and activists often place on the “real” thoughts or stories calls attention to the predicament of locating the Truth in any one story, individual or tale. As I have also realized in my ethnographic research, her informants' voices shifted according to context. A search for the “real” story thus points out the naïveté of doing so: how does one locate or define the “authentic” self? What is an “authentic” self anyway (Walley 1997)? Acknowledging the complex dimensions of this type of quest, however futile, and the ways it may shape the narrative exchange is critical for recognizing the interpretative elements in storytelling. Just as Walley heard shifting and at times contradictory tales, the stories I heard during this project are not unmediated life narratives but constructed responses to my interview questions, my assumptions of my participants and their assumptions of me. My construction of the interview experience and my relationship to the participants as well as to the organizations through which I met them elicited particular stories. Recognizing these stories as situationally and relationally constituted is not to question the truth or candor of the tales. Rather, it is proof that stories are actively constructed within an encounter as true events, while not necessarily being the Truth.

Hearing different accounts and more fleshed out versions of tales I heard during my interviews, suggests that I heard only one version of a story with many layers. For example, one participant talked about his nursing course, describing in detail what he was studying and how his examinations were proceeding. He described an enormous sense of pride about having an opportunity to give back to his



community and “to make up for lost time.” This individual spent two years in denial about his HIV status before beginning to absorb the positive-living messages he was receiving at his clinic. Becoming a nurse and talking about HIV in a positive light with his patients is his way to “repay society for the time [he] spent in denial.”

When I asked a staff person about the nursing program this person was doing, she shockingly replied that he was not in any type of school, let alone nursing. She described how he had been “dreaming of being a nurse. But when the chance comes, he fizzles out. He has been lying to everyone about being a nurse.” When I learned this, I was offended that the participant would lie to me and quickly circled the area in my notes as a place to edit out. I now realize that by simply discrediting this individual's story, I validated the staff member's story over the participant. I did not consider why the discrepancy in the two stories might exist or the importance of telling a story about failed dreams as embodied reality. Finally, this participant's self-described denial is still a stance vis-à-vis HIV and worthy of analysis. Like his fictional nurse identity, “denial” may not be a form of blindness, but a deliberate statement. It is, in other words, itself a story important of examination.

The stories I share in my thesis are therefore not stories *as they are*. They were constructed during a specific dialectic encounter, interpreted by a specific me. My interpretation is everything and it shapes my thesis. The conclusions I draw are therefore accurate as true conclusions to situated and contextualized events.

### **Technicalities**

I used a mapping and coding strategy to analysis my interviews. After filling in the notes taken during interviews, I created “Topics by Page” in which I put a

different topic as the heading for each page, recording what participants thought about that topic. I also performed a domain analysis, placing each participant's name in the center of a large piece of paper, with major themes from the interviews in bubbles around the name. The key word categories and domain analysis were combined for thematic analysis within and across interviews. My methods were largely dictated by a lack of electricity in Zimbabwe, though I do not see my approach as a disadvantage to synthesizing what is important to each person's narrative. On the contrary, the physical layout of the maps and pages helped me to envision the often complicated "road map" of each participant's life story.

I transcribed the Zimbabwean interviews, large pieces of which I personally conducted in Shona, the major native language. Although I am proficient in Shona, the delicacies of word choice and many layers of symbolism may have been lost on me. I took this risk in favor of connecting with participants on a more comfortable plane than English would have provided. My American interviews were conducted entirely in English; two participants spoke English as a second language to Spanish.

The interviews, which total four from the United States and ten from Zimbabwe are the foundation of my thesis. I have dispersed different pieces of our interviews throughout the thesis. In total, I share stories of James, Maria, Cathy, and Robert, Sammy, Grace, Denzel, Thembiso, Jack, Thomas, and Prince<sup>4</sup>. Due to the sensitivity surrounding our conversations and the stigma associated with HIV, I have used pseudonyms for all my participants. I have also generalized my research sites to prevent tracking participants.

Three of my four American participants wanted to share their name and

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<sup>4</sup>I have only included seven Zimbabwean participants for reasons of space. The three individuals I don't explicitly include have tales largely resonant with those I share.

pushed me to ignore my confidentiality agreement. They wanted to demonstrate to the world that they are not closeted about their HIV status and that it does not bring them shame. They would like to challenge the world to meet their confidence. I have with difficulty opted to disregard their wishes so as to protect the identities of my other participants. I do not know the extent to which they are connected and do not want to disclose information through indirect association. Participants in Zimbabwe had a much more acute fear of identification; they were all very adamant that I store my notes in secure places both in Zimbabwe and the United States so as to protect their identity. These two different reactions reveal much about the social response to HIV in their communities and my participants' personal experience with community reactions.

### **Conclusion**

I have picked several main themes through which to illustrate the major dimensions of my participants' tales and my interpretations of them: experiences with and conceptualizations of stigma, community, and religion. As participants talked about experiences of loss, sickness and joy, they narrated a changing construction and perception of selfhood. They also described a fluctuating relationship between their sense of self and their HIV status. These topics are contextualized within a multidimensional perspective of the global HIV/AIDS epidemic as well as within a discussion of narrative construction and the value of storytelling. I also discuss participants' negotiation between different systems of beliefs and their understanding of time and the future.

I have chosen to focus on fourteen in-depth interviews rather than a larger

cohort based on survey data to look beyond the surface of my participants' stories. Anthropology has long honored the tension between universalizing and particularizing; I pick up this thread by illustrating the complex movement between individuals and their social contexts. Humans are particular beings and though it is important to generalize and make groups based on commonalities, much can be learned by studying the particular.

The literature I have read provides an opportunity for triangulation between my analysis and my participants' stories. In the following chapters, I engage with published research accounts on HIV illness narratives, literature on illness narratives more broadly, ways of conceptualizing the self, models for understanding experience and the way these narratives fit into the medical paradigm in which participants are being treated for HIV.

My goal is to demonstrate the complexities inherent in life narratives, particularly those that include a life-threatening diagnosis. By focusing on issues surrounding the moral, the social, the existential and the everyday, I present one way of learning how HIV-positive individuals make sense of their illness experience and its relationship to other areas of their lives. Such considerations are critical to effective and meaningful care, treatment and healing of HIV and other chronic diseases. Engaging with challenging topics through an anthropological and narrative approach may enrich and deepen the way healthcare providers, government officials, citizens and activists can understand and respond to people living with HIV.

**CHAPTER 2**

**HIV AND AIDS: A MULTIDIMENSIONAL INTRODUCTION**

## **Introduction**

HIV and AIDS are a virus and syndrome respectively, which occur within and on the body. However, HIV and AIDS are not confined to one's physical dimensions. This chapter provides a basic yet thorough multidimensional background of the HIV and AIDS epidemic across the globe, and most specifically in Zimbabwe and the United States. As to be expected of an epidemic that complicates and intertwines social and moral meanings, biomedical and other ways of healing, and economic and political systems, the literature on HIV is diverse and expansive. I have contextualized my thesis and the perspectives of my participants among multiple interpretations of the epidemic.

Anthropology is uniquely situated to integrate and identify “contextual factors that predispose individuals and communities to HIV” (American Anthropological Association 1997). Among the many anthropologists who have written about the HIV epidemic, Ida Susser, Patrician Whelehan, and Paul Farmer stand out as influential players. They have situated the symptoms and infections men, women and children must face alongside their social, economic, political and religious choices and decisions (Farmer 1992; Susser 2008; Whelehan 2009). More importantly, they are part of a movement of social scientists who recognize that HIV must be tackled as a social phenomenon. In the early to mid 1990s, as the epidemic passed from one community to another, social scientists pushed to move popular dialogue around HIV/AIDS away from strictly biological and moral terms to paradigms which acknowledged the importance of an individual's social and economic environment. Anthropologists, sociologists, medical historians and activists pointed to the intimate relationships between contracting HIV and social stressors such as poverty, gender power imbalances, ethnicity, and low educational attainment (Faubion 2009). A more

nuanced and informed understanding of how and why such stressors impact people living with HIV/AIDS began emerging and influencing popular discourse. Paul Farmer and other early writers were particularly influential in pushing against biomedical research's vertical emphasis on disease transmission, pre-existing medical conditions and drug treatments (Farmer 1992; Faubion 2009).

In his earliest work on the epidemic Paul Farmer focuses on the impact of social, economic, and political structures on the transmission, treatment, prevention and discourse around the global HIV epidemic (1992). Drawing on his experience treating HIV-positive individuals in Haiti (and in later books, in Russia), Farmer links the events and structures of the world AIDS pandemic to the lived experience of people with AIDS and their caretakers. He argues for critical medical anthropology as a holistic, integrated and multidisciplinary approach towards addressing the HIV/AIDS epidemic. This discourse has influenced my project and my focus on the larger environment in which my participants' exist and function.

Critical medical anthropology (CMA) shifts analysis from the realm of the individual to that of the group, addressing the infrastructure of societies and the effects of culture change on traditional beliefs and practices (Farmer 1992; Whelehan 2009). Most importantly, CMA positions socioeconomic and political factors as key determinants of health and healthcare. Whelehan juxtaposes statistics, charts, and scientific explanations of the epidemic with discussions of the social, political and economic landscapes of HIV infection to illustrate the importance of a multidisciplinary approach to the HIV/AIDS epidemic. As the discourse around HIV continues to be dominated by biological and individualistic terms, it remains important to follow the cue of social scientists in drawing the lens wider to include national and global social, economic and political structures.

Ida Susser continues within the same frameworks of Farmer and Whelehan to contextualize the HIV/AIDS epidemic along gender lines. She also calls attention to globalization and structural violence as key contributors to the demographics of HIV/AIDS. Using ethnographic data collected in the late 1990s through the early 2000s from across Southern Africa, Susser examines the varied ways in which neoliberalism facilitates, fosters and exploits particular ideologies of gendered subordination, and in the process increases HIV transmission. Her emphasis on the local echoing the global has helped me think about the ways in which my participants' stories are both products of their local environments as well as large-scale political and economic policies and social norms (2008:217). Most specifically, she connects the local activities of health activists and the social movements around AIDS in Southern Africa with a wider battle for local, national and global democracy. How then should my participants' narratives be understood and positioned within these global movements?

Farmer, Whelehan and Susser echo Didier Fassin's concern with bodies and memory in the context of the South African HIV epidemic. Fassin identifies contextual factors that predispose individuals and communities to HIV (Fassin 2007). His work illustrates the importance of considering past, present and future ways of knowing and socially interacting and their relationship to the HIV/AIDS epidemic. In thinking about my participants' navigation between different periods within their life and the social contexts in which these periods are situated, Fassin's emphasis on synthetic storytelling informed my narrative analysis.

Using an ethnographic, culture-specific and culture-sensitive approach, these anthropologists are able to illustrate the commonalities and differences between a variety of individual and community responses to HIV (Whelehan 2009:8). Their



approaches are complemented by the work of epidemiologists, virologists, geographers, historians and economists using a multiplicity of discourses to understand the global HIV epidemic (see CDC 2006; Engel 2006; Pope, White and Malow 2009). Together they challenge dominant Western biomedical disease ideologies to look beyond the body for comprehensive understanding of the HIV epidemic.

I have included a few statistics to provide perspective on the scope and breadth of the epidemic. Yet statistics lack depth. For that I look beyond the numbers to the complex, multifaceted and at times contradictory narratives of my participants. Their lives with HIV can never be summarized with a statistic, a neat medical chart or a set of risk variables. The tragedy, complications and at times, unexpected joy, HIV has brought is shared through their rich stories. Embracing the complexity in these narratives is important to effective HIV-related support and intervention. HIV support programs must integrate several paradigms. The key to understanding the HIV epidemic and those it infects and affects lies not solely in the black and white of blood test results and medical procedures, but in the relationships individuals have between their experience with HIV and the other dimensions of their lives.

### **An American Beginning**

1981 is generally referred to as the beginning of the HIV/AIDS epidemic in the United States. On June 5<sup>th</sup>, 1981, the Centers of Disease Control and Prevention issued its first warning about a relatively rare form of pneumonia, *Pneumonia carinii*, which had appeared among a small group of young gay men in Los Angeles, California (Engel 2006). This troubling form of pneumonia was later determined to be AIDS-related. As a result of these first cases, gay men were thought to be the

major source and cause of infection. As more information about AIDS, Acquired Immune Deficiency Syndrome, became available throughout the remainder of the decade, other marginalized communities such as intravenous drug users, were added to the list of “high-risk” groups. A catchy term “4-H” quickly became popular both in the media and medical communities for identifying those at risk: homosexuals, heroin (implying intravenous drug users), Haitians, and hemophiliacs. One will notice that 4-H does not explicitly include heterosexual women and men (Engel 2006). Stigma and discrimination often accompanied ill health as the public quickly couched the disease in terms of morality and “otherness.” The 1980s saw fear coupled with increasing data on the AIDS epidemic and the United States and abroad, creating unease in the capabilities of modern medicine and perpetual nervousness in the hearts of clinicians, patients and citizens.

In 1984, the virus that cause AIDS, Human Immunodeficiency Virus or HIV, was identified by Luc Montagnier in France and Robert Gallo of the National Cancer Institute in the United States. It became apparent that there were two main strains of the virus: HIV-1 seemed most prevalent in the United States while HIV-2 dominated Africa and South America. Identifying the cause of AIDS allowed clinicians to solidify modes of transmission: sexual intercourse, mother-to-child transmission, intravenous drug use, blood transfusions and all other activities which could expose individuals to infected blood or bodily secretions.

From the beginning, AIDS was a class, gender, racial and political issue. Although these categories have the ability to infect everyone, and although it was medically evident that HIV knew no borders, HIV and AIDS had been engrained in the American public and to much of the world as a gay and foreign disease. Victims were constructed as morally problematic others, occupying the recesses and discarded

spaces of society. The public's reaction to HIV and AIDS seemed to capitalize on the shame surrounding the socially marginalized groups AIDS seemed to disproportionately affect, directly and indirectly causing those at risk or already sick to delay seeking help (Engel 2006; Farmer 1992).

President Ronald Reagan first mentioned the word AIDS in public in 1986; not until April 1, 1987 did he deliver his first speech addressing the epidemic. In the interim, the first antiretroviral drug, Zidovudine or AZT, was approved for dissemination. Though not without its complications or side effects, AZT offered the first real hope of treating the AIDS epidemic. However, few could afford the costs of medication and need far outweighed availability. Citizens groups like the AIDS Coalition to Unleash Power (ACT UP) and the National Task Force on AIDS Prevention were formed and became vocal in the fight to get drugs approved faster and at lower costs to patients.

ACT UP and other activist groups represented a turn in national rhetoric about HIV. In an effort to counter the victimization, blaming and silence surrounding HIV, a grassroots People with AIDS Self-Empowerment Movement was founded in the early 1980s (Callahan and Turner 1997). Based in San Francisco and New York, the movement began with the belief that those diagnosed with AIDS should "take charge of their own life, illness, and care, and minimize dependence on others" (Callahan and Turner 1997). Deliberately avoiding "patient" or "victim," the movement settled on People with AIDS (PWA), seeking to restore agency to HIV-positive individuals and their caregivers. Though few medical remedies existed in the early and mid 1980s, the focus on "positive living" and "living positive" sought to illustrate the vitality of HIV-positive individuals: a diagnosis with HIV

or AIDS did not mean the end. ACT UP and other groups organized prevention campaigns, safe sex workshops and tried to create support for needle exchange programs. The movement and its rhetoric spread throughout the country and the world as more people began organizing around HIV/AIDS; Nyeredzi Inopenya, for example, was founded to educate, counsel and inspire youth to “live positively” with their HIV status.

Although federal funding for research grew throughout the 1990s, many involved in the fight against AIDS argued that more effort should be focused on massive educational campaigns to stop the spread of the virus. They also protested that if AIDS was affecting white, heterosexual, middle class men, the country would be a flurry of activity to save every life. This politicized tone influences the stories of a few of my participants who were and are involved in campaigning for the rights of HIV-positive individuals.

Throughout the late 1980s and early 1990s, HIV in America seemed to pass first from gay urban men, to intravenous male drug users to their male and female partners and then into the predominantly urban poor, and heterosexual black and Hispanic communities. As it made its way throughout the country and the globe, different theories popped up to explain why predominantly marginalized communities seemed disproportionately infected with HIV. Theories ranged from Tuskegee-like scenarios of tainted vaccines to deliberate government genocide, to “white man's last job” on the African continent (Engel 2006; Farmer 1992; Fassin 2007). These theories waned and waxed, their presence reflecting how socially constructed and morally imbued the epidemic was and continues to be.

By 1988, more than 66,000 Americans had died from AIDS and as many as 1

million were estimated to be unknowingly infected (Kaiser Family Foundation 2007). Incidents of children being forcibly removed from school because of their HIV status, family homes burning down, and public taunting peppered the newspapers. However, it wasn't until the 1988 Fair Housing Amendments Act that federal law protected people living with HIV and AIDS under the discrimination clause. This housing act has been a critical resource for Maria, a Hispanic participant living in federally subsidized housing with her husband and teenage daughter. As she struggled with drug addiction and HIV-related depression, the government support she received was and continues to be, a lifeline; she cites it as supporting evidence for how HIV may be a blessing in disguise.

Maria was diagnosed with HIV in 1993, though she believes she could have been infected as early as 1988. By the early 1990s, the epidemic began to shift from young, white middle-class male homosexuals to lower-class black and Hispanic women and their regular sex partners, most of whom were IV drug users (Center for Disease Control 2008). Although blacks and Hispanics together represented only 19% of all Americans, by 1990 they represented 38% of AIDS cases. Of those that reported being infected through drug-related activities, a full 80% were black and Hispanic. HIV-positive women and children were and still are, overwhelming black and Hispanic: nearly 70% of HIV-positive women and 80% of children are black and Hispanic (CDC 2008, Engel 2006). As HIV once again shifted to a marginalized population, the disconnect between those with funding and support and those continuing to get infected stressed social divisions. As several of my participants describe, even among those infected or supporting HIV-positive individuals, not everyone was given the same worth, respect or care (Farmer 1992; Fassin 2007).

Throughout the early 1990s, skepticism grew across mainstream America that

HIV would reach the epic scale once imagined by medical communities and the media. Disillusionment and disinterest on the part of the public and “AIDS burnout” from those that had been actively involved, led to a growing complacency and a slackening of safe sexual practices. At the same time, HIV continued to spread at epidemic proportions among blacks and Hispanics, particularly women and the children they birthed. HIV was also alarmingly spreading throughout Africa in segments of the population it did not seem to reach in the United States—elite, upper class professionals, as well as into South America, Asia and Europe. Though political and moral fights over clean needle exchange programs, and who should pay the overwhelming cost of AIDS-related care continued intensely, the general American public began to relax that the epidemic had left them unscathed.

### **The Focus Shifts Abroad**

The 1990s saw a shift in global dialogue about HIV and AIDS as new drugs were discovered and discussions of national responsibilities for treatment and prevention programs intensified. The 1996 discovery of the “cocktail,” a combination of protease inhibitors that reduced HIV viral loads in the bloodstream, allowed HIV-positive individuals, and their caregivers as well as government officials around the world to begin conceptualizing HIV in terms of chronic disease and the growing challenges this would place on medical facilities. Though dilemmas such as convincing pharmaceutical companies to focus on a line of ARVs with little expected profit continued into the 1990s and 2000s, America and the Global North's attention shifted to Africa, the continent viewed as the “hotbed” and “true origin” of HIV (Engel 2006:211; Farmer 1992; Fassin 2007; Whelehan 2009). Not unlike the United States, African governmental and public denial, delayed many countries' response to

the epidemic. Recently liberated countries feared admitting to yet another problem that could soil their reputations and negatively impact trade and tourism. Though the response varied across the continent, several governments, spurned by zealous church leaders and nationals convinced HIV was a white problem, dragged their feet on education and prevention campaigns. Some, most notably South Africa and Zimbabwe, outright denied the existence of HIV and its relationship to the AIDS epidemic (Engel 2006; Fassin 2007). The actions of Thabo Mbeki in South Africa and Robert Mugabe in Zimbabwe stand in stark contrast to governments in west Africa who candidly and aggressively confronted HIV and AIDS, helping to dramatically lower the scale of the epidemic within their borders.

Much like the United States, the epidemic in South Africa was quickly wrapped in sociocultural and political terms (Engel 2006; Susser 2009). In the final years of apartheid, AIDS rhetoric was involved in the critique of the apartheid government. However, in the newly formed democracy, President Nelson Mandela rarely mentioned AIDS in his speeches. In the late 1990s, at a time when political decisions around the economy were being molded to fit the global capitalist scene, South African government rhetoric around AIDS took explicitly anti-West, anti-capitalist and anti-colonial tones. In early 2000, newly elected President Thabo Mbeki began promoting the scientifically marginalized opinions of AIDS denialists, comparing their marginalization to the ANC revolutionaries who had fought apartheid (Susser 2009:97). Denying a link between HIV and AIDS, Mbeki attributed AIDS to poverty, insisting that there were African solutions to the disease. Prohibiting the distribution of critical ARVs such as HAART treatment and Nevirapine to pregnant women and newborns, he insisted on remedies such as garlic and the African potato (Fassier 2007; Susser 2009). President Robert Mugabe of Zimbabwe emulated many

of Mbeki's decisions and rhetoric around HIV and AIDS, many of which were situated within a “nationalist” or “traditionalist” and patriarchal perspective (Susser 2009:98).

### **HIV and AIDS in Zimbabwe**

Zimbabwe is experiencing one of the harshest AIDS epidemics in the world. Though the current data represents a decrease from a decade ago, around one in ten people are estimated to be living with HIV (AVERT 2010). The tense political and social climate has made it increasingly difficult to respond adequately to the epidemic, which AVERT, an international AIDS charity, estimates has claimed more than 83,000 lives and left one million children orphaned (AVERTing HIV and AIDS 2010). Zimbabwe has the highest number of orphans in proportion to its population and among the lowest life expectancies in the continent, 46 years, as a result of HIV (UNICEF 2010). President Robert Mugabe, who has held the role since Zimbabwe gained independence from Britain in 1980, has been widely criticized by the international community for his lack of response to the epidemic as well as other medical and social ills facing his country (Chinaka 2008). As a result, Zimbabwe has become increasingly politically and economically isolated, which forces citizens to face severe health, economic and political crises alone and without substantial assistance.

The first AIDS case in Zimbabwe was reported in 1985. Many government officials and healthcare personnel dismissed symptoms of HIV and AIDS as the regular course of ailments associated with malnutrition and poverty (Thomas July 2 2010: personal communication). In fact, youth and staff members at Nyeredzi Inopenya describe much of the resistance to HIV education and prevention



campaigns as stemming from the government and the Ministry of Health. Although the National AIDS Coordination Programme (NACP) was set up in 1987, it was not until 1999 that Zimbabwe's first HIV and AIDS policy was announced. At this time, an AIDS levy was introduced on all taxpayers to support the newly formed National AIDS Council (NAC). However, with a rapidly diminishing tax base, little commanding authority, poor organization and financial support, all regulating bodies and legislation from the policy have remained meager at best. Coordination between different government agencies, non-governmental organizations, religious groups and healthcare facilities is poor and disorganized, leading to massive fund misuse and inadequate service delivery. That said, many non-governmental and religious organizations have self-coordinated without the government and been able to offer support and services to some of the more than 1.2 million people estimated living with HIV (AVERT 2010).

At the end of the 1980s more than 10% of the adult population in Zimbabwe was reported to be HIV-positive. This figure more than doubled over the next decade, reaching its highest in 1997 at 26.5 percent (AVERT 2010). The epidemic in Zimbabwe, unlike the initial stages of the American epidemic, is not confined to a single segment of the population. The virus is classified as HIV-2, and unlike HIV-1, which dominated the American epidemic in the early 1980s, is spread more easily with a shorter time between initial infection and illness. Many Zimbabweans are also co-infected with tuberculosis, and other viral, bacterial, and sexually transmitted infections, hindering their immune system's ability to respond strongly to HIV and making them more susceptible to serious opportunistic infections.

The government's response to HIV and AIDS has been heavily compromised by numerous economic and social crises that have dominated political attention.

Human rights abuses and media repression, along with tumultuous land reforms and Operation Murambatsvina, have contributed to the continuing chaos in the country. President Mugabe's land redistribution campaign, which began with Parliament motions in 1979, spun out of control in 2000 as pro-Mugabe teams marched violently onto white farms to drive all residents out, slashing productivity and leading to economic disaster (AVERT 2010). Operation Murambatsvina, initiated in May 2005 and represented by the government as an “urban beautification” program for the capital Harare, destroyed thousands of homes, businesses and healthcare facilities and left over 700,000 people homeless. These two politically motivated movements increased poverty and reduced access to education and healthcare. They also increased mobility, separated families and widened sexual networks, all important factors in spreading HIV (AVERT 2010).

In the last ten years, historic economic inflation has forced the government to “dollarize;” the American dollar replaced Zimbabwean currency in January 2009 after the annual inflation rate soared above 89.7 sextillion ( $10^{21}$ ) percent and businesses, schools and hospitals collapsed (NY Times 2009; Hanke 2009). Serious outbreaks of cholera, shortages of electricity, food and basic supplies, and unemployment of over 80% have all contributed to social tension. The political violence and human rights violations surrounding the disputed presidential election in March 2008 between incumbent Robert Mugabe of the Zimbabwe African National Union-Patriotic Front (ZANU-PF) and challenger Morgan Tsvangirai of the Movement for Democratic Change (MDC) created a culture of fear and silence throughout the country. Police brutality and “midnight missing” stories have become normalized, particularly in rural areas (The Zimbabwe Situation 2009). The fear of being reported when talking about even the most benign topics has seriously impacted organizations' efforts to

create a supportive environment for discussing HIV. Aligning all non-governmental organizations and most educational facilities with Tsvangirai's opposition party during the 2008 election, the ruling party's ban on NGOs seriously curtailed efforts to treat and prevent the widespread HIV epidemic. Nyeredzi Inopenya has courageously remained open throughout the political mayhem, though there are parts of the country they do not travel to for fear of political and physical repercussions. The danger associated with Nyeredzi Inopenya participation becomes important in several of my participants' conceptualizations of themselves and their friends; each activity they successfully attend becomes a badge of honor.

Medical facilities have also been adversely affected by the political disruption of the last decade and most particularly, the last five years. Doctors have joined teachers and other government employees in semi-regular striking since 2007. The prolonged disputes after the 2008 election have meant that most government employees have gone unpaid for months at a time; when they are paid, the salary barely covers monthly transportation costs (IRIN 2008). Those that can afford to come to work struggle to treat patients with the few remaining medical supplies. Limited access to medical professionals and medications has meant that most HIV-positive Zimbabweans are living without treatment.

As a sexually transmitted infection, HIV has most severely affected the economically productive bands of society. AVERT estimates 14.3% of adults 15-49 are HIV positive while UNICEF puts that number at 15.3% (UNICEF 2007; AVERT 2010). Second to young adults and those in their thirties, HIV has infected over a million children through mother-to-child transmission, a mode the United States and other developed countries have largely eliminated with effective screening and diligent follow-up and drug treatments for pregnant women. Without functioning

medical facilities, over 150,000 Zimbabwean children are now living with HIV. This leaves a young and infected population in the care of grandparents. Many of these grandparents have watched their children and other grandchildren die from HIV with little relief for their physical and emotional suffering. Nyeredzi Inopenya joins other organizations in expressing concern about the burden of care placed individually on these grandparents as well as on Zimbabwean society as a whole (AVERT 2010; Thomas 2010; UNICEF 2007). They have focused on improving psychosocial support to HIV-positive youth and their caregivers as well as public educational campaigns as two possible solutions to the many challenges facing Zimbabweans.

HIV remains just one of the many crises Zimbabweans must face every day. Several of my participants remarked that HIV and AIDS is not the culmination of a disaster, but just one more episode in a line of tragedies. Such sentiments are important to remember when considering personal, societal and government discourse around the HIV epidemic (Fassin 2007; Wikan 2000).

Despite the efforts of non-governmental organizations and healthcare facilities, the epidemic remains couched in moral and stigmatizing terms. For example, a common slang term for an HIV-positive person is *mumwe ane matuck shops*. Literally translating to “a person with a tuck shop,” the saying refers to the immoral behaviors that often occur around small corner shops, such as sexual activity and alcohol consumption. The tuck shops explicitly refer to an individual's swollen glands, which are taken to be a sign of approaching death. In the face of this seemingly bleak phrase, most of my participants at Nyeredzi Inopenya share that improvements have been made in the last decade to fight stigma and spread information about HIV. They remain confident that someday, “even in Zimbabwe, HIV will just be a disease.”

While I was writing this thesis, IRIN, a humanitarian news and analysis source maintained by the UN Office for the Coordination of Humanitarian Affairs, released a report stating that sexual behavior change was a driving force behind the 13% drop in Zimbabwe's HIV prevalence between 1997 and 2007. The report cited research from Harvard University's Daniel Halperin which suggests that “the community sort of 'got it:' there was a change in norms and that became part of popular culture” (IRIN 2011). The report ignores the political turmoil and economic collapse mentioned above that has forced many to leave their homes and abandon regular medical appointments, as well as the increasing numbers of AIDS-related deaths due to disruption and lack of medical treatment. I believe the report has overemphasized the impact of their sexual education in light of the tumultuous societal backdrop in which their programming took part. This seems to be an unfortunate incident of isolating factors and misattributing cause and effect.

Most specifically, I am concerned about the reports' disjuncture from the experiences and opinions of many of my participants and staff members. Though the study took place in another part of the country and worked with a slightly older age cohort, I would be hard pressed to find societal norms vastly different across the country. Participants, friends and daily gossip have all relayed the twin faces of programming such as that done by Harvard University; Zimbabweans deliver the answers the researchers want, or comply with the study until the release date and then return to old habits (Personal communication). Participants gave one example of a teacher that repeatedly scolds them about abstinence, faithfulness to one's partner and safe sex; the same teacher is known to have many girlfriends. Stories like these are numerous among Zimbabweans and point to a darker side that researchers seldom want to acknowledge.

Although I have not focused on the representation of AIDS, it is important to acknowledge the influence of media, government and research depictions of the epidemic in shaping public discourse about HIV. The IRIN report joins a collection of literature and media hype that is desperately looking for positive highlights among the devastation and sorrow HIV/AIDS has wrought (IRIN 2011). Though optimism is important, it can be dangerously misleading, as Sammy, a HIV-positive 21 year old from Zimbabwe, makes clear. As she describes the shift in media attention away from “skinny dying people in wheelbarrows” towards living with HIV, she points out the fallacy it creates: “So people might not be dropping dead. Now we are more hidden in the crowd because of ARVs. But the dangers are still there—people still have to be careful. And because the immediate threat of death and that fear is gone, people are getting careless. So maybe all the fear was good.” Sammy touches upon the delicacies and complexities surrounding an epidemic that is ever growing and shifting in social meaning and representation.

### **Conclusion**

As governments, non-governmental organizations, clinicians, health educators and others seek to balance the statistical realities of contracting HIV with optimism that the world can “beat the virus,” the social, political and medical realities continue to change. On World AIDS Day 2009, American President Barak Obama lifted a 22-year old prohibition on HIV-positive individuals entering the United States, signaling, if only symbolically, that the era of HIV-related stigma and discrimination had come to an end. Though the realities of being HIV-positive still include harsh and life-threatening experiences, the fate for many others has improved. With medical advancements, improved screening and testing and a better

understanding of the complex needs of HIV-positive individuals, HIV has become a manageable chronic illness for many in developed countries. However, this fate still remains out of reach for millions more. Within and between countries and continents, one's experience with HIV reflects other inequities and inequalities. The global South, particularly sub-Saharan Africa, has borne the majority of the epidemic without the same access to funding, government and medical infrastructure as countries in the global North.

Approximately 25 million individuals worldwide were estimated to be living with HIV and AIDS at the end of the millennium. That number has since climbed to 33.3 million, with 22.5 million of them living in sub-Saharan Africa (Kaiser Family Foundation 2010; AVERT 2010). The face of HIV has changed since the beginning of the epidemic; what began as a predominantly white, middle class homosexual American male epidemic has grown to encompass people of all ages, races and creeds, but most particularly impoverished African women and children.

A virus with links throughout society, HIV affects how many think, feel, see and relate to the world they live in. Whose story is told, whose plight is answered have perhaps as much to do with the political, social and moral constructions of the epidemic as one's proximity to a healthcare facility. Intertwined with the biology of the virus are a multiplicity of meanings, meanings which overlay conversations about opportunistic infections and drug regimens with those about disclosure, relationships and spirituality. In the chapters that follow, the stories of HIV-positive individuals from Zimbabwe and America offer the opportunity to go beyond data reports towards understanding life with HIV.

**CHAPTER 3**

**A CASE FOR NARRATIVES: UNDERSTANDING HIV THROUGH  
STORIES**



I am like the birds free flying in the wind. Someday, I will become even more free. I will become like the wind. There will come a time when I won't have to be a secret, always straining myself. Someday it will even become a joke. But for now, I will keep talking. Life was so hard before because I didn't have space to just *talk* about what was going on inside my body because everyone would have a [negative] reaction. The support group was a good change of scenery. People started feeling free. It was wonderful to talk and not feel isolated. We all realized we were not alone; we could tell each other stories and people would listen and actually hear. Life became easier because I could share my thoughts with people.

I now think of myself as a flower. There is this flower in Zimbabwe that blooms for many months and then slowly starts to die by losing its petals and then sending seeds into the wind. I am like this flower. When I talk about HIV with other people, even when I am not talking about myself specifically, I am sending petals and seeds to other people. Educating people about HIV is my duty now, just like the flower blooming beautifully. When I die, my seeds are those conversations, so people don't live in so much fear and ignorance. I will not just go without leaving anything.

Sammy, 21 years old

### **Introduction**

Sammy is the creator of Nyeredzi Inopenya's symbol and design. When she learned at age 14 that she had been HIV-positive since birth, she felt that “a mountain with no door” had been put in front of her life, blocking out all the sun. After several months of living with fear of disclosure and death, she learned about Nyeredzi Inopenya's support groups. As she began sharing her story with other HIV-positive youth, “a rock had cracked open a door. Sun came from behind. I came from behind the mountain of HIV.”

As Sammy shares her story about growing up without answers for her constant illnesses, her father's unexplained death and the murmurs that always followed her and her mother, she describes a transformation in her approach to life and her conceptualization of her HIV status. Sharing her story with others facilitated a reconceptualization of herself as a person *with* HIV rather than an HIV-positive *person*. This proved therapeutic because it moved Sammy through an interpretive

framework that made life with HIV more manageable and intelligible (Danforth 1989). Forming a community around shared experiences and telling stories about events and emotions she had never been able to express freely enabled a healing process in which Sammy began to separate her sense of selfhood from her HIV status. Talking about her body as a physical entity that was diseased but also growing with ARVs, helped her envision her personality as detached and “beyond HIV: I wasn't just a disease. I am Sammy.” This declaration and the accompanying liberation from fourteen years of unanswered questions, depression and fear, invigorates Sammy to talk. Sharing her story, even in opaque ways which do not reveal her status, is important for her and many of my other participants. The opportunities for self-reflection, contemplation and community-building that surround storytelling are powerful resources for people living with HIV, their caretakers and clinicians and policymakers trying to better understand the epidemic.

Narrative, as an active process of making and assigning meaning, is often able to offer healing to those with HIV and other chronic illnesses. This chapter highlights narrative's relational quality and therapeutic powers. These powers come from its ability to facilitate the processing and organization of meaning and emotion to life's experiences, as well as its ability to reinforce different boundaries and conceptualizations of the world (Brody 2003). As a social interaction, storytelling allows tellers and listeners to maneuver within various social frameworks; through this process, listeners and tellers can reinforce or challenge different conceptualizations of sickness, healing and the body. The benefits and disadvantages of narrative frameworks, which have the potential to provide structure and explanation to an individual's life, will be discussed alongside the ways that participants do and do not use frameworks for self-conceptualization, HIV causality

and a sense of purpose. I will end with an examination of several narrative frames that my participants use, such as Narcotics Anonymous, support groups and religious testimony, and the impact these may have on their stories. Above all, I wish to illustrate the importance of narrative as a tool for understanding of the HIV epidemic; part of this process involves a critical look at narrative as a healing tool.

### **An Expansion of Arthur Kleinman's Illness Narratives**

Storytelling opens doors that biomedicine usually leaves closed. Arthur Kleinman and his 1988 watershed book *The Illness Narratives: Suffering, Healing and the Human Condition* mark a monumental step in the incorporation of stories of sickness into biomedical interaction. Kleinman was compelled by his experiences as a physician to address the increasing difference between “a patient's experience of illness and a doctor's attention to disease” (1988:xii). Based on the fundamental premise that “the experience of talking about the actual experience of being ill has a therapeutic value,” Kleinman traces the process of creating meaning around illness “out of the very stuff that makes up our personal and cultural dilemmas” (1998:xii, 144).

Kleinman states that illness has meaning because of “its culturally shared significance” and that clinicians must dedicate themselves to the interpretation of illness narratives as a way of improving clinical care (1988:9). Furthermore,

Each time a disease is assigned a social meaning, the client is encased in an exoskeleton of powerfully peculiar meanings that the client and his or her caregivers must deal with and which heavily contributes to one's illness experience....The meanings of all symptoms are dependent on local knowledge about the body and its pathologies. Clinicians must acknowledge and seek to understand these meanings (1988:22-3).

Through ethnographic interviews with his patients, Kleinman sought to

elucidate the distinctions between illness and disease, curing and healing. Much like Danforth's conceptualization of religious narrative as moving the ill from suffering to alleviation or at least tolerance of their illness, Kleinman describes the importance of healing "in the messy confusing context of lived experience" (Danforth 1989; Kleinman 1988:206). Technological intervention may ameliorate or even cure a disease, but often does little to address a patient's illness; for this, healers must start "really listening to the interpretations of illness narratives" (1988:9).

I too am concerned with the interpretation of illness narratives and their relationship to my participants' lived experience with HIV. Kleinman's discussion of the importance of the psychocultural dynamic between one's social world and the personal experience of being ill marks an important turn in biomedical consciousness about the unique details of an individual's life which may heavily construct his or her illness experience. Published almost 25 years ago, *Illness Narratives* set an important trend in thinking about the construction of illness as distinct from the experience of disease.

This thesis takes Kleinman's inquiry into the social experience of being ill a step beyond the directly biomedical. In his pursuit of illness narratives, Kleinman asked his participants to share how their life had been affected by illness. However, much can be revealed about the contextual framing of "illness" without imposing a direct correlation between "illness and life" (1988:3). In much the same way that Alia Wahid's 2009 Mount Holyoke College thesis, *Rural Patient Pathways to Care in the Egyptian Healthcare System Renegotiating Breast Cancer in the Doctor-Patient Relationship*, critiques Kleinman's concept of "illness narrative," I argue for the lens around narratives of sickness to be widened past the explicitly biomedical.

Kleinman relates:

Illness narratives edify us about how life problems are created, controlled, made meaningful. They also tell us about the way cultural values and social relations shape how we perceive and monitor our bodies, label and categorize bodily symptoms, interpret complaints in the particular context of our life situation; we express our distress through bodily idioms that are both peculiar to distinctive cultural worlds and constrained by our shared human conditions.

We can envision in chronic illness and its therapy a symbolic bridge that connects body, self, and society. This network interconnects physiological process, meanings, and relationships so that our social world is linked recursively to our inner experience. Here we are privileged to discover powers within and between us that can either amplify suffering and disability or dampen symptoms and therefore contribute to care (1988:xiii).

There are several issues, however, with this construct. Firstly, Kleinman's "illness narratives" assume that people afflicted with chronic illness will or should inevitably factor "illness into their discourse about 'life'" (Wahid 2009:51). Secondly, stories about illness seem to be invariably about the body; his discussion of illness narrative remains intimately tied to physiological signs and symptoms. This approach ignores important non-bodily manifestations of illness, such as the other "context of our life situation" he so pointedly mentions (Kleinman 1988:xiii). However, he seems unable to leave the biomedical construction of the body as the center of illness and disease.

My participants' narratives point to the importance of regarding illness as both beyond the body and not inherently related to one's discourse about life. Though I was interested in my participants' illness experiences, I was also drawn to how these experiences fit (or did not fit) into their larger conceptualizations of their lives. I therefore broadened Kleinman's question of "how has your life been affected by illness," to "tell me about your life." Drawing upon the anthropological method of

life history (Mattingly 1998), I wanted to situate illness within the framework of a whole life, rather than, say, a clinical conversation. By offering a processual rather than a static view of cultural life, life histories are useful in looking at how illness shapes a person's sense of identity and selfhood, as well as how people find coherence and continuity in their lives (Mattingly 1998:13). Though my framing in this thesis focuses on illness narratives, asking after my participants' life is not a contradiction. Rather, it allows me to ascertain how my participants' experiences with illness fit within their discourse about life.

Even after my open-ended beginning, many participants asked, “do you mean [life] with HIV, or just my life?” This illustrates not only a demarcation many participants described in greater detail as we proceeded, but also their understanding or assumption of what I thought was important. Having been introduced through the context of HIV support organizations and clinics, participants often began with a litany of symptoms and treatments (or lack thereof) until I would reemphasize that I wanted their entire story. At this point, the medical was quickly dropped, often never to be mentioned again, as though participants sensed a rare opportunity to share their full tale. Many said just this; they thanked me for the chance to “tell the whole thing.” Positioning illness within the context of religious, political and social lives offers clinicians and practitioners the opportunity to look more holistically at a disease. The “whole thing” lies not in the *either/or* but in the *and/also* of compassionate moral deliberation and ethical decision-making (Anderson and Montello 2002:93).

Much can be revealed about the contextual framing of “illness” without imposing a direct correlation between “illness and life” (Kleinman 1998; Wahid 2009). Wahid describes a series of events as waves of various lengths floating along a linear continuum of life, intersecting each other at various indiscriminant points

(2009:51). She points out that “although there may be commonalities between the ways ‘life problems,’ ‘illness events’ and the general concept of ‘life’ are discussed, no two discourses are identical,” nor does “illness” necessarily run parallel to the entire continuum of an individual’s life (2009:78). This challenges Kleinman’s assumption that people afflicted with chronic illnesses will or should inevitably factor “illness” into their discourse about “life.”

My participants in Zimbabwe and the United States pointed out that HIV was not always intrinsic to their life discourse. As participants shared stories of family, drug treatments, periods of incarceration, religious transformation and sexual identity, all within the same interview, an image of a map with many differently sized concentric circles came to my mind. These circles, each representing a sphere of meaning, life experience or event, float along like bumper cars. But rather than aggressively colliding before ricocheting in another direction, the borders of these circles are porous and permeable. Their interaction is expressed in intricate ways in an individual’s narrative, ways that Kleinman’s discourse of biomedical illness experience does not allow. Looking to the interaction of the circles as important sources of meaning-making differentially situates participants’ various life experiences as both encompassing and independent of illness experience. Some of the circles bump incredibly often, suggesting that certain spheres of life become intricately related to chronic illness. However, in a departure from Kleinman’s conjecture that life and illness must necessarily become linked and follow similar patterns, some of the circles do not overlap at all, or do so infrequently (1988:152). How the circles meet and mesh and my participants’ articulation of this meeting inspire me to rethink the depth, interconnectedness and the multiplicity of effects “illness” has on the lives of the chronically ill (Wahid 2009:51).

Both Kleinman and Wahid frame illness in inherently negative terms when discussing “illness and its problems/restrictions” (Kleinman 1988; Wahid 2009). I posit a reframing of “illness” as a life problem. My participants illuminate how an HIV diagnosis can be the impetus for a spiritual or religious transformation, a restructuring of life along different terms and the grounds for new, positive improvements. This constitutes an important challenge to most of the literature and public opinion on HIV and chronic disease more generally, which describes illness as an end. Arthur Frank points out that although critical illness leaves no aspect of life untouched, its ultimate value is that it teaches us to be alive. Not every piece of an illness experience is wrapped in despair and shame (Frank 1991). My participants share that HIV has taught them as much about being alive and fully embracing oneself as it has about sickness. These sentiments should not lead to romanticizing the often horrendously painful bodily and social experiences of living with HIV. It is merely, but importantly, to point out the many dimensions of an illness experience and the need for society to listen, witness and validate all components. I therefore have retained Kleinman's phrase “illness narrative” to encourage readers past the biomedical towards an appreciation for the multidimensionality of illness and the messy, complex and intricate stories which flow from such experiences.

My participants' narratives point to a shift in paradigm from “HIV is a death sentence,” a stigmatizing assumption and sadly, often a medical reality, towards life with HIV. Their strong counter-reactions to “outliving their term” attest to the medical advancements and wider access to treatment that have transformed HIV from a rapidly deteriorating disease to a manageable chronic illness. While this new reality remains tragically out of reach for millions, access to medication and social services focused on living with as opposed to dying from HIV, have fundamentally influenced



my participants' narrative and their conceptualization of their illness. Such a shift requires a societal and theoretical repositioning of responses to HIV.

### **Narrative as Healing**

Many of my participants describe narrative expression and story sharing as therapeutic. Jack, a 19 year old at Nyeredzi Inopenya describes the tension that gets released when he shares his story and listens to others like him: "When I learn about people like me, it empowers me to speak up about myself and my experiences. It empowers me to live better." Drawing on the reciprocity of narrative expression, Jack's sentiments resonate with many of my participants who cite the strength in relationships grounded on narrative commonality. Maria, for example, a 34-year old Hispanic American, describes the "lifting of my spirits and burdens" when she tells her story at Narcotics Anonymous and HIV support groups. The ability to tell her "whole story" and to have people truly listen provides respite from the silence she and many other participants remain enmeshed within during their everyday lives. Integral to her narrative experience is also the satisfaction she receives from having people not only listen but value and validate what she is saying.

My participants find stories so powerful because stories create a sense of agency, taking the wounded and the ill out of the passive role society and the medical sphere frequently assigns them and into one that is capable of healing (Frank 1995:xii). In a paradigm shift that refers to the important distinction between curing and healing, the chronically and seriously ill regain the voice that illness has taken away through the process of narrating life experience (Frank 1995:xiii; Danforth 1989:52). Danforth and Frank both contend that the distinction between disease as a

“malfunctioning of biological processes” and illness as a “psychosocial experience and meaning of perceived disease” must be paired with a distinction between curing, which deals with disease as a natural condition, and the process of healing, which deals with illness as a cultural condition (Danforth 1989:52). Maintaining these two distinctions, I draw upon Frank's conceptualization of stories as dialogic social experiences as well as Howard Brody's description of narrative healing to illustrate the value of narrative as a tool for understanding experiences with HIV (Brody 2003; Frank 1995).

Brody points out three major components that must occur for the meaning of an illness experience to be shifted towards positive healing: the illness experience must be given an explanation the individual finds acceptable within his or her belief system and worldview (Arthur Kleinman calls this “an exoskeleton of powerfully peculiar meaning”); he or she must perceive being surrounded and supported by a group of caring individuals; and he or she must achieve a sense of mastery over the illness experience, either by feeling personally powerful enough to conquer the illness or feeling that his or her powerlessness can be compensated for by the power of a caring group (Brody 2003; Kleinman 1988:22 see also Frank 1995, 2010; Hunter 1991; Charon and Montello 2002 for similar arguments). Stories told within the medical setting must offer explanations for illness, but must also facilitate a caring relationship. When a cure is unavailable, the ability to tell the story of the illness and give it meaning may symbolically, even if not pharmacologically, lead to healing. Participants shared that by creating a safe space for open narrative expression, my interviews and their support groups facilitate a healing process as important to surviving with HIV as their daily medications.

Therefore, illness narratives create the opportunity for healing by facilitating a recasting of illness within a person's understood moral and social order; through the story's adaptability to alternative endings; and by placing "the human drama of illness" in the foreground (Mattingly and Garro 2000:8). Narrative restores the "who" of a medical case history, which for so long has described only the "what" of a disease. Illness narratives, in offering the ill a framework through which to describe the lived experience of being ill, can help listeners and tellers understand the often intangible experiences of sickness.

However, not all my participants appreciated this opportunity for narrative articulation and formation. To some, it was a baffling experience of being asked to share or produce a narrative they had not conceptually formed. This range of responses illustrates the activity and dynamism constantly surrounding narrative: life is not static and neither should be the modes with which we share or analyze our life experiences. However, much of the literature on narrative suggests that linear, coherent and internally consistent stories are the goal of narrative expression and the highlight of narrative healing, particularly for those with chronic illness (Frank 1995; Kleinman 1988; Ochs and Capps 1995). In a judgment that values coherence above fragmentation, these authors reclaim that though contradictions in an individual's illness experience may not disappear, they should be held together by a larger frame or explanatory model. It is these frames or models that are credited with moving a chronically ill individual from the traumatizing experience of being ill, through a positive transformation in which he or she can now endure the illness (Danforth 1989; Frank 1995; Ochs and Capps 1995). Through a process of telling a story, one works to form a memory and meaning structure to support events and experiences;

succinctly put, “talking is remembering” (Frank 1995:61). When the ill person cannot come to terms with aspects of his or her life experience or has a frame that does not seem sufficiently answer his or her persisting troubles, the narrative experience is deemed faulty, incomplete or chaotic and perhaps even a failure.

It often remains unclear whom these authors are referring to why they write about the holes in an individual's story. It is the teller who feels his or her own tale is not answering the questions that he or she feels it should answer? Or is it the listener who finds the tale “unhear-able” (Diedrich 2007:17)? Chaotic narratives are characterized by an absence of sequential narrative order or discernible causality, challenging Western expectations for identifiable beginnings, middles and ends (Frank 1995). Is this trope so foreign that the listener actually stops listening at the level of witnessing, the central component of the healing narrative process (Frank 1995:110)? Frank provides some clarification, suggesting that chaotic narratives are deemed “failures” by the listener, and by American modernist society as a whole:

Stories are chaotic in their absence of narrative order. Events are told as the storyteller experiences life: without sequence or discernable causality. The lack of any coherent sequence is an initial reason why chaos stories are hard to hear; the teller is not understood as telling a 'proper' story. But more significantly, the teller of the chaos story is not heard to be living a 'proper' life, since in life as in story, one event is expected to lead to another. Chaos negates that expectation. In these stories the modernist bulwark of remedy, progress and professionalism cracks to reveal vulnerability, futility, and impotence.

Those living chaotic stories certainly need help, but the immediate impulse of most would-be helpers is first to drag the teller out of this story, that dragging called some version of “therapy.” Getting out of chaos is to be desired, but people can only be helped out when those who care are first willing to become witnesses to the story. Chaos is never transcended but must be accepted before new lives can be built and new stories told (1995:97).

Perhaps the discomfort with nonlinear and chaotic narratives is the degree to which these stories reveal our shared vulnerability. Chaotic stories upset the balance

between a therapeutic language and one that privileges normative moral and social conditions. The liminal place of chronic illness challenges the normative restitution narrative of “yesterday I was well, today I am sick, tomorrow I will be fine again” (Frank 1995:84). As Frank confesses, “society prefers medical diagnoses that admit treatment, not social diagnoses that require massive change in the premises of what that social body includes as parts of itself” (1995:113). Chaotic narratives represent a call to society to recognize its role in creating and perpetuating these nonlinear, incoherent narratives. Frank describes a “backslide into chaos” when those who share incoherent stories are not validated; more pointedly, individuals who tell “unrecognizable” tales are not cared for by their audience (1995:113). By concentrating on illness narratives as formulated responses to past and present experiences, I too may have contributed to the “nonlistening” of my participants’ stories.

The reliance on frameworks as a therapeutic narrative tool should also be problematized. Perhaps linearity and coherence are incorrect measures of narrative success. One of the most powerful aspects of narrative is its fluidity; many of my participants remarked that storytelling is most therapeutic because the story, including its accompanying framework, can always change. Mattingly and Garro place importance on being open to these changes and the reasons they might have occurred as critical aspects of narrative's healing capabilities (2000:3). Listeners must therefore look beyond normative frameworks when listening to illness narratives to allow and foster the ebb and flow integral to sorting through life's events and placing them within meaningful systems.

Acknowledging that these systems may not carry the same meaning to the

listener and the teller is an important critique of the authors who deem chaotic narratives failures (Frank 1995; Kleinman 1988; Ochs and Capps 1995). Mattingly and Garro offer “that if the audience doesn't know why the point matters to them, if the events in the story never touch them, then the story doesn't work” (2000:3). However, this does not mean that the narrative failed the teller. The non-use of master narratives to explain their HIV illness experience is not inherently a sign of my participants' failure or chaos. Rather, it may represent a different subject position in one's interpretation of life. It may also illustrate the boundaries of narrative as therapy; perhaps these participants do not seek or cannot find healing through storytelling. Thus, while much can be gained by comparing individuals against normative frameworks, overemphasizing the importance of narrative formation and coherence may perpetuate suffering and ignore an individual's needs. I therefore present narrative frameworks as simply one tool to be considered when seeking to understand an illness experience.

Though narrative frameworks should not be the only benchmark of a therapeutic narrative experience, the contrast between tales of participants who use a framework to assign life meaning, and those that have not been through this process as completely is noteworthy. The stories offered by James, an African American in his early 50s, and Maria, a Hispanic American in her thirties, illustrate a narrative trope common in Narcotics Anonymous and other recovery programs. Their stories demonstrate how fully a narrative frame can be used to reframe one's lives within a culturally specific narrative form or genre (Mattingly and Garro 2000:26). Through the process of learning the NA model, Maria and James have learned how to understand their lives as NA lives, and themselves as NA drug-users. Each refers to

the NA model as a resource in understanding and reconstructing their past. Further, James and Maria describe how the process of narrating past events helps them shape future experiences. Such a phenomenon resonates with J. Bruner: “we *become* the autobiographical narratives by which we 'tell' about our lives, so that a life is not 'how it was' but how it is interpreted and reinterpreted, told and retold” (1987:15 in Mattingly and Garro 2000). Examining the narrative frameworks my participants use as well as their points of departure from these structures thus offers insight into their (re)construction and (re)interpretation of life's experiences.

### **Representative Narrative Frameworks: Quest Narratives**

Grouping my participant's stories into common narrative frameworks is helpful as clinicians, Nyeredzi Inopenya staff members and participants themselves look for patterns within their own story as well as relationships between their stories and others. Though I did not specifically ask participants if they felt narratively related to other individuals, each participant who used a readily identifiable framework expressed connection to others through shared narratives. For example, participants at Nyeredzi Inopenya were comforted and strengthened by knowing that others at the organization not only had similar stories but had learned similar ways of expressing and dealing with life's experiences. This was most frequently expressed through comments about gossiping; Grace shared her relief that “no one can say anything here that I couldn't say about them.” This unspoken contract and common narrative trope allows participants to feel comfortable sharing stories they frequently keep guarded. “Freer” in their speech at Nyeredzi Inopenya than most other places in their lives, participants gain a sense of community through common stories and expressive frameworks.

Nyeredzi Inopenya's primary tool in offering psychosocial support to HIV-positive youth is to lead youth to a repositioning or restructuring of their life approach from overwhelming disappointment, pain, depression and suffering towards acceptance and positive living. The staff strives to help youth see themselves as agents of change and as strong individuals with the inner power and community resources to move past HIV stigma and discrimination towards self-assurance. They achieve this reformulation in self-understanding through a model of hero work.

Nyeredzi Inopenya helps youth visualize themselves as their own heroes. The organization's director states that this process is “therapeutic because it helps restore agency, authority and power to the youths' lives, even if only in the story. Telling the story doesn't change their daily realities of illness or stigma or blame, but it starts a process of feeling assertive over their lives” (Thomas July 2, 2010: personal communication). As a narrative process, Nyeredzi Inopenya constructs a master narrative into which youth insert their own particulars. Though providing a deliberately structured frame could be limiting and exclusionary of other experiences, the hero framework is general enough to allow for malleability. My participants remarked on the power of being offered and supported in narrative construction and expression, particularly those who face (d) serious stigma and discrimination. Arthur Frank describes the importance of fostering the process of a sick person “finding their voice to restore the moral agency that illness makes us sacrifice” (1995:132-4). Creating stories about illness is a form of perseverance for my participants, a way to become “active heroes” of their own life. This assertion of self is an important reversal from the passive roles into which society and the medical establishment often slot the chronically ill (Frank 1995).

Nyeredzi Inopenya's hero framework of struggle-trial/test-



rescue/transformation can be categorized as a quest narrative (Frank 1995:115). Prince, Sammy, Grace as well as Maria and James in the United States have quest narratives; their stories are dispersed throughout the thesis. Their stories meet HIV head on, accept it and seek to use it, rather than letting it control them. This process was not instantaneous but rather fostered by Nyeredzi Inopenya, family and friends and personal commitment to positive living. Their devastation with their HIV diagnosis was transformed as an occasion for a journey towards a new life and a new way of thinking. Participants with quest narratives each describe a moment or process of transformation in which they reformulated their conceptualization of themselves and their HIV status. These shifts are marked by divisions in time and self-identification; participants describe to varying degrees, different and separate selves.

The key therapeutic dimension of quest narratives is the restoration of personal agency and the sense that something powerful will be gained through the experience, in this case, acceptance of life with HIV (Thomas 2010; Frank 1995:115). Quests place the formulation of stories as integral to bodily, mental, and spiritual healing as gained through communal storytelling. Frank advocates for this narrative approach, stating “your silence will not protect you from the illness. Your stories must be shared” (1995:133). Nyeredzi Inopenya takes this message to heart, strongly placing narrative formation as an important tool for working through, accepting and valuing emotions and experiences. The organization holds writing workshops and has produced two books of youth testimonies. For those that have difficulty writing, I started an audio library project which centered on several main themes of life with HIV in hopes of cataloging experiences for the shared benefit of the youth. My participants expressed relief and gratitude at the opportunities I and Nyeredzi Inopenya presented for narrative expression.

The therapeutic value of storytelling also seems to have a cap. One individual at Nyeredzi Inopenya declined participation in my interviews and audio library project because “all the time, we are telling our story. It’s always AIDS AIDS AIDS. We want to tell other stories and we want to just live our lives without always talking about it.” Hope, a spunky eighteen year old, is something of a Nyeredzi Inopenya poster child; she is part of the storybook, is on the dance team and had a video made about her life. The video is shared within the organization and occasionally to donors like UNICEF as an example of positive living. She is “sick of always being asked my story.” Such a fierce reaction suggests that there is a limit to narrative expression as a healing tool; if overused, it loses its powerful as a form of unique formulation and contemplation.

Hope feels that if people are always nagging her to tell her story, the story becomes less about her and more about them with each retelling: “if you want my story, just look at the video, it will tell you everything. You don't need me to tell you.” Such a statement is a critique against the dialogic and actively synthetic aspects of narrative which are touted as its most integral component (Brody 2003; Charon and Montello 2002; Frank 1995; Hunter 1991; Kleinman 1988). It also raised questions about the relationship between the narrator, his or her story, the listener, and the motives behind the storytelling interaction. Hope feels most disengaged from her story because “people are just using it because it’s a good one for success. I came back from the grave with the help of ARVs; my mom had already bought my coffin. I found Nyeredzi Inopenya and became strong and now look at me-beautiful, vibrant me!” This sarcastic shorthand of her life highlights the importance of reflexively monitoring the elicitation and use of stories at Nyeredzi Inopenya and other similar organizations.

Hope's resistance to sharing her story also questions my assertion that stories are invariably "therapeutic," and that those I have perceived as in need of narrative outlets, may not in fact want to participate in this exercise. Perhaps I and other researchers have made too much of illness narratives as a critical piece of processing and healing one's traumatic experience with chronic illness. Or perhaps we misread what we hear; placing importance on illness as the most influential shaper in an individual's life experience. Social anthropologist Unni Wikan asks, "How can we know that the illness narratives we elicit as researchers tap the experience of suffering? People's compelling concerns could be different; they need not be the illness, even when illness looms large in a person's life" (2000:218). Taking this one step further, perhaps eliciting narratives may even cause or perpetuate the suffering researchers intend for narrative to alleviate. Though this seems to be true in certain circumstances, such as Hope's "overexposure" to narrative extraction, the majority of my participants have valued the opportunity to share their story. Rita, an eighteen year old Zimbabwean, remarked "talking helps me heal. It doesn't give me answers, but it helps me heal my sadness and helps me understand my life with HIV." Storytelling therefore still holds an important place in understanding and witnessing life with HIV.

Hope's story shorthand points to the danger of whitewashing or romanticizing illness and its social, emotional, physical and mental consequences. Story repetition as well as a reliance on quest narratives risk presenting "too clean" an illness (Frank 1995:135). This danger is realized as Hope hurries through the emotional turmoil of being gravely ill as a teenager and the potential but daunting road to recovery with ARVs. In the American Northeast, two of my participants also use narrative frameworks which run the risk of romanticizing the struggle one may have accepting

HIV, drug addiction and incarceration.

### **Narcotics Anonymous and Spiritual Transformation**

Maria and James both suffered serious drug addiction and have used Narcotics Anonymous as a resource for repositioning their lives. NA offered them a chance to conceptualize their lives as products of their own making, not as divine punishment for inherent moral flaws. Reclaiming their sense of agency back from heroin and cocaine removed layers of isolation, depression and desperation. NA's narrative trope helped them reframe and reinterpret many of their life experiences into a model they realized others shared. Finding strength in shared experience, Maria and Thomas describe NA as a resource for moving their lives in a new direction. Their stories are found throughout the thesis; both share a time of hitting rock bottom, recognition and admission of their addiction, a slow uphill battle to sobriety, a self transformation and a constant vigilance of their thoughts and actions to prevent a return to drugs. This frame follows an NA standard which helps addicts recognize and categorize their experiences (NA World Service 1988).

Like Nyeredzi Inopenya's hero model, the NA framework is also a quest narrative. Instead of personal agency and commitment to self-led positive living, NA relies on personal surrender and humility to a Higher Power as a first step towards life transformations (NA World Service 1988:47). The core of NA's recovery program lies with their Twelve Steps and Twelve Traditions which lead addicts through a process of admission and acceptance of their drug addiction, and a turn towards God for solutions and progress. Though God is never defined nor is there an endorsement of any particular religious or spiritual doctrine, there is a fundamental emphasis on the power of God and the necessity of placing an addict's life in His hands. The

language of recovery follows Christian spiritual transformations very closely:

“addiction, like a devil, is a cunning enemy. We must pray for knowledge of God's will for us and the power to carry that out” (NA World Service 1988:13).

Furthermore, the twelfth and final step of recovery is a spiritual awakening which comes after “turning our will and lives over to the care of God,” and being “ready for God to remove our defects of character and our shortcomings.” Maria and James, as well as several Zimbabweans who describe similar “awakenings,” construct axes around which they narratively structure life; they speak of periods “before” and “after” their transition in which the way they viewed themselves, the world and their relationship to or understanding of HIV changed. These episodes illustrate the opportunities storytelling provides for actively “working out” complicated emotions, events or situations as well as the fluidity inherent in creating and positioning someone's self within a tale (Diedrich 2007; Charon and Montello 2002).

James's story is peppered with NA phrases to describe his experience with HIV, life on the street, and the spiritual awakening he had in jail and its “transformational effect on [his] life” as well as phrases specifically from his Pentecostal church. It is potentially noteworthy that both Maria and James, who credit NA, education about HIV and trust in their clinicians to their spiritual transformations, belong to Pentecostal churches. Prince, a 22 year old Zimbabwean youth also has an explicitly Pentecostal narrative of spiritual rebirth through acceptance of his HIV status. Other Zimbabwean participants share an emphasis on transformation without connecting it explicitly to a religious doctrine. Their stories point to the malleability of narrative frameworks as well as the permeability of socially and culturally familiar structures which knowingly and unknowingly become part of one's story (Frank 2010).

Though the NA framework was instrumental in moving Maria and James beyond the portion of their lives “ruled by heroin,” Maria shares her discomfort with NA's emphasis on surrender and submission to the quest. Though this process is intended to restore agency to the addict by connecting him or her to a Higher Power, Maria believes “it's dangerous to lie down waiting for God. You can do something yourself as you wait.” She appreciates the emphasis on the quest and living in and for the moment, as it keeps her mind “growing forward.” However, she wants to be “driving her life, not giving it over to someone else.”

This differs from NA doctrine and from James, who clearly places his life in the hands of God, pointing to the value of not over-grouping stories. Though Maria uses NA as a way of interpreting the world and as a framework for her story, she retains an important level of individuality. However common and integral frameworks are for therapeutic narrative construction, storytelling remains a unique social experience. Furthermore, stories can only retain their healing power if they are returned to the teller; though the listener(s) and teller share a narrative interaction, the story must remain with the teller (Frank 1995:110). This is not to say that narrative healing does not occur with identification and communion with larger narrative frameworks or groups of people with similar stories. It is simply to point out the importance of balance, balance between narrative isolation and communal takeover, and between under and over-grouping of stories and their narrative frameworks.

## **Conclusion**

Narrative ethics illustrates that stories are intertextual, crossing between the teller's and listener's tales, and into the larger canon of shared moral imagination

(Zoloth and Charon 2002:31). Healing through and with stories is therefore about making a link between one's own humanity and that of the storyteller. Entering into this witnessing position empowers both teller and listener to create a relationship based on the complexities, contradictions, and moments of vulnerability and pride inherent in all our lives. Witnessing my participants' lives through shared narrative experience, allows me to push beyond symptoms and diagnosis to the complex and diverse aspects of living with HIV. We, as clinicians, as family and friends, as listening citizens of the world, cannot provide a right and good healing action without understanding what HIV and other illnesses do to a person's narrative account of his or her life. We must dedicate ourselves to witnessing this process, to engaging in the network of social reciprocity and what it means to simply *be with* others in a human relationship (Brody 2003; Jones 2002:61). This witnessing must apply to incoherent stories as equally as those that are articulate; looking past normative frameworks and story expectations is critical to offering healing through storytelling. We learn the most about what it means to be sick when listening to the stories people tell about sickness (Brody 2003); perhaps one of those stories is the need to look beyond stories as much as it is to look within them.

This chapter argues for the use of narrative as an important tool for understanding the diverse experience of living with HIV, while also acknowledging its limits. I have focused on literature within the broad fields of socio-narratology and narrative ethics to argue for a view of narrative as an interactive, dynamic process between teller and listener, and against constructing illness narratives only within a biomedical realm. Arthur Frank defines socio-narratology as “attending to stories as *actors*, studying what the story does, rather than understanding the story as a portal

into the mind of a storyteller. Of course socio-narratology is interested in storytellers and story listeners, but they are understood as being enabled to be who they are because of stories” (2010:13-4). Socio-narratology emphasizes the role stories play in making life social; stories and humans work together, “in symbiotic dependency, *creating the social* that comprise human relationships” (Frank 2010:15). Narrative ethics together with socio-narratology position my thesis within the literature on the interactions between stories, and their tellers and listeners (Brody 2003; Charon and Montello 2002; Frank 2010).

Storytelling allows individuals to reinforce boundaries and conceptualizations of the world, sort through life's events and actively and continually respond to changing characteristics and positionalities. The fluidity inherent in narrative allows one to embrace many aspects of life, even those that may not fall neatly within a framework. These frameworks can both help and hinder the expression and listening of a story; truly listening to a tale sometimes involves looking beyond normative categories of stories to offer healing and support.

Stories are a critical resource for understanding the HIV epidemic because they offer a lens wider than any singular system of belief or model of interpretation. A blended synthesis of potentially many life influences, HIV illness narratives allow the teller to move beyond the traditionally validated biomedical interpretation of signs and symptoms to incorporate other modes of understanding and assessment. In this way, they offer the listener insight into the many dimensions of any individual's life which HIV not only impacts, but actively informs. Such insight remains critical for comprehensive treatment and support of HIV-positive individuals. Finally, because stories retain “interpretive openness,” they can help express how life may have turned



out differently (Frank 2010:34). Though a biological cure does not yet exist, a narrative approach towards the HIV epidemic helps to illustrate the importance of healing.

**CHAPTER 4**

**“LET ME TELL YOU, THE FUTURE IS PROMISING.” EXAMPLES  
OF HIV ILLNESS NARRATIVES**

## Introduction

This chapter contains pieces of stories I consider important for situating my thesis within the reality of my participants' lives. Because Chapters 5, 6 and 7 focus on the specific themes of stigma, community and religion, this chapter highlights other dimensions of my participants' narratives. I have included three vignettes: Maria, who describes a moment of self-reclamation and transformation; Cathy, who illustrates the challenges of narrative expression, and Jack, who shares the continuing difficulties he has living with HIV. These stories are representative examples of the rich and powerful stories I heard.

My desire to share my participants' "full story" stems from my assumption that my retelling of their story is equally representative of their life as their embodied lived experience. I wanted to recreate the stories I heard in Zimbabwe and the United States as if to bring readers back in time to the scene of our interviews. However, sharing narratives is far from that simple; just as our narrative encounter was full of tensions, so too is my reconstruction of my participants' words. Narratives are never simply a mirror of lived experience or "an ideational cosmos....Telling a story, enacting one, or listening to one is a constructive process, grounded in a specific cultural setting, interaction and history" (Mattingly and Garro 2000:22).

Recognizing the layers embedded into the stories below points out the construction inherent in storytelling. The participant and I co-constructed his or her narrative during our interview; I have further framed their words into a readable vignette. Recognizing the fallacy of wanting to share unmediated, uninterrupted or raw stories, I now place the vignettes into their proper social location as multiple layers of lived experiences. Doing so does not detract from their truth value or narrative importance. Rather, it marks my thesis as a co-authorship of narration about

living with HIV. Just as my participants and I shared a story during our interviews, I now offer a story to be shared with readers.

**“I started eating the way *I* wanted to eat”: Self-Reclamation**

Maria has a beautiful, shy smile and thoughtful eyes. Eager to tell me her story, our conversations are fluid, rolling from one topic to the next as she recalls different moments in her life and their relationship to her present emotions. The main tenets of her narrative are her relationship to her family, her spiritual connection to God, a transformation in her self-conceptualization and how each of these has informed her experience with HIV.

The youngest of twenty children, Maria grew up in a “dysfunctional” family. She describes a childhood full of verbal and physical abuse by an alcoholic father, sexual molestation by her half-brothers and several suicide attempts to escape it all. “Unmanageable” after years of neglect and negative attention, she turned to drugs and prostitution at the age of 14 “to cover all my pain. All the stuff that I went through, it wasn't my fault. I didn't expose myself to that. I was in so much pain that I wanted to find something that gave me gratification immediately.”

By the age of 17, with infections everywhere, people thought she had AIDS. This embodied presence of HIV became important in Maria's conceptualization of HIV and morality in the years after her diagnosis. A brother brought her to the Northeast to help her get clean and her life began to change. However, a positive HIV test provoked a decade and a half of fear of dying. Not knowing much about HIV, testing positive

was like oh my god, it was so dramatic. I just came out of drugs and my self-esteem was down on the floor. I looked like an old lady. I was just starting to get clean and look for a new life and now I got this. It was the worse news

they could ever give me because I thought I wasn't gonna get it but I did. It made me feel my self-esteem more down, that nobody was gonna love me, that I was gonna die, that my hair was falling [out]. But my hair wasn't falling; it was in my mind. It made me feel that my future was over.

Narcotics Anonymous, education about HIV and a moment of self transformation have enabled Maria to change her self-perception from an angry victim of abuse and neglect to the self-assured mother and wife she is today. She describes an incident at her mother's house as a major breakthrough in her efforts to change her self-perception. The sister who used to beat her was also visiting; as they shared a meal, Maria says

I had that fear again. Always when I see her, I was shaking like crazy. And I couldn't sit and eat. You know how sometimes when you eat, you hit the spoon with the plate? I used to do that when I was little and I would get hit very bad for doing that. So, I started eating in my mother's house, and I was shaking like crazy. And I said, 'what the heck is going on? I'm 20 years old. Nobody can hit me because I'm not a baby.' So you know what, I start eating and I start *slamming* the spoon against the plate. And I did it on purpose, you know what I mean? I start eating the way *I* wanted to eat, not the way *she* wanted me to eat before, because she couldn't say nothing to me. And since that day, I have NEVER felt no fear around her.

The italics and capital letters reflect Maria's emphasis; this incident is an act of self-reclamation as she recounts it today. She was able to break herself from her sister's abusive grasp to eat the way she wanted to. She has pride in her voice as she recounts the next chapter in her life in which she began to focus on what she wanted to do, not what someone else wanted. This process of acting for herself was scary in its newness and Maria frequently had relapses in "negative thinking", such as a continued struggle to learn new tasks at work and dating someone who verbally abused her in ways similar to her sister. She cites an irrational comfort in the familiarity of the abuse, which she gradually identified and sought to address. As she actively worked to counter these thoughts with positive ones, she gravitated towards

individuals who respected her and who she could respect and value. Maria says she often uses memories of abuse to propel her forward in life; recounting these experiences with me is an act of reinforcement and empowerment of her “new self” and reminds her of the progress she has made.

This type of empowering ritual points to the therapeutic healing of narrative expression, formation and recitation. Many authors discuss how narrative serves as a tool for self challenge and articulation (Brody 2003; Charon and Montello 2002; Diedrich 2007; Frank 1995 and 2010; Hunter 1991; Kleinman 1998). Most relevant is Diedrich's discussion of how narrative “helps one become cured in effect if not in reality” (2007:94). Maria has not been cured of her HIV, or the other opportunistic infections accompanying her status; she knows this but “feels more healthy when I talk about all this stuff.” Storytelling thus represents an opportunity to transform events, situations, emotions and characters from an “undifferentiated clump” into a meaningful structure, signifying a “therapeutic outcome” (Diedrich 2007:94). Narrative's ability to offer clarity on topics such as causality, purpose, sense of worth and connection to others, builds upon Danforth's trajectory of bringing sick individuals from curing towards healing by offering a model or framework for assigning meaning (1989). As discussed in Chapter 1, Danforth, like Diedrich, illustrates narrative's potential to move individuals through an illness experience by offering them an explanatory framework (1989:51).

Just as important to her self-conceptualization and narrative expression has been Maria's re-conceptualization of HIV. When she was first diagnosed more than 15 years ago, she thought she was nothing because she

was HIV.<sup>5</sup> I felt yucky about myself. I looked at myself in the mirror and I was only seeing myself like that. But then it changed because when you keep reading...the HIV disease is only about the immune system. I never saw it that way. I always saw it like this disease, like oh my god, all this stuff in my body, I'm going to be a leper. But then they told me that this disease is about the immune system, it's not that you're infected all over. It's inside your body only. I'm HIV but now it's like a second disease because now there are diseases that are worse than HIV.

She describes sexually transmitted infections and multiple sclerosis as worse than HIV. She also adds, "I don't want to have HIV but I compare a person that has this and that and it makes me feel good. Because I'm not the only one in this world that has diseases. But any diseases you have in your body, if you don't take care of them, you can die." By creating a community of the diseased, she reduces the power of public stigma and personal fears (Rabinow 1996). This imagined community relieves Maria of her fear of isolation; she gains strength from knowing that many people share her narrative.

She has been able to conceptualize HIV as a disease she can live with because she understands HIV as something that is "inside me but not me." Locating HIV inside her physical body has freed Maria from the public moralizing she felt earlier when she had visible sores. Her re-conceptualization of HIV as a separate entity from her personality has been facilitated and helped by medical improvements. Maria illustrates many of my participants' relief and excitement with how ARVs "hid HIV inside me."

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<sup>5</sup>I have not analyzed the particular language my participants use when discussing their relation of the self and their HIV status because of the language barriers between myself and my participants. Several participants in the United States speak Spanish as a first language; all my Zimbabwean participants are native Shona speakers. Comparing sentences such as "I am HIV," versus "I have HIV" versus "I am HIV-positive" and other variants my participants use could indeed be very insightful to their self-conceptualization and its relationship to HIV. I have resisted doing because such sentences could simply be a product of language usage and not inherently reflective of their mental processes.

Separating her personhood from her body as it is linked to HIV has been coupled with a re-conceptualization of God and her purpose in life. After her diagnosis with HIV, she “cleaned all those bad thoughts,” such as the resentment and anger she had towards God and the guilt inspired by a Pentecostal church for her drug abuse. She believes God has kept her alive as a role model for others dealing with HIV and drug abuse. Further, she sees God in a guiding role, with herself at the helm of decision-making; though God can suggest, she must be responsible and accountable for her actions.

Repositioning her relationship to God as more of an equal than a helpless sinner has been facilitated through the narrative framework she learned to use with Narcotics Anonymous. Overcoming a serious drug addiction has allowed Maria to gain control of her life in a way that was impossible “when she lived by heroin's rules.” Narcotics Anonymous taught her to see herself as a person *with* an addiction and *with* a disease, rather than an illness as her whole life. Mentally and narratively learning to separate her sense of personhood from her publicly stigmatized and moralized drug addiction and HIV status illustrates a “disease theory of addiction.” This framework operates on the premise that addicts are addicts because they have an addiction, not an inherent flaw in their person, their upbringing or their moral code (NA World Service 1988). Maria realized that she had a disease of addiction which functions the same as her disease of HIV: with diligence, care and determination, she could overcome her drug addiction just as she could overcome a paralyzing fear of death. Situating her experiences within a larger framework of self-empowerment and stage-wise changes helped Maria to partition her life into sections she could easily make sense of and address. Sharing a common narrative with other drug addicts helped her move beyond thinking about herself as a loner and failure. This has



propelled her to become the best mother she can; her past of familial abuse and drug addiction inform her mothering such that her daughter will never have to experience the life Maria used to lead.

Though she can never be sure where, when or how she got HIV, Maria prefers to think she contracted HIV from drug use as opposed to from sexual abuse by her half-brothers. This allows her to take control and ownership of HIV. It is not something God sent to her as a punishment but something she chose. While she doesn't rule out the possibility that God might be trying to send people a message with HIV, she prefers to think about HIV as a disease without moral implications. She also describes HIV as "just like any other disease," reducing the power of a public stigma she has too often experienced.

Going to church and Narcotics Anonymous positively influence her self-assurance and keep her from forgetting her past. They create a support structure and through what each institution represents, hold her accountable to herself and their respective communities: "They remind me to take care of myself. Because I can't forget that I came from the streets and that I have to take care of myself and my body and my thoughts." Sharing and repeating stories has been an important feature of the church and NA; accessing their narrative tropes has helped Maria organize and make sense of her experiences. Doing so has enabled Maria to be purposefully engaged with her family and herself as she strives to live a "normal" life, a life without drugs, where kids are safe and where people have healthy relationships.

### **"I'm not sick sick:" Challenges with Acceptance**

Cathy, a short, thin middle aged Hispanic woman, is smiling at her young grandson as we begin speaking. She seems distracted beyond her toddling grandson;

she is waiting for her ride to the methadone clinic and gets up frequently to look out the window. Through the disjuncture of watching her grandson, answering the phone and nervously checking the window, it emerges that Cathy's narrative is largely shaped by a past and present of drug abuse both in response to her HIV status as well as to other life challenges. Cathy has struggled to cope with her diagnosis and finds it difficult to answer some of my questions. Her story is disjointed and at times difficult to piece together.

She was diagnosed in 1994 immediately following the HIV-related death of a serious boyfriend and not long after her father died from HIV-related opportunistic infections. Upon finding out her status, Cathy “went crazy because that’s a big thing for me. I start doing a lot a lot a lotta dope. I didn’t even care. I wanted to die at that time. I was gonna use dope till I died.” Before she found out she was HIV-positive, Cathy describes her future as “beautiful; my mind was clear. I could do anything I wanted.” After learning her status, she thought her future was over because HIV would kill her. Now, a decade and a half later, she continues to struggle to think long-term. Her years of homelessness, heavy cocaine and heroin use and her familial and financial struggles attest to the controlling grip HIV and drug use have had on her life.

According to Rose Weitz and Arthur Frank, Cathy has an “incomplete explanatory model” for HIV because her explanations fall short of describing why she personally has been infected with the virus (Frank 1995, Weitz 1991:72). Cathy believes God sent HIV as a lesson and as a warning that the world is ending soon. She cites stories of fathers raping their children, the January 2010 earthquake in Haiti and the biblical references to catastrophe which come after moral decay as proof that “the end is coming soon.” Raised a Catholic, she no longer attends church because

she feels as though she cannot enter that “holy space until I am real.” Though HIV did not change her relationship with God, her origin story is serving as an impetus to “get ready;” this includes trying to end her drug habit, be a good mother and grandmother and start returning church.<sup>6</sup>

Cathy believes that “God gave us the virus as a lesson. God didn’t give it to me, I took it myself.” HIV is a punishment, sent from God as a moral wake-up call. In this statement, Cathy states her role in acquiring HIV, despite her inability to relate to herself as an HIV-positive individual and her strong desire to be HIV-negative. Assenting to a moral framework in which HIV is but a part, Cathy describes a religious model to explain HIV causation and her status.

Later in the interview however, Cathy seems to forget her framing of her infection as “something I took myself.” She begins to cry as she narrates her frustration and confusion at why she is HIV-positive. She does not define herself by her HIV status; she thinks she is HIV-negative because she “isn’t sick sick”. Distancing herself from her status allows Cathy to conceptualize herself as “normal,” a term that seems to signify a status that exceeds one only associated with HIV. The phrase represents her desire to be healthy, to be involved with her grandchildren’s lives and to stop doing drugs. These desires often only remain dreams as Cathy struggles with her methadone program and to monetarily and emotionally support her family. The discrepancy between her daily reality of going to the methadone clinic and visiting doctors and her ideal life therefore present a challenge for her self-acceptance and a fracture in her explanatory model (Weitz 1991:73). Though Cathy

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<sup>6</sup>I spoke with Cathy only one week after the January 2010 earthquake in Haiti; the magnitude of destruction seemed to serve as a reminder of a ticking clock towards the end of the world. Its eminent coming was a predominant theme throughout the interview, perhaps due to the proximity of our conversations to the disaster. It is important to consider this context when analyzing her story; speaking with her later in the year may highlight other concerns.

has a model for explaining HIV causation, including a personal role in acquiring the virus, it seems to fall apart, or fall short of fully explaining her HIV status.

Cathy describes herself as a good mother, and prides herself “on being the boss” of her household. For someone who spent time living on the street and continues to struggle with drug use, having control is an attribute she actively seeks. Avoiding the street has become a sign that she is addressing familial issues and thus living up to her standard of being a good mother. As part of her self-positioning in the world, Cathy creates opposite moralizing zones between the street, a place that has trapped her and made her suffer, and church, a place she strives towards.

Cathy linguistically condenses past events that occurred over decades into one short time span while stretching out events that occurred a few days ago into much larger spaces. For example, she describes taking her ARV medication routinely and not being “sick sick.” However, “routinely” is a complex term. Cathy describes adhering to her ARV treatment “for a long time now” just as she describes not using cocaine for a “really long time.” In fact, Cathy mentioned using cocaine 4 days before I spoke with her and has been struggling to adhere to her medication since she started treatment several years ago. A renewed round of methadone treatment along with increased responsibility for her grandchildren are viewed as accomplishments; she states that the love her granddaughter has for her is “saving me.” These positive moments seem to take up more narrative and emotional space, perhaps signaling their importance and the struggle that accompanies them. Her skewed framing of time may signify a coping mechanism for balancing her daily reality with what she had dreamed would happen. Equally important, it speaks to the difficulty Cathy has had and continues to have in conceptualizing her daily life as an HIV-positive person.

Cathy's distortion of narrative time and her strategy of separating her self-

conceptualization from her HIV status points to the need to analyze contradictory or inconsistent narratives beyond labeling them chaotic (Frank 1995; Kleinman 1998; Ochs and Capps 1995). Perhaps Cathy's narrative frame, though difficult for me to recognize and understand, holds importance for her as she seeks to organize life events and emotions. Focusing on how Cathy constructs her story as well as where the silences fall, may reveal more about how she understands her life history than focusing on the dissonance of her story when compared to normative narrative models. As Cathy continues to struggle with her drug addiction and her self-conceptualization, her story implores readers to struggle past the disjunction to validate and witness her pain (Frank 1995).

### **“I Like that I am Handsome, Humorous and Caring:” Learning to Live with HIV**

Jack is nineteen and consumed with all the latest trends in teenage life. With a ravenous appetite for texting and talking about the freshest gossip, it is difficult to sit him down for an interview. A true socialite, he jumps up from his plastic green chair each time someone walks through the Nyeredzi Inopenya gate. Despite our disruptions, Jack shares a chronological life narrative, organized by events and location changes. In what feels like a timeline, Jack describes shuffling houses and caretakers without a stable and consistent role model. The contrast between his jovial self and his flat tone might be a coping mechanism, or a sign of weariness at telling his story, as he recalls a life filled with rupture and sorrow.

Jack spent his childhood moving around Zimbabwe as familial conflicts and economic hardship plagued his family. He and his siblings were divided between relatives when it became too difficult for his mother to feed them all; when he was

nine he had to adjust to only two small meals a day and shortages of school and basic housing supplies. Throughout his childhood he was frequently sick and was forced to rely on others for completing the most basic physical tasks. This instilled chronic low-esteem and self-frustration and stigmatization.

Jack tested positive for HIV in 2007. He retested several times because he couldn't believe he had HIV—he had never had sex and his parents were strong and healthy before they died. Jack strongly ties physical appearance to HIV status despite knowing that “HIV can hide under people's skin so you won't know.” This correlation plagues Jack's confidence; now that he has grown with the help of ARVs, he is vigilant of his appearance for signs that “he is giving away his status.” Though he describes liking his “new ARV body,” he carries a heavy sense of physical inadequacy especially as he hopes to become romantically involved. His concerns over his sexual appeal resonate with all my Zimbabwean participants who were born HIV-positive and are now reaching sexual and cultural maturity but “are still looking like babies. Who will treat us seriously if we look like children? We need to start running *kumusha* but we can't even get a girlfriend.” Jack is speaking about the cultural expectation that young Shona men will start taking over village responsibilities and bring home a wife. The pressure he feels to hide his status and look strong is compounded by Zimbabwe's economic and political difficulties which makes saving for a bride price nearly impossible.

Jack shares that the most difficult aspect of his transient life has been the absence of a role model; his father and mother died when he was three and nine, leaving him without “anyone to make proud or to be taught how to be a good person.” He feels slighted by HIV:

I didn't do anything for HIV to come inside me. I don't hate my parents,

because you should never do that, but what can I think? If I didn't have HIV I would have a different life; I would be a different person. My health has been stolen from me, and socially, I would have many friends and happiness. I am paralyzed by HIV: When I think about myself, I think about HIV. In public- what do they see in me? Are they ok with my status? If I told them, would they still play with me? Because of HIV I look down on myself. It oppresses me. I think I can't go the extra mile because of my status. I am trying to get past these thoughts with Nyeredzi Inopenya but I haven't made an impact. I like that I am handsome, humorous and caring but these are little things compared with the pain of HIV. My family is broken and separated and people don't talk anymore because of the pain of HIV. HIV has made my life very hard. I am still very down because of HIV.

HIV factors into all the decisions Jack makes including his prospects for romantic relationships and employment, family life, self-confidence and how he interacts with friends and strangers. As a youth staff member for Nyeredzi Inopenya, Jack spends about three full days a week conducting home visits to other HIV-positive youth, making clinic referrals and holding educational workshops on positive living, overcoming stigma, and ARV adherence. He places enormous pressure on himself to inform as many people as possible about HIV; he believes that the virus is a ticking clock sent by God as punishment for human sin and a sign that the world is ending. When his clients do not adhere or fall ill, he feels personally responsible and is overwhelmed with failure. Visiting Nyeredzi Inopenya

releases my tension. When I walk in the gates, I feel free and safe from my burdens. There is a sense of belonging here that I don't know other places. I learn to be in control of HIV so I can just live. Talking creates a look back feature that helps me understand where I am coming from and where I am going. It helps me understand myself and the values and morals I have. Stories are nice to hear because I learn from others how to empower myself.

He describes the opportunities to tell stories and share the burdens of being HIV-positive as “medication for my emotions. It helps me look within the walls of fear, shyness, scaredness to realize my strength within. But I am still struggling to take these messages outside.” Jack is referring to his situational negotiation of self-

identity and how his multiple senses of self interact with different people in various times and places. He describes not disclosing his status beyond the walls of Nyeredzi Inopenya “as a security. If I disclose, I will be devalued and associated with promiscuous activities.” Jack also describes the benefit of equanimity when he does not disclose: “People don't remember much about HIV except that we have to be treated differently. Like we need special attention during sports and special food. If I keep HIV inside me, I can just be a normal kid. Also, I won't get stigmatized.”

The confidence he gains from not disclosing helps him separate HIV from his self-identity; he is slowly realizing that HIV “affects just my body. It doesn't have to affect my whole life.” This process has been difficult for Jack and is often interrupted or set back when he experiences stigma or discrimination. He describes himself as living positively with HIV because he is learning about the virus and how to live for the future as “any regular person.” Though Jack is often depressed about his HIV status, he is grateful that he didn't find out until he was 16; he feels that HIV is easier to understand now that he is older. Also, if he found out when his parents were alive, it would “have posed a challenge. I would want to ask my parents questions [about how they got HIV] children shouldn't ask parents.” Several participants also mention the benefit of not having their parents available for questioning or explanations; it would create tensions that could not be appropriately resolved but would eat away at my participants. As Jack continues to try to “move forward”, he focuses on “preparing for God, living a responsible life and enjoying friends like him.” The sense of community he feels at Nyeredzi Inopenya has become an important safety net as Jack continues to adjust to living with HIV.

## **Conclusion**



These stories illustrate some of the dominant themes among my Zimbabwean and American participants as they shared about their HIV illness experience and their lives as a whole. Many participants interpret HIV through a Christian framework as either a sign that the world is ending or as a blessing and special purpose from God. Experiences with stigma and discrimination vary from entire families abandoning participants to complete familial acceptance and little public stigma. Although all my Zimbabwean participants were infected with HIV through mother-to-child transmission, they did not learn their statuses until their teenage years. My American participants on the other hand were affected as young adults or in their early 30s through sexual intercourse and/or intravenous drug use. The mode of transmission and the sense of agency participants see themselves having in acquiring HIV affects their stories in different ways. The way they were told and the events surrounding diagnosis, such as familial deaths from HIV or personal illness, influence how my participants conceptualize HIV and their relationship to the virus.

It is important to note that my participants, with the exception of Robert, spent very little time describing the bodily experience of living with HIV. Medical complications, opportunistic infections, and drug regimes were generally absent from our interviews. In Zimbabwe this may be associated with the chronic lack of medical treatment when my participants were younger; biomedicine may not play a large role in their stories about past sicknesses as a result of its scarcity.<sup>7</sup> More broadly, it may signify a distinction participants made between our interviews and the clinical conversations they have about HIV. Though I framed my project as about HIV illness narratives and life stories, I often heard stories that only peripherally mentioned HIV.

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<sup>7</sup> At the time of our interviews, participants in both Zimbabwe and the United States had reliable access to ARVs and routine medical exams.

This suggests the many ways HIV can manifest in people's lives and the often unspoken influences one sphere of life has on another. The following chapters consider three such manifestations: experiences with stigma, community and religion.

**CHAPTER 5**

**EXPERIENCES OF STIGMA AND DISCRIMINATION**

## Introduction

Social science research on stigma has grown tremendously in the past two decades, resulting in varying definitions and conceptual models. Most discussions of HIV and AIDS-related stigma take as their starting point the classic work of Erving Goffman, who in 1963 defined stigma as “an attribute that is significantly discrediting” which, in the eyes of society, reduces the person or persons who possess it (Goffman 1963). Based on experience with people suffering from mental illness, possessing physical deformities, or practicing what were perceived to be socially deviant behaviors, Goffman said that the stigmatized individual is seen to possess an “undesirable difference.” Importantly, he pointed out that stigma is conceptualized by society; the key to understanding and addressing stigma therefore lies not only in addressing an individual's stigmatizing experience but also the larger social construction of that individual (Goffman 1963).

Since then, different approaches have been taken towards understanding and analyzing HIV-related stigma. One school of thought focuses on the individual, conceptualizing stigma as a characteristic mapped onto people, who in turn by virtue of their difference, are understood to be negatively valued in society (Alonzo and Reynolds 1995; Maluwa *et al* 2002). Such an approach leaves stigma vaguely defined (see Link and Phelan 2001) and is largely psychoanalytical, incorporating social-cognitive approaches. Another school emphasizes the social forces at work in the construction and enactment of stigma and thus analyzes societal structures such as economic, political and religious thought (Castro and Farmer 2005; Goffman 1963; Liu 2009; Parker and Aggleton 2003). This latter school approaches stigma as a dynamic relationship between individuals and society, rather than a fixed attribute.

Stigma thus becomes a social process to be understood through a biosocial framework which draws upon qualitative and quantitative methods to assess the epidemiological, social and economic impact of HIV and its associated stigma (Castro and Farmer 2005).

To broaden the lens of stigma research away from the individual receiving the stigma towards the society which constructs the stigmatizing process is to properly situate stigma as a designation that *others* attach to someone, not something *in* the person stigmatized (Parker and Aggleton 2003). Work on HIV-related stigma from authors such as Parker and Aggleton, Castro and Farmer, and Liu focuses on the structural conditions (and in Castro and Farmer's case, forms of structural violence) that are exacerbated by the many meanings assigned to HIV and which are used to exclude HIV-positive individuals.

I utilize mixed approaches in an attempt to understand the stigmatizing experiences of my participants in Zimbabwe and the United States. Rather than approaching stigma through an examination of American and Zimbabwean society, I advocate for the detailed stories of a few individuals to demonstrate the varied and complex ways in which HIV-positive individuals experience stigma. The fear that an individualistically focused approach will lead to stigma's location within the individual has already been realized by my participants. As they recount their experiences with stigma, it is evident that they locate stigma on and in their physical bodies. Some have internalized the stigma, leading to self-stigmatization. Individual responses to stigma must therefore continue to be examined alongside analysis of structural conditions. This vantage point provides a better understanding of the process of stigmatization and how various characteristics, qualities and marks are

chosen and become “spoiled and devalued” (Goffman 1963). By focusing on the active negotiation between individuals and societal conditions, I demonstrate how individuals come to locate stigma internally and thus how the societal process of stigmatization is enacted.

In this chapter I describe my participants' experiences with stigma as they occur within the frameworks of their social, economic and political surroundings. Such contextualization is critical to fully understanding how my participants view their HIV diagnosis and live with its varied consequences. I will discuss the relationship between physical appearance, religious conceptualizations of HIV and preexisting stereotypes, with HIV-related stigma. The dangers of not locally grounding HIV interventions are exposed through an exploration of how objects such as watches and baby bottles accrue stigma. Finally, I will challenge the notion of a unidirectional “stigma trajectory” in light of my participants' oscillating relationship with stigma (Alonzo and Reynolds 1995).

### **Power Imbalances and Lack of Education**

When discussing stigma, my participants implicitly, and often explicitly, place stigma within a framework of power imbalances. Sammy, a 21 year old expecting first-time mother and one of the original members of Nyeredzi Inopenya, relates HIV-related stigma in Zimbabwe both to the history of how HIV came to the country and to the power imbalances erected around knowledge of HIV. She says

HIV is a secret because we are in Zimbabwe. When it came to our country it was kept a secret. When they started talking about it, they just scared people instead of educating them. So now, to educate is hard because there are a lot of people who are still scared. Before 2000, we heard about HIV only as HIV means AIDS means dying. It was a combined disease. People didn't talk about sexual activities. People didn't understand about surviving. Only HIV is *chiwere chapedza musha* (The disease that finishes the village). And the

pictures of skinny skinny people in wheelbarrows going to hospital to die.

The “they” in Sammy's description are government officials and health personnel. Her conceptualization of stigma focuses on the power imbalance between HIV-positive individuals, those that have information about HIV and those that stigmatize. She cites the lack of education around HIV and the secret atmosphere at hospitals as key elements in the perpetuation of stigma: “They [the doctors] are trapping people. If people don't know anything about HIV, they will be scared and will listen to whatever the doctors say. Then the doctors can experiment on you. But if they give them all the information they have, the people will stop coming back. They will think things through themselves and make their own decision.” Sammy is fearful of clinical experimentation; in this instance she is referring to a fear that doctors will prescribe ARVs but they will actually be sugar pills, or some other type of medication related to doctor's private research interests.<sup>8</sup> She describes the power imbalance as most severe in rural areas; education about HIV is still very limited and often localized around a clinic post such that the vast majority of people remain uneducated about HIV. When they come to the city for treatment, “they know nothing except that they should trust the doctor. So the doctor does whatever he wants to them.”

In Sammy's description, those with knowledge about HIV enact their power over those that do not by not fully disseminating the information (Castro and Farmer 2005). This imbalance of education follows societal lines of who has access to other types of knowledge: health personnel in urban areas generally have more information than those in rural areas as a result of income status and poor infrastructure in rural

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<sup>8</sup>Sammy mentions a few times that particularly in the city hospital, doctors are more interested in pursuing research topics than treating their patients properly and comprehensively.

areas. By withholding information, health personnel contribute to people's fear of HIV. Fear of the unknown, as well as a fear of death and disease, contribute to the stigma around HIV by creating a void of information into which people insert stigmatizing ideas and actions.

Sammy's conceptualization of stigma and the role she feels doctors and hospital staff play in heightening and perpetuating fear and discrimination are consciously factored into her care and treatment choices. She narrates her sister, Loretta, having a "scary and tricked" experience when doctors experimented on her during childbirth without her consent. As Loretta began having severe contractions, she requested pain medication. The doctors refused to give the medication unless she consented to a spray treatment during the delivery of her baby. Loretta did not want this treatment nor would the doctors give her a clear explanation of the treatment. As the pain of childbirth intensified, Loretta grew desperate for alleviation. Sammy describes her sister as "almost delirious" before the doctors agreed to give her pain medication, only after forcing to give a "false" consent to the treatment. Sammy describes the consent as "false" because "my sister clearly told them she didn't want to treatment. By not giving her medication, they forced her to get the spray treatment they were eager to try. No one except the doctors knows what this spray is; they don't tell people anything in there [hospital]."

A few weeks after Loretta left the hospital, the baby began losing his hair and weight. She learned that other mothers that had the same spray treatment during childbirth; their infants were also getting ill and several had died. Health officials came to her door one day to ask after the baby but Loretta refused to speak with them. Sammy spoke with them and the two officials seemed nervous and shifty, as if they were in trouble. The baby got better but after several months of precarious health.



The experience has convinced Sammy never to go to the hospital; she now receives treatment only from out-patient clinics. When she started seeing a new doctor, she demanded all the details of her medication and treatment plan be clearly explained. Her trust in her clinicians is contingent on feeling like an equal partner in her health care choices. Once she describes sensing that her doctors were hiding something from her; she demanded to be informed and when they didn't open up, she left. She explains that after fourteen years of not having answers about the illnesses that plagued her body, she has every right to know everything the doctors know. Her self-assertion is a point of pride for Sammy after years of being stigmatized for symptoms she had no answers and therefore no control over.

Sammy is encouraged by the increased accessibility of the Internet and cell phones in Zimbabwe and their role in potentially reducing HIV-related stigma. She believes that as the flow of information becomes more available and more reliable, the opportunities to ridicule those you can classify as “not like you” will decrease as people learn that “HIV is just like other sicknesses-it’s just a sickness.” She thinks the terrifying newspaper images of emaciated people being pushed in wheelbarrows to overcrowded hospitals with shelf after shelf empty of supplies will be replaced with images of everyday people living their lives.

Robert, a middle aged Italian American, also relates access to education with HIV-related stigma. He describes a hospital incident in 1997, shortly after his diagnosis, in which the nurse’s aide never brought him his lunch tray after finding out he was HIV-positive. His anger towards individuals ignorant of HIV seeps through: “I started to cry because I realized that if I was stigmatized in the hospital, where people are suppose to know better, what was waiting outside? It was 1997. HIV had been around for a while, and here this woman was treating me like a leper.” He expects

people not to stigmatize, and “to know better” than to act “as if you can get AIDS by hugging.” His demands are highest on health professionals and those with a college education, who should “be above discrimination. Like my niece; she went to college and met all kinds of people. So she should be good at adjusting and accepting different sorts of things. But she's done with me-totally cast me away. And she went to Brown!”

Like Sammy, Robert envisions and experiences stigma as a socioeconomic and moralized entity. They both state that “there is no excuse for stigma, especially after all these years.” Sammy laughs after saying this, adding “especially in Zimbabwe where you know almost *everyone* has it. It's so sad but it's also like, hey-don't say stuff about me because I could say the same about you!” Robert does not laugh when talking about stigma; he shares that he has become more belligerent as the years have progressed: “it [HIV] is in the newspapers every day. There are movies-popular ones too, like the one with Tom Hank. What kind of excuse can people have anymore? Are they living with their head in the sand?” He has also suffered tremendous emotional distress in the years since his family abandoned him after learning he was HIV-positive.

His comments and those of other participants expose how often stigma and discrimination still occur despite what one youth described as “HIV overload.” Though the number of bulletin boards in Zimbabwe and movies about HIV in the United States may continue, more focused work must be done to educate people throughout the world about acceptance and positive living.

### **Physical Appearance**

My participants describe carrying stigma on the body in a physically tangible

sense. The relationship they draw between bodily appearance and stigma challenges the argument that stigma should not be focused too narrowly or individualistically (Link and Phelan 2001; Maluwa *et al* 2002). My participants do not experience stigma as a group of HIV-positive individuals. Nor do they necessarily have an understanding of larger societal norms or how HIV-related stigma fits into these paradigms. Stigma is an individual experience expressed on their bodies, bodies which are brought into the public realm by those that stigmatize. They describe the possibility of withdrawal from this public scrutiny only when and if their bodies are changed by medication. Approaching stigma from their individual stories offers insight into how socially constructed stigma came to be located and carried on my participant's bodies.

Sammy and Grace, a 21 year old very active in Nyeredzi Inopenya, both characterize their childhoods as times of "being the poster child for sickness." Both experienced stigma because their bodies did not grow properly. Their bodies became public spectacles through which people could judge them. At the time, no one (including themselves) knew it was HIV so the taunts and persistent questions of villagers were general ones of "why are you so small? Why is your skin wrinkly?" When Sammy and Grace began taking ARVs as teenagers shortly after learning their status, both responded positively to treatment and began growing. The "new bodies [they] got with ARVs" has meant the disappearance of stigma, and a tangible boost of confidence. Stigma was most powerful and harmful for them because it was the public judgment of a body they wanted no one to notice and one they had no explanations for. Without answers for their childhood illnesses, they felt a distance from the bodies and selves society had publicly judged. Sammy describes her body "slipping into quiet" as it filled out: "my body just became my body. It wasn't

something people always stared at, so it started becoming mine.” When her body was so obviously different from others, it was too public for Sammy to feel ownership of. As it became hers, she no longer conceptualized stigma within her physical body, but as something people did to her.

Denzel, a strong fit 19 year old, also describes stigma in relationship to physical appearance. Growing up with little illness, he did not experience stigma as a child because no one perceived him as HIV-positive. He has remained healthy throughout most of his life, which he relates to his confidence: “Because I’m strong, no one will think I have HIV. No one will treat me differently so I can just keep quiet about my status. This makes me feel stronger than HIV.” Denzel credits his self-confidence and his ability to accept his status to the minimal amount of stigma he has received: “If I was always getting picked on, I wouldn't feel this good about myself. The HIV would beat me down.” His comment demonstrates the importance of considering public opinion on HIV when analyzing different experiences with stigma as well as the relationship between stigma and self-perception (Liu 2009).

Thomas, an eighteen year old, has not received this kind of confidence boost. He has turned the stigma he used to give to others inward, believing “laughter is all around me. Wherever I go, I think people are laughing at me because I am little and weak. I hate my body. It causes me to cry.” Thomas found out his status six years ago at age 12. He has not accepted his status, stigmatizing himself and fighting serious depression. He says his life is “completely ruined by HIV. My life would have been great if I was negative. Now that I have HIV, there’s no turning back. I will never accept my status.”

These anecdotes clearly illustrate a connection between physical appearance and the degree to which participants self-stigmatize. A quiet ruthless anger seeps from

Thomas as he describes the limitations HIV has placed on his body: small in stature and strength, he is unable to work in the fields at a comparable rate with his peers. He makes explicit the connection between physical appearance and self-stigmatization: “I hate HIV because I am small. If I had HIV and was bigger, my life wouldn’t be completely ruined because I would still look healthy. But I am small and HIV-positive.” After experiencing taunting and other forms of discrimination, Thomas avoids activities which he knows will prompt questions, and friends he thinks are suspicious of his status.

This purposeful avoidance of certain places, activities and individuals demonstrates Thomas’s perception of a “stereotype threat” (Link and Phelan 2001:374). Thomas’s fear of rejection, humiliation and pain result in strained and constricted social networks, low self-esteem and a compromised quality of life. He describes spending long hours alone crying when he used to play sports with friends; he is convinced they will not want to play with him without any proof that this is true.

Addressing Thomas’s experience with stigma must involve initiatives to improve his self-perception as well as population-level interventions to reduce stigma. His story also raises questions about the “location” of stigma: is it located within Thomas's conceptualization of himself and his social network? Is it located among those he describes as stigmatizing him? Or is stigma a relationship, existing in-between Thomas and those with whom he interacts? Didier Fassin writes that AIDS is a “biological phenomenon that shakes or strengthens the existing social structures and representations but does not create them ex nihilo” (2007:32). HIV and AIDS uncover “preexisting stigmas, aggravated by the negative associations connected to the infection,” which exist within the relationships people have with themselves, others and society at large (Fassin 2007:32). HIV-related stigma,

discrimination and devaluation of identity do not occur naturally but are created by individuals and communities, who, for the most part, generate stigma as a response to their own fears (Brimlow; Cook and Seaton 2003). Addressing stigma therefore becomes a multi-pronged intervention against an individual's feelings and conceptualizations and how these interact with societal norms, behaviors and understandings of HIV.

Grace stigmatized herself in a similar fashion before her body started growing with antiretroviral treatment. As she grew, she began to like the body she had detested and tried to distance her sense of self from. Accompanying this “new body” has been information about HIV, and Nyeredzi Inopenya's supportive environment; these three facets of her life now make it easier to accept her status. They also mark a transition in Grace's self-conceptualization in which she distinguishes between her “old” self and the “new” one. Her old self internalized the stigma and discrimination she was a victim to whereas her new self has physically grown to disguise many of her HIV-related symptoms and emotionally matured to “fight off the hurtful comments.”

Maria reclaimed her body from public scrutiny in much the same way as my Zimbabwean participants whose bodies grew with ARVs. When she had sores on her body before she even knew her status, people taunted her, calling her *sidas*, a discriminatory Spanish term for HIV-positive individuals. Later, when she started treatment and gained back weight she had lost through drug use and illness, “the virus went inside me where no one could see.” Locating HIV inside her physical body freed Maria from the public moralizing she felt when HIV was an obvious piece of her physique. “Making HIV invisible” made “HIV just like any other disease,” reducing the power of stigma and helping Maria regain control of her body and illness in much the same way that Grace and Sammy did as their bodies grew with

ARVs. It also enabled Maria to separate her personhood from her physical body as it is linked to HIV. This separation was possible only after a long period of struggling to accept her HIV status, end her serious drug addiction and overcome a past of familial emotional and physical abuse. These changes facilitated a self-assurance that is obvious as she says

Now I don't have a problem to go outside and say I'm HIV. You know, (laughs), I'm gonna make a shirt that says 'I'm HIV. You got a problem?' because there's lots of discrimination outside. And I went through a lot of discrimination. But you know what? I learned that if you can't love me the way, whatever, cuz I'm not a virus walking.

Maria's conceptualization of her personhood, her body and HIV are in continuous dialogue with her surroundings, her physical health and her emotional confidence. Analyzing stigma is thus only complete when one considers the social context in which and through which, stigma and individuals exist.

### **A Challenge to a Unidirectional "Stigma Trajectory"**

As Maria narrates her shift in self-conceptualization "as a dirty leper with my self-esteem down on the floor" to the proud, confident mother and role model she considers herself today, one sees her changing experience with stigma. Her confidence improved as she learned more about life with HIV and as her body healed and grew; she no longer self-stigmatizes. However, her perception of stigma remains correlated to bodily symptoms: when she becomes ill, she grows fearful others will be able to tell that "this is AIDS sick" and will discriminate against her.

Maria's fluid experience with stigma represents a "stigma trajectory." stigma may vary within an illness experience as much as it can vary across illnesses (Alonzo and Reynolds 1995). Alonzo and Reynolds consider several medical demarcations within HIV and AIDS and the possible experiences individuals may have with stigma

at these stages or phases. Their progression from the “at-risk” stage in which individuals recognize a past or present action as “high-risk,” through physical illness and death, illustrates unique stigmatic qualities at each phase. Their outline is one of progressive degeneration of body and spirit and increasing stigma.

My participants' oscillating experience with stigma challenges this unidirectional approach. Further, Alonzo and Reynold's model is based on assumptions that do not hold true for some of my participants. It assumes that individuals are knowledgeable enough about HIV to recognize an action as “high risk” and then conclude the need for testing. Unfortunately, the individuals categorized as “high risk” or “at risk” are often the ones least informed about HIV and also have the most difficulty accessing testing. The authors also ground HIV in a biomedical sphere, assuming that individuals experience “an HIV trajectory” through laboratory tests, CD4 counts and diagnosed opportunistic infections (Alonzo and Reynolds 1995:306). My participants in Zimbabwe, infected prenatally, neither had knowledge of their status or their parents until their teenage years nor frequent medical experiences. Those in America have more regular access to medical facilities and treatments but also do not conceive of their experience solely in biomedical terms. When they discuss HIV and their embodied experiences of illness, they do not use medical language; they do not necessarily even discuss the body when describing symptoms or consequences of being HIV-positive.

My participants do, however, experience stigma in different phases. These phases are not unidirectional in the negative progression that Alonzo and Reynolds suggest, but rather contingent upon the amount of support they receive from family and friends, and their understanding of HIV. Though their different phases of stigma are indeed related to their physical health, this is only one vector of their “stigma



trajectory” (Alonzo and Reynolds 1995:306).

Alonzo and Reynolds describe stigma as “a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons” (1995:304). While several of my participants have unfortunately been in this position, it has not been the permanent change in self-perception that the researchers project. Those who experienced a change in self-perception due to their HIV status and the associated stigma, also describe a dynamic process of continual adjustments and shifts in self-perception. Several of my participants narrate only occasionally or among specific people, identifying as HIV-positive. They describe being able to “shake off” discrimination as they receive support and acceptance from family, friends and strangers. Though stigma has certainly played a role in my participants' self-conceptualization, it has not produced the “radical change” in self-identity that Alonzo and Reynolds predict (1995:304). Their model must be expanded to include the oscillating, rather than unidirectional “stigma trajectory” that my participants experience as they suffer different opportunistic infections, encounter support networks and HIV education as well as stigmatizing situations.

Robert’s complete loss of familial and friend support networks demonstrates the powerful connection between self-perception, support and stigma. Expecting his family to take care of him, their stigmatization and complete abandonment caused a crisis of self-conceptualization in which Robert was no longer able to define himself in terms of his family. He struggled with this gap between his projections of himself and the lonely reality he faced. During this time, he struggled to accept his status and was severely affected by the stigma he received from family, friends and the public. Emotionally and linguistically replacing his biological family with his clinic staff helped build a new support network which eased his lonely reality. Though he

describes himself as generally “over the blow,” and more confident in his self-conceptualization, moments of stigma still affect him, especially in times of visible illness. However, Robert’s “stigma trajectory” is not only based on his physical experience of HIV. Rather, like my other participants, the physical experience of HIV is just one component of how he understands himself and his relationship to his community through the experience of stigma.

Much of the literature on HIV-related stigma and discrimination was written in the pre-ARVs era of the epidemic, in which most HIV-positive individuals experienced a rapid and sudden loss of health without much medical alleviation (Link and Phelan 2001). HIV was therefore much more of a life-threatening illness and was popularly characterized as such. Medical advancements and earlier testing and treatment have helped HIV become a manageable chronic illness for those with regular access to healthcare facilities. These changing characteristics of the HIV epidemic are important to factor into an analysis of HIV-related stigma; my participants articulate shifting experiences with stigma as more education and medication became available. It is therefore important to contextualize not only the different experiences of HIV-positive individuals, but also the literature written about the subject.

### **Preexisting Stereotypes and Moral Overtones**

Knowledge of preexisting stereotypes is critical to understanding individual experience with stigma (Liu 2009:398). One must be aware of relevant stereotypes already attached to a group or characteristic and how these stereotypes interact with HIV-related stigma. Often, negative perceptions of HIV are reinforced by preexisting negative conceptualizations and/or treatment towards individuals society has already

cast out. For several of my participants, HIV-related stigma is particularly strong as a result of conflation between HIV and homosexuality, and HIV and leprosy.

For Robert, stigma has been experienced in the conflation of identities. A gay man who was active in the 1980s and 1990s helping other HIV-positive gay men, he resents the incorrect societal conflation between sexual orientation and HIV status:

When I got diagnosed with HIV, it was like having to come out all over again. The gay issue and the AIDS issues went hand in hand then. The smarter people knew they didn't but the majority of the population was still stigmatizing. People either hated me because I was gay or were afraid to touch me because I had AIDS.

He continues by saying, "my status holds me back [when I meet people]. The stigma is very prevalent still and I don't want to be judged as a gay person or as a person with AIDS. A lot of people just put you in a box. I classify myself as both [gay and HIV-positive]. What I tell people depends on the people I'm with but usually the last thing I'll tell someone about myself is that I have HIV." Like Sammy in Zimbabwe, Robert cites the way that HIV came to be known in the United States as instrumental in the construction of stigma. People's fear and disgust of homosexuality played into their reaction towards HIV and its victims, "doubly stigmatizing" HIV-positive individuals.

This term is an example of "structural violence," demonstrating the roots stigma has in historical processes (Castro and Farmer 2005:54). Castro and Farmer illustrate how stigma is a social and political phenomenon grounded in historically rooted social processes much larger than the physical or verbal manifestations of a stigmatizing act. Diseases have a social course because pathology is always embedded in social experience; racism, sexism and poverty exacerbate one another and add to societal conceptualizations of infection and disease. The stigma already attached to groups such as homosexuals, drug users and impoverished individuals is

only amplified by HIV and AIDS (Castro and Farmer 2005; Fassin 2007). Addressing the root causes of stigma therefore requires addressing structural violence and the many social, political, economic and historic elements that interplay with disease to create a complex and multivariate stigma experience.

It was quite distressing for participants to be perceived as lepers. Many experience stigma through a religious and moral lens, which further exacerbated the conflation between HIV and leprosy. Some also understand HIV as a sign from God that the world is ending, heightening experiences with stigma as messages of impending doom. Even those who do not interpret HIV through a religious framework describe feeling isolated as a result of people's fear of contagion. Support groups, clinic visits and religious services are cherished opportunities for hugs and embraces and for the normalcy that surrounds HIV within these spheres. When my participants feel supported and safe from stigma, they can relax about their status and joke about something which everyone around them is constantly making so fearful and dreaded.

In Zimbabwe, these jokes are often about how my participants acquired HIV. They were born HIV-positive in the late 1980s when HIV was just beginning to be understood and talked about in Zimbabwe. At that time, and continuing throughout the epidemic, HIV transmission was greatest through heterosexual sex. This immediately aligned the virus with a public moral and religious discourse of promiscuity. To relieve the tension my participants feel surrounding the stigma of being born with a virus conceptualized as sinful, they sometimes joke that they must have been "baby sleepers," sleeping around as infants. ARVs were not available when they were born; it was and still is widely assumed that anyone born with HIV before the late 1990s died within the first years of life. Therefore, the public assumption is

that my participants are falsifying their mode of transmission because it would have been impossible to have survived an HIV-positive childhood without ARVs. Grace turns the stigma she and others of her generation face on its head by describing herself as “a pioneer of the HIV generation.” Surviving into her twenties is a tremendous source of strength and motivation for her and others I spoke with. While this doesn’t inspire her to disclose her status, it does give her pleasure in knowing that she is part of the small fraction of her generation that has survived.

### **Objects as Sites of Stigma**

Beyond the physical location of stigma on their bodies, my participants also describe the stigmatization of specific objects and habits. Watches, baby bottles, pillboxes, drinking water throughout the day and eating healthy foods are several examples. Understanding why and how these objects and habits became associated with HIV leads to a historical and cultural examination of how they came to be known and understood within their specific contexts (Alonzo and Phelan 2001; Liu 2009). Performing this examination is central to approaching stigma as a dynamic process between individuals and their particular contexts rather than viewing stigma as a static or concrete perspective “picked up and exerted on people” (Alonzo and Phelan 2001:303; Castro and Farmer 2005).

Watches and baby bottles are not widely used in Zimbabwe. This is both resource and culture driven: few have money to spend on watches and baby formula. Second, it is a Shona cultural norm to breastfeed. Not breastfeeding is viewed with suspicion and fear; it is understood to be a sign of spirit intervention or witchcraft (Bourdillon 1976). As modes of HIV transmission were elucidated and bottle-feeding became a suggested practice to decrease mother-to-child transmission, the habit was

associated with HIV. Further suspicion and fear were aroused as those that bottle-fed, afraid of stigma, remained secret about their reasons. Though few publicly connected HIV and bottle-feeding, more people started bottle-feeding at the same time that information about HIV was becoming more wide spread. The two, shrouded in secrecy, were publicly aligned.

Watches also became associated with HIV through a similar mechanism. Few people in Zimbabwe wear watches. Daily agendas are organized more by task than time; people will work to finish a task regardless of the time such that knowing the exact time carries little weight. As organizations started making watch donations to children so they could better adhere to their medication, people got suspicious: why do children, who spend their days playing, need to be concerned with the time? As the rationale became publicly known, watches became a stigmatized object associated with HIV.

Several habits, such as drinking water regularly and eating a balanced diet, that Nyeredzi Inopenya emphasizes as critical to staying healthy, are often the source of much stigma. The traditional Zimbabwean diet consists of *sadza*, a corn porridge, dark greens cooked with tomatoes, and chicken. Many participants come from impoverished households, eating twice a day (or less) and well under the suggested caloric intake. As immune-compromised individuals, nutrition has an added importance which is highlighted mainly through the inability to meet suggested diets. My participants mentioned that though people may not know anything about HIV transmission or how to protect oneself, they know that HIV-positive individuals are supposed to drink water and eat foods outside of the traditional diet. Meals then become a constant source of fear as participants worry about what portion they will be served and what comments will be made. One participant remarked, “We don’t

have different food at home. We eat what everyone else eats. But every night, someone mentions that I should eat healthy. But we have no money to buy that kind of food so it just builds tension.” This tension between knowing the importance of a balanced diet, the unavailability and expense of food in recent years and the desire to blend in, add to my participants’ concerns at each meal. It also points to the utility of a critical medical anthropological (CMA) approach to HIV (Whelehan 2009). CMA, by arguing against the artificial separation of local settings from macroeconomic and political contexts, focuses on addressing structural issues such as the availability and price of nutritious food and safe drinking water as part of the biosocial framework necessary to respond comprehensively and effectively to HIV-related stigma (Castro and Farmer 2005:57; Whelehan 2009).

### **“Briefcase” Strategies and Unintended Consequences for Stigma**

HIV has connections and consequences throughout society (Castro and Farmer 2005; Diedrich 2007; Fassin 2007). Therefore, it is critically important for HIV-related organizations to consider the context in which objects such as watches and baby bottles exist before instituting strategies and practices that may create stigma. Shao-hua Liu, in his exploration of a small minority community’s experience with AIDS before and after a Chinese state agency’s intervention, demonstrates the consequences of a de-contextualized approach to a crisis so imbedded in local particularities (Liu 2009). He states that the inconsistencies between intervention models and local “moral worlds often arise when agencies employ ready-made and portable tools imported” from a Western vantage point to deal with the complexities of an epidemic “rich in historical, economic, social and cultural tension and meaning.” Ignoring local particularities in favor of “briefcase concepts” often has the

opposite effect on the situation an agency or NGO was seeking to ameliorate (Liu 2009:397). For example, he found that HIV-positive individuals in this Nuosu community suffered little stigma until the state agency held educational campaigns about HIV and AIDS, which terrified villagers. Previous to the intervention, villagers had linked AIDS to their established knowledge of illness and therefore did not identify it as a new or threatening disease. The state agency upset the villagers' conceptualization of HIV-positive individuals by describing AIDS as outside of the local sickness model. Suddenly a disease which had been seamlessly incorporated into traditional thought become a feared entity; the state agency unintentionally created the stigma they had been instructed to fight (Liu 2009).

Liu's argument for locally consistent models for intervention is particularly important to consider when discussing Nyeredzi Inopenya's model for psychosocial support and how they incorporate local understanding of the mind, body, and interpersonal relationships. Receiving large portions of their funding from American and British based donors such as UNICEF and Oxfam, Nyeredzi Inopenya is often at odds with these organizations' directions (Thomas July 2, 2010: personal communication). With the exception of their director, the organization's all-Shona staff allows them to constantly dialogue between local ways of knowing and understanding HIV and the directions they are nudged by Western donors. This largely allows them to avoid instituting poorly contextualized programs that end up creating stigma (Liu 2009).

One successful example of locally contextualized programming is Nyeredzi Inopenya's soldier game. This game educates youth about HIV, infections, antibodies and CD4 cells using Shona conceptualizations of the body as composed of strong and weak warriors and enemies. The enemies are the HIV virus and other opportunistic



infections, the warriors are T-cells. As the enemies get stronger and more unified against the warriors, the body is less and less able to control infections and the individual's CD4 count drops. When the warriors call for assistance from ARVs and a healthy lifestyle, the CD4 warriors regain their strength to defeat the enemy. The integration of local understanding and biomedical conceptualizations of the body allows Nyeredzi Inopenya to bring in new information while remaining grounded in the local context.

The game also highlights the connections between cultural frameworks, social organizational realities and the human experience of disease. In an introduction to medical anthropology, Joralemon (2006) points out that the disease-as-combat metaphor carries significant cultural assumptions about ways of conceptualizing the body and organizing social structure. Both American and Zimbabwean participants discussed HIV as an enemy to be “conquered,” “defeated,” or “killed,” and discussed no cost as too high in finding a vaccine (Joralemon 2006:8). The “never surrender” of Nyeredzi Inopenya's soldier game as well as America's framing of the “war against AIDS,” highlights the integration of social patterns with conceptualizations of disease.

Attention to local particularities involves understanding the various meanings associated with different objects or habits as they might relate to HIV (Castro and Farmer 2005; Liu 2009; Sontag 1978). Nyeredzi Inopenya once received a grant of several dozen watches from a donor eager to deliver a solution for proper medication adherence. The effectiveness of the idea however was contingent on the local context; the youth, fearful of attracting unwanted attention and stigma, refused to wear the watches. They said they would rather ask others for the time than wear a watch. This essentially got Nyeredzi Inopenya back to the original challenge with youth

forgetting to check the time and then forgetting to take medication or taking it at inconsistent times. The difficulty with time-keeping also relates back to Shona organization of the day around tasks rather than hours. The situation has been augmented slightly by the recent affordability of cell phones. However, relying on cell phones as time-telling devices also presents a challenge given the unpredictability of electricity in Zimbabwe. Though battery-powered watches last much longer than a cell phone charge, dispensing watches is altogether unviable given the stigma.

A similar situation exists for a donation of pillboxes, which were intended for storing a week of medication. The youth were to fill the slots in the pillbox for the week and carry it with them so that they could take their medication regardless of where they were. However, the pillbox, 6"x4," was too big to be unnoticed when carried. The youth liked the idea of the pillbox, citing its helpfulness in keeping track of medication. What they needed though, was a pillbox where each day's case detached so they could easily carry the individual case in a pocket or purse.

These examples demonstrate the importance of active dialogue with the local context and those the intervention seeks to impact. They also illuminate the flux between certain objects and habits and their associated meaning. Perhaps if healthy food becomes more widely available and accessible, it will not be so closely associated with HIV; if watches suddenly become very trendy, then perhaps their association with taking ARVs will decrease. Until then, Nyeredzi Inopenya must brainstorm ways to assist and educate youth without creating or exacerbating stigma.

## **Conclusion**

Several themes can be extrapolated from my participants' experience with

stigma. For some, stigma is carried on the body and experienced in relation to their physical appearance. As their bodies change with medication, their experience with stigma and the way they relate stigmatizing experiences to their self-perception has changed. For others, stigma is felt most through a conflation of identities between homosexuality, leprosy, promiscuity and HIV. These experiences are both physically marked through sores as well as through habits that society associates with leprosy and “immoral” sexual behavior. In an effort to avoid or minimize stigma, my participants create multiple and different stories about themselves. They have different stories prepared to share with people depending on the time, place, social dynamics and the reason for the conversation. Keeping track of what they have told to whom adds stress and anxiety to daily interactions. Stigma, therefore becomes an integral part of their narrative experience with HIV. The fluidity between different aspects of my participants' lives and their narrative construction of these experiences must be carefully examined when analyzing illness narratives.

Such themes have clear overtones to the societal structures which actively interact with individuals as they assign meaning to daily events and experience life as a social being (Parker and Aggleton 2003). As a synthetic process with links to broader societal notions of power, domination and social inequality, stigma can only be fully understood when it is placed within a context of relationally and dynamically produced social meanings. Doing so situates stigma within a biosocial framework, one that complements conventional epidemiology with anthropology and sociology (Castro and Farmer 2005). This approach demands that HIV-positive individuals' voices and experiences are not only heard and documented, but validated as much as “the experts” (Castro and Farmer: 57).

Approaching stigma through an individualized vantage point allows me to

fully explore my participants' experience with HIV-related stigma and how this experience fits into their larger illness narrative. Taken as one component of a story which spills from the body into culture, politics, the environment and religion, exploring stigma in this contextualized manner illustrates the importance of doing so. One cannot hope to successfully address HIV-related stigma without consulting affected individuals. It is their voices and their stories which should guide the interventions, not a globalization anti-stigma agenda (Castro and Farmer 2005; Liu 2009). Interventions must be dynamic and responsive to the changing and particular needs of clients. "Briefcase concepts" are thus detrimental to any intervention seeking to ameliorate the complex implications of HIV, a disease which demands a fully contextualized approach.

**CHAPTER 6**  
**EXPERIENCES WITH COMMUNITIES**

## **Introduction**

As I argue in the preceding chapter, one's experience with stigma fluctuates as other aspects of life, such as physical appearance, social environment and political climate, vary. Participant's experience with and conceptualization of communities also vary in similar ways. Though few participants use the word "community," each describes belonging to a group. They also describe a relationship between accepting their status and the degree of support and inclusiveness they feel from their communities. Most actively sought, and continue to seek, supportive communities to deal with the consequences of their HIV diagnosis. For some, this means finding a community to fill the physical and emotional void left by family and friends after disclosing one's status. For others, it is a search for information about HIV that brings them into the folds of a community supportive of HIV-positive individuals.

These communities however, are not necessarily related to HIV in overt ways. For example, James, Denzel, and Grace spoke of finding communion in groups as diverse as a church Bible study, a basketball team and some neighborhood friends for gossiping. Some participants have had very little change in the communities they identify with; others have completely lost touch, willingly or unwillingly, to networks they considered vital before their diagnoses.

This chapter argues that looking beyond the individual is a critical step in understanding experiences with HIV. The literature almost uniformly argues that HIV-positive individuals experience a sense of connection to other HIV-positive individuals on the basis of their shared status (Stoller 1998; Thornton 2008;

Whittaker 2010)<sup>9</sup>. These authors further state that HIV becomes, either positively or negatively, a dominant identifier and a key way individuals identify with and find communities. These connections, whether actualized or imagined, become sources of support while presenting opportunities for engagement with the society that often marginalizes them.

Some of my participants indeed described a sense of communion with other HIV-positive individuals. However, they use this unity privately for personal strength, not for activism or as capital for membership to other communities (Stoller 2010:11). Most importantly though, my participants do not uniformly identify as HIV-positive individuals or use their status to create commonality. The way they conceptualize themselves and relate to groups is situationally dependent. At times, participants describe strongly identifying as HIV-positive individuals and cite the strength of identifying with other HIV-positive individuals. In other instances, they describe “pushing aside their HIV status” to embrace other identifiers. Self-conceptualization and community identification is thus a much more fluid and dynamic process than the literature suggests. I argue that understanding relationships between self and others requires the study of context and situational dynamics.

### **HIV: Not always a primary identifier**

My participants' stories demonstrate that not everyone sees their HIV status and/or the behaviors which put them at risk for HIV as entrance requirements into a

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<sup>9</sup>I should acknowledge that the uniform position the literature I cite seems to take most likely reflects the individuals they had access to rather than the true spectrum of HIV-positive individuals. Just as my research is a product of the individuals I specifically spoke with at Nyeredzi Inopenya and the Northeast clinic, so too are researchers constrained by those that return their phone calls or surveys. All these individuals potentially demonstrate a learned way of approaching the epidemic, rather than an unmediated response.

community. This directly challenges Robert Thornton's theory that individuals gain access to HIV-related communities through their “acts of infection,” particularly sexual intercourse and sexual networks (2008:29). He claims that as private, socially invisible acts, sexual networks form the basis for unimagined communities (2008:23). These unimagined communities then become an integral part of how individuals who acquired HIV through sex identify with others.<sup>10</sup>

My participants who think they acquired HIV through sexual activity do not consider the act when making relationships with others or trying to form communities. In fact, some of my participants purposefully emotionally distance themselves from their HIV status so that they can feel part of their communities, and at times avoid making connections solely on HIV status. Thomas, the 18 year old who struggles to accept his status, deliberately partitions himself into “the boy I am at Nyeredzi Inopenya” and “the boy I am outside.” Outside the organization, Thomas disassociates himself from thoughts about HIV so that “my mind can blend in with everyone else.” Not thinking “like I have HIV” is Thomas' “access key,” to communities at church, school and in his neighborhood (Thornton 2008:29). He also distances himself from his HIV status at Nyeredzi Inopenya:

I know I come here because I have HIV. I want to come here because it is helpful to be with other people like me. But I don't think about having HIV when I am here. I never think about HIV except when I am too sad. And everywhere.... Even though I act like them, I don't feel like them because I myself know that there is a difference between us. It keeps me apart.

Thomas's difficulty accepting his status limits his engagement in communities both at Nyeredzi Inopenya and beyond as an HIV-positive individual.

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<sup>10</sup>An interesting expansion of Thornton's work would be the validity of his argument with those who acquire HIV through intravenous drug use. Do his same arguments about unimagined communities resonate with this group of individuals, about whom one could argue also participate in a “private, socially invisible acts?” (2008:23)



Though the separation he feels from others deeply troubles him, he articulates no desire to accept his status. His quote describes two different “them”s: the individuals outside of Nyeredzi Inopenya whom Thomas assumes are HIV negative, though this may not be the case, and those at the organization, whom he knows are HIV-positive. Within the organization, he feels distant from the self-confidence and positive-living that many of the youth have been able to embrace after receiving psychosocial support. Outside of Nyeredzi Inopenya, he keeps himself apart from others whom he fears and often assumes, will discriminate against him. His assumption and his unconditional refusal to disclose eliminate potentials for commonality and support as much as possible stigma and discrimination. Distancing himself from the group is a form of self-stigmatization he explicitly acknowledges: “HIV caused self-discrimination in me.”

Thomas presents a challenge to Nyeredzi Inopenya as they try to help youth incorporate their HIV status into their daily lives. He does not incorporate his status into his life or conceptualization of self. He tries everyday “to forget I have HIV.” He describes himself as a “man with much suffering;” it is from this vantage point that he positions himself towards his communities of Nyeredzi Inopenya and his neighborhood. His story illustrates the challenges individuals may have accepting their HIV status and the implications this has for their engagement with others.

Finally, this anecdote challenges the literature which suggests that HIV is unconditionally an identifier for HIV-positive individuals. HIV's priority is dynamically related to one's ability to accept one's status, which in turn is related to relationships with one's community. The circularity of this argument highlights the constant negotiation between self-conceptualization and community involvement. Thomas is unable to fully access Nyeredzi Inopenya's support because he has been

unable to accept his status and therefore is not able to incorporate it into his self-conceptualization. This renders it difficult to participate in discussions about HIV and the self, central themes of the organization.

Thomas's story also calls into question the very premise of Nyeredzi Inopenya's strategy to move HIV-positive youth into new "positive" identities. Perhaps by concentrating so dominantly on positive living, Nyeredzi Inopenya creates a standard which inadvertently leaves youth unable to access the organization's psychosocial resources. More dangerously, it may push youth that do not feel able to reach or access the standard of positive living into the margins of the physical community at organization events as well as the emotional margins of dejection or failure. Perhaps then, Thomas' story plays an important role in reflecting upon the positive and negative implications of "identity building" projects.

### **Accepting Status and Feeling Part of a Community**

The participants who identify as HIV-positive have all been able to accept their status and incorporate it into their self-conceptualization. The support and education they receive from their communities, be they Nyeredzi Inopenya or another HIV support group, a church group or family and friends has and continues to help them accept their status. Accepting their status allows them "to be more free" in their interactions with both HIV and non-HIV-positive communities. This is not because accepting their status has enabled them to disclose it to others. In fact, none of my participants openly disclose their status. Rather, accepting their status and incorporating this into their understanding of themselves has made them "more at

ease” with themselves, facilitating more “deep” relationships with others.<sup>11</sup>

Like Thomas, 20 year old Thembiso describes a relationship between acceptance of HIV status and a sense of belonging in a community. She describes how the support she receives from her family and Nyeredzi Inopenya help her incorporate HIV into her self-conceptualization. This in turn allows her to feel more closely related others. When I first approached Thembiso for an interview, she was hesitant, saying, “I don’t have much to say [about HIV] because my family loves me.” This demonstrates the strong relationship she makes between familial support and acceptance of status. It also illustrates how little she narratively articulates thinking about HIV. HIV has been publicly constructed as a scary, anxiety ridden disease which she does not consider herself to be experiencing. The virus is “not a big deal because my family treats me the same and I haven’t been too too sick. It lets me be free in life.” Thembiso describes this freedom as a freedom to relate to others and be confident both within Nyeredzi Inopenya and beyond. Her confidence actively counters stereotypes that HIV-positive individuals can never have high self-esteem simply because they have HIV. By incorporating HIV into her self-understanding, she is able to participate fully in her school and church communities because “HIV is me. I accept that but also just let it be. I act like any person would.”

The desire for regularity and normalcy, to “act like any person” is a common theme throughout my interviews. My participants, regardless of the degree to which they accept their status, do not like to think of their involvement with others outside of Nyeredzi Inopenya or the clinic through an HIV-positive lens. Though they may

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<sup>11</sup>Some may argue that it is society that needs to become more accepting of HIV-positive individuals, rather than the individuals themselves. I agree. This introductory paragraph however focuses on my participants' ability to accept their status in their own terms, as an individual moving towards a community.

identify as HIV-positive individuals within a support group or clinic setting, they do not use HIV as a dominant identifier in all their relationships. Furthermore, they do not necessarily relate to other HIV-positive individuals just because they have HIV.

This stands in contrast to arguments that HIV often replaces other identifiers such as class, race or sexual orientation as one's dominant identity (Stoller 1998:11). The priority ascribed to HIV in identifying a person may or may not be of up to the individual; society may not see beyond their status while they view themselves as, for example, a queer who also happen to have HIV. Outsiders may simply stop at queer or at HIV. In this shifting of identifiers that society and individuals make throughout the course of an illness experience, Stoller argues that many HIV-positive individuals come to identify with other HIV-positive individuals experiencing the same process of upheaval.

Paul Rabinow offers a similar framework with his notion of “biosociality.” Using the Human Genome Initiative and related developments in biotechnology as a lens through which to discuss post-disciplinary rationality, Rabinow defines biosociality as a rearticulation of the body and society (1996:91). Writing alongside the mapping of the human genome, he illustrates the challenges biotechnology and genetics place on normative social and ethical practices. He suggests that being able to sequence our genomic composition will test the boundaries of the social/nature divide in the ways that individuals feel connected to their physiological and social selves, and to other human beings. Rabinow relates

My educated guess is that the new genetics will prove to be a greater force for reshaping society and life than was the revolution in physics, because it will be embedded throughout the social fabric at the micro-level by a variety of biopolitical practices....In the future, the new genetics will cease to be a biological metaphor for modern society and will become instead a circulation network of identity terms and restriction loci, around which and through which a truly new type of autoproductio will emerge, which I call

'biosociality.' (1996:99).

He claims that new groups and individual identities and practices will arise out of these new biological truths; “it is not hard to imagine groups formed around the chromosome 17, locus 16,256” (Rabinow 1996:102). These new identities are decontextualized from their social environment to a degree I find alarming; Rabinow's opinion seems undifferentiated.

Defining the self as biological does not apply older conceptualizations of the word, that is, the socially, historically and culturally situated self. In an era of biological risk factors, it is no longer who one is, but what one does that defines the self, and his or her relationships to others. My participants, in choosing to focus on these older conceptualizations of identity, deny the priority of HIV that Rabinow's biosociality suggests. Robert, for example, uses neither his HIV status nor his sexual orientation, both (arguably) biologically relevant identifiers in Rabinow's biotechnological social world, as primary identifiers. Rather, he retains the primary identifier he has used throughout his life, that of a designer. Robert does not necessarily relate to other gays or other HIV-positive individuals, challenging Rabinow's suggestion of biological communion. He explains that “the discrimination I got from the gay community for being HIV-positive and the HIV-positive community for being gay put me off to everyone. You would think that sharing these hard experiences would make people welcoming. But they don't.”

Rabinow also suggests that older forms of cultural classification will not necessarily disappear but will have new meanings reassigned to them as the practices that constitute them change (1996:103). The multiple identifiers and their situational negotiation amongst my participants contest Rabinow's supposition that new cultural classifications (biosocialities) cross-cut, and partially supersede older categories. He

goes so far as to state that the newer categories will eventually redefine older categories. Though there is certainly interplay between classifications such that, for example, conceptualizations of HIV affect what it means to be gay in America and vice versa, I do not think older categories are completely redefined by newer ones. Nor do I think newer categories necessarily have the power to supersede or overthrow older classifications and social divisions. Robert's negative experience with an HIV support group explicitly highlights the disconnect between new HIV-positive identities and older identities rooted in racial, social and historical difference.

He describes walking into a big gym for a lunch support group; food was spread out along the side and tables were organized in pairs in the center of the basketball court. It was his first time attending this support group and he had been nervous the preceding few days. Now, when he walked into the gym,

You could actually cut the tension. The druggies were sitting at one table and Heaven forbid me, this little faggot walked over and sat with them. Then there was the black table and the Hispanic table. Those machos certainly didn't want me messing with their jive. I guess all the gays knew not to come to this group, because I was the only one. I tried really quietly to just slip into a seat, but that was impossible since everyone was looking at me. I ate lunch but didn't feel a thing. I was too paranoid someone would jump me. And gosh, I don't know what would have happened if a woman walked in. This type of thing happened all the time—groups got started only to fall apart because people couldn't work together. It was naïve to think that just because of AIDS, suddenly all these different types of people who had long-term hate between each other would just start hugging. But that's what everyone thought. So now we have the black AIDS support group, the one for druggies, the gay one, the Latina women group. So no one has to work out their differences. It does make people more comfortable, which is what a support group is supposed to do. But man, it's sad. No one is forced to examine their beliefs. Like the druggies will just keep thinking that gays, us fucking sinful guys, did this to them; that they didn't have any part. But after all that stonewalling, it's not gonna be me that advocates for change.

Robert's story illustrates the difficulty in bringing distinct groups together, often under a false or even nonexistent sense of unity. It challenges Rabinow's claim

that contemporary identities will be increasingly formulated around “genetics, immunology and environmentalism” (1996:103). Robert's frustration around the false sense of unity HIV and AIDS has created around disparate individuals also calls into question Nyeredzi Inopenya's focus on the HIV-positive aspect of an individual's identity. Not only have my participants demonstrated the fluidity with which they construct their identities, they also articulate not always (or ever) placing HIV as a primary identifier. By focusing on HIV, perhaps Nyeredzi Inopenya and their counterparts run the risk of ignoring other identifiers which may impact group dynamics and create false or shallow communities. Finally, the constant dominance of HIV in their approach to psychosocial support potentially ignores the dynamism in my participants' construction of their identity and social relationships.

### **A Space for Being Normal**

Though my participants do not always identify as HIV-positive individuals or use this identity as an access key, many do use HIV to connect to others within the realm of Nyeredzi Inopenya. While this may seem obvious, it is noteworthy in light of the distinctions participants draw between their self-positioning within and beyond the organization. The fluidity between the various frames participants use to understand themselves in the different contexts therefore both supports and argues against Stoller's notion of HIV as a dominant identifier (1998).

Though my participants do not explicitly reference Nyeredzi Inopenya as a “community,” it is clear that they cherish the sense of belonging and normalcy at the organization. Many participants credit it with restoring hope after their HIV diagnosis. Jack shares, “Without Nyeredzi Inopenya, my future would not be as bright and I would lose confidence in myself. It is difficult to relate to people I don't

know are positive because our lives are so different. Here, I know I can relate to anyone.” Put another way, Thomas says, “here, I don’t have to worry about what I say because there is nothing I can say that doesn’t happen to them. So there is no room for rumors.” The organization is a community of related individuals whom participants draw upon for strength, encouragement and insight. It is also housed in a wealthy, predominantly white and ex-patriate suburb of Americans, French and Italians. It takes youth at least one *kombi* (public bus) ride to reach Nyeredzi Inopenya. The distance from their physical home and community releases youth from fear that someone will spot them visiting the organization and subject them to questioning. Operating out of a one-level ranch with a large grassy yard, the spacious facility acts both as a “dream house” and a welcomed luxury from many of the areas the youth live. The organization thus becomes a tangible site for their aspirations in addition to acting as a physical container for the youth, who live all across a large city.

Within the sphere of Nyeredzi Inopenya, Jack considers himself an HIV-positive individual. Beyond the safety net of friends and staff, his sense of self modulates from that of an HIV-positive person to a “normal teenager who does what everyone else does.” He positions himself within his wider communities “without thinking about HIV. I like to forget I have it with them so that I can act just like them.” HIV introduces habits and thoughts which set him apart from his HIV-negative peers, or rather individuals whose status he doesn’t actually know but assumes are negative. Within Nyeredzi Inopenya, he enjoys the normalcy around topics like ARVs, abstinence and positive living. However, he consciously leaves these thoughts at the organization’s gates when he enters his larger community: “Here, we talk about things that are important for HIV-positive people. But normal



people don't talk about them so I don't want to always be thinking about things that normal people don't think about." The 6 foot wall surrounding the organization's perimeter, a standard for communities across Zimbabwe, becomes both a physical protection from outsiders as well as a mental barrier between different self-conceptualizations which Jack and his friends describe.

Though he and others take steps to distance themselves from their HIV status to feel closer to members of the wider community, they narrate struggling to relate to non-HIV-positive individuals. The majority of my participants assume that they are HIV-negative and often suffer from thinking they are the only HIV-positive persons in their communities. Others, such as Grace, "assume everyone is positive until proven otherwise."

For both Jack and Grace, HIV then becomes a common identifier, with its members making "a community of disease." Maria also uses this term to describe the bond she feels to individuals she either knows or assumes are HIV-positive and furthermore, to all the HIV-positive individuals she will never meet (Rabinow 1996:99). It is a way for Maria to deal with the isolation her HIV status first imposed on her: "I felt like I was the only one. But I knew that was impossible. Now I just think of the other people out there that have to be positive and it comforts me." Though Maria may never meet those she considers a part of her community, the unity she envisions between them strengthens her. Grace uses similar language as she elaborates on her "positive until proven" theory:

Everyone is positive until proven negative. Unless you can show me your VCT result. We are almost all the same in Zimbabwe because transmission is so high. This comforts me because I am in the group with everyone else.

However, she also says, "I don't think of myself as an HIV-positive person. I

forget my status now that I am healthy. I just take my pills and know that they will keep me alive and Nyeredzi Inopenya will keep me alive.” This apparent contradiction stems from Grace’s narrated separation of selves. When she first learned her status, at age 14, it brought relief by offering an explanation for a lifetime of unexplained illnesses for which she blamed herself. It also explained the identity of the medication she had been taking twice daily for the past year. As happens with many HIV-positive children in Zimbabwe, caretakers often hide their status and the identity of the ARVs to protect the child from the anticipated trauma of learning his or her status. This “protective nondisclosure” is also to protect the family’s honor; children are not trusted to keep the secret of having a highly stigmatized disease. This practice is questionable in who it serves to protect and the underlying subtext for needing to “keep the silence.” Grace shares that her grandmother would make up varying explanations for why Grace always had to take the pills at specific and why she could not miss a dose: “some days it was for my head, some days for the liver or my back. As a sick child, I didn’t think too much of it. I mostly was happy to get something, even if I learned later that it wasn’t the whole truth.”

Despite the relief, learning she had HIV brought depression and fear of death and discrimination: “I thought now that I knew I had HIV, other people could look at me and see I had HIV.” She was consumed by thoughts about HIV “as a monster inside my body eating me.” A story her grandmother told her about playing with a broken condom when she was very young plagued her as she learned about HIV’s modes of transmission. She says,

having HIV made me feel inferior because I was always sick. Now that I am learning about HIV and how it lives in the body, I don’t have to think that I’m HIV-positive anymore. I just have a disease inside me but it’s not me. There are two Grace’s. The one that is seventeen and below who was shy and not confident and who absorbed people’s laughter. Now there is me, the Grace

since I was eighteen. After I started going to support group and getting educated about positive living, I started loving myself and seeing that I could have initiative even if I was HIV-positive. Now when people make jokes about HIV, I realize that I laugh because I don't think of myself as HIV-positive. The funniest part is when people compliment me on my good hair. They always ask how I get such nice long hair. I just laugh inside because it's my ARVs that make my hair so beautiful. Can you believe it-they don't know it, but they are jealous of my ARVs! I am even confident enough to take my medication during class. I realized that if I just smile and drink the tablet with my water bottle, no one will think it's strange because I am so normal when I do it. If I don't make it a big deal, neither will they.

Conceptualizing herself as HIV-positive now would mean a return to the period of illness, depression and low confidence. Grace narrates this separated identity along a continuum with a clear break between selves as she gained support from Nyeredzi Inopenya. Part of living positively is acknowledging this break and using it to "move me into the future. When there is only sickness, there is stagnation and no meaning in life. With ARVs, my life gains meaning as I get healthier. It lets me leave HIV behind." HIV is therefore conceptualized in negative past terms and diametrically opposed to how she conceptualizes herself now and in the future.

Though she distances her personal relationship with HIV, she is daily involved with HIV-related activities such as running an Adolescent Corner for a clinic while HIV-positive youth wait for their appointments, and working as a youth staff member for Nyeredzi Inopenya. Commenting about these activities she says, "they make me feel good-that I am really giving back to my community so that others maybe don't have to suffer like I did. I want to tell them all about the change positive living made in my life. Like how I am studying at University and going to get a degree in Sociology. And that I will become a famous film director someday. That I will have a family and live and love them. Even the little stories like how I started to run track and even won, will make a difference. An HIV-positive girl winning!" In

sharing these stories and running clinic activities, she relates to other HIV-positive individuals while making a personal distinction between herself and HIV.

### **Community and Identity through Dance**

Laryssa Karen Whittaker describes the therapeutic power of music in articulating identities and forging new ones in the face of HIV. While the details of her argument may not seem immediately applicable to my thesis, her approach to music as a connection between individuals as well as between the different faces of one individual, resonate with much of Nyeredzi Inopenya's model. The organization is very focused on educating youth about HIV and how they can live long fruitful lives even with their positive status. It is as much about forging a new positive identity as it is about coming to terms with one's HIV status and the identity one conceptualized before diagnosis. Central to the social experience of being HIV-positive is the constant negotiation of identities that both the individual and society assign to themselves and each other (Whittaker 2010:177). While some of my participants actively seek the identities of their "first life" before HIV, others embrace their HIV status and the positive changes they feel it has brought. They use their HIV-positive statuses to varying degrees to conceptualize themselves and their roles within their communities.

Whittaker is correct that identity is often a primary concern for HIV-positive individuals (2010:177). Struggles to eliminate the negative aspects of their HIV-positive identity are often a contributing factor to the physical experience of being ill. My participants indeed associate the stress that accumulates as they worry about being "visibly HIV-positive" with their physical health. In Whittaker's example, music, with its lyrical potential and its semiotic capacity to express identities, is a

vital and potent resource for HIV-positive individuals to creatively and synthetically “work through challenges in identity.” At Nyeredzi Inopenya, a dance group fills this role as a physical and metaphorical enforcement of positive HIV identities and the ability to survive.

The surrogate family that is built through the time spent together in rehearsal and performance gives members of the dance group strength to work through the complexities associated with an HIV-positive identity. My participants would agree with those in Whittaker’s research that “people can be musically rescued from the grief that is ‘killing us’” (2010:185). The dance group members both collectively and individually discuss the transformative power associated with physically moving a body most people, including themselves, thought should be dead. The liveliness of their songs reinforces the life that the youth still have inside them and ahead of them. Performing these dances is a public statement that they, HIV-positive youth, have vitality, hope and spirit. Getting support from the audience is praise both for their skill and their mentality.<sup>12</sup>

Despite the feeling of community associated with the dance group and the support this communion brings as the youth struggle with their HIV-positive status, they do not always embrace this community or its associations with HIV. When the dance group is performing outside of the UNICEF world, the members deliberately minimize any connections to HIV. UNICEF, a major donor of Nyeredzi Inopenya, often sponsors the group to perform at HIV-awareness programs. Within that sphere,

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<sup>12</sup>The importance given to the youths' display of vitality, both by UNICEF and Nyeredzi Inopenya, as well as by the youth themselves, raises questions about the privileging of a certain kind of selfhood. Carl Elliott (2003), as previously discussed in Chapter 1, points out how construction of the self hinges on cultural norms and favored patterns of behavior. Nyeredzi Inopenya's emphasis on positive living and my selection of particular kinds of stories validate particular selves, a process that then excludes other modes of expression.

it is assumed by participants that the youth are HIV-positive; the youth assume the audience makes this connection. The youth are usually comfortable with this implied disclosure because presence at an UNICEF event is a sign of support for HIV-positive individuals.

Outside of this assumed safety net, however, the youth are very concerned about disclosure. When they introduce themselves during a performance, they do not mention their HIV status nor do they explicitly connect themselves with Nyeredzi Inopenya's goal of delivering psychosocial support to HIV-positive youth. When I ask if the audience will still make the connection between the logo on their shirts and its message to help HIV-positive youth, they answer in the negative. One youth responds very definitively that people will only think they are supporters of the organization, not clients. I was suspicious of this. At a multi-organization celebration, I thought everyone there assumed the Nyeredzi Inopenya youth were HIV-positive; in speaking with several participants, they indirectly revealed their agreement with me. The dancers did not agree. Whether they truly believe this or it is a coping mechanism, I will never know.

Navigating the delicacies surrounding disclosure at this event suggest that more complex identity work might be at play as the youth move through their social worlds. The layers to consider in a single decision about wearing a T-shirt with the organization logo on it involve overlapping, yet discrete, circles of individuals, a consideration of the motives of everyone involved and an assessment of the risks and benefits. As a multidimensional decision, the pieces are not easily extractable or necessarily distinguishable. Addressing the complexities in identifying as HIV-positive must therefore be paired with addressing the complexities of community relationships.

## Conclusion

My participants narrate the value and harm in identifying as HIV-positive both in terms of self-conceptualization and community engagement. Those that describe a separation of selves share a fear that presently identifying as HIV-positive will bring back experiences of self-stigmatization and depression. Those that do incorporate HIV into their identify often do so situationally, depending on whom they are with, their location and the reason for their interaction, as well as their physical health. My participants describe an oscillating relationship to HIV as an identifier with different symptoms and infection flare-ups. For some, becoming ill helps them relate to Paul Rabinow's biosocial community, as Maria does to strengthen herself during periods of sickness. Others despise identifying and communing with other HIV-positive individuals when they are sick because it reinforces the underlying reason for their illness. On the other hand, some participants, such as Prince and Grace, use their past illness experiences like trophies. They are the few of their generation that have survived this long with prenatal HIV infection; their physical and mental strength makes them proud to associate with other HIV-positive peers, even if only internally.

The variability my participants demonstrate between ways of conceptualizing the self and the implications different conceptualizations have on community engagement illustrates the futility of pinpointing one identity or one way of relating to communities. In this chapter I have illustrated the importance of fostering dialogue between different conceptualizations of the self and one's community as an individual works through the changes brought by his or her HIV diagnosis. I have also demonstrated the value in embracing a range of identifiers and the various meanings

they hold for HIV-positive individuals as they negotiate their status within and between communities. This approach will help interventionists understand and potentially address the advantages and challenges situational negotiation may bring to self-conceptualization and community involvement.

My participants also negotiate between systems of belief and causation as they seek to make meaning of their illness experience and other life events. The next chapter will focus on how my participants navigate Christian and biomedical frameworks to understand their HIV infection. As with negotiations of the self, using different frameworks to explain purpose and causation points to the importance of comprehensive interventions which seek to understand how individuals formulate their world and how HIV fits within this formulation.



**CHAPTER 7**

**NAVIGATING RELIGIOUS AND MORAL SPACES**

## **Introduction**

Given the strong foundation of faith amongst my participants and the importance of faith as a community discourse in Zimbabwe, understanding how religious beliefs influence my participants' understanding of HIV is critical to understanding their illness narrative. At antenatal clinics in the Democratic Republic of Congo, Maman et al. illustrate through open-ended interviews with HIV-positive women throughout their pregnancies the importance of faith, spirituality and their relationship with their pastor and church as sources of strength as they learned their HIV status (2009:965). Demonstrating the centrality faith plays for these women as a source of ongoing psychological support, all 40 women they interviewed spontaneously mentioned their faith and/or the role of their religious leaders in their disclosure and coping experiences. Though these women have strong convictions in the power and goodness of God, they also articulated the importance of medical treatment and care (2009: 968-9). Acknowledging and understanding how HIV-positive individuals and their caretakers negotiate and rely upon different belief systems is critical to developing and implementing effective prevention, treatment and care strategies.

In this chapter, I will explore a very similar negotiation between Christian and biomedical belief systems that my participants use to understand their HIV infection. My approach to religious frameworks and narrative healing is strongly grounded in Danforth's conceptualization of religion as capable of shifting an individual's interpretive framework from one of distress to one of affirmation and support (Danforth 1989; see Chapter 1). To this end, I will outline several tenets of thought that contribute to my participants' conceptualization of their HIV status and their religious belief. A discussion of the polarization of moral spaces will illustrate how

my participants actively create frameworks for separating what they conceptualize to be their past lives with past selves. These selves exist in a distinct realm from their conceptualizations of present and future selves. I will discuss the role participants see God playing both in their lives as a whole as well as specifically regarding their HIV status. Finally, a discussion of HIV origin stories will illustrate how participants use different theories about HIV to strengthen their relationship with God.

All my participants identify as Christians, though they belong to many different denominations. I have avoided, except in the most general sense, specifying or describing the churches or doctrines they adhere to because it would falsely suggest that these labels alone give insight into an individual's narrative. The variety of responses and the different directions participants have taken similar religious teaching speaks to the individuality of narratives. Grouping participants by religious denomination might lead to stereotyping and detract from the uniqueness I believe central to narrative expression. However, my participants might not agree with me. I never asked about whether or how they identify as Christians with a common narrative trope. For that matter, I did not ask if they identified with any type of narrative trope. Exploring the contribution religious denomination makes in my participants' illness narratives would certainly enhance my discussion.

### **“Learning my status brought peace to my life”**

Some of the women Maman et al. spoke with in the Democratic Republic of Congo spoke of “missing peace” upon learning their HIV status (2009:967). Many of my participants describe the opposite: learning their status brought peace of mind because it gave a name to a life of unexplained illnesses and the trials of being

publicly ill. Their diagnosis allowed them to pinpoint, to start treatment and to control a body that had often seemed lawless and unresponsive. The act of naming HIV, learning about it and its opportunistic infections brought a new sense of authority to their lives. Further, their diagnosis allowed them to begin answering questions about parents, relatives and friends' deaths.

Sammy describes her diagnosis “as finally getting to be comfortable with myself.” Learning her status seven years ago, at age 14, ended a life “of being a poster for sicknesses” and living without answers. The relief that came with identifying the cause of her stunted body and serious illnesses brings a smile to her face even now. She shares that before she learned her status, she “never had a chance in my whole life to talk about what was going on in my body.” Support groups helped her share her thoughts, which had previously been encased in silence.

Life before was like a jump ball because I didn't know what was happening; I was just always sick. I didn't know what was going on within me. My status liberated me because now I knew what was going on with me. I could go out for sports and I could socialize with people because I wasn't afraid anymore of what would happen to my body. I knew now that it was HIV. Now I could breathe around people because I had answers for myself.

The psychological relief of learning her status brought physical and emotional relief. Though she does not disclose her status to non-immediate family members, she can now make logical excuses so that people can help her should she get sick. This frees her from the stress of having to constantly be on her toes with new lies. Her relief is further enhanced by the new opportunities for storytelling that the support group invites as discussed in Chapter 3.

Sammy feels “such relief from learning I have HIV because God has given me an answer. To learn God's purpose for me in this life keeps me drinking my pills. I

want to be here to learn from Him why I have this disease.” Learning HIV's modes of transmission have given Sammy a biological explanation for her illness; faith in God will lead her towards a spiritual one. She elaborates that,

I know I need to take my medication so my body stays healthy, so that the HIV virus stays small inside of me. My strength to survive comes from knowing that—that the HIV virus is a small place in my body that most of the time is walking in the water around my body. When I drink medication, it gets stuck on the water in one place. It sticks right here [points to an area below her right breast]. That is where I always hurt the most so HIV must get stuck there.

But I need to believe in God too because He is the one that puts us here and gives us ARVs. These pills are His relief for our suffering. He sees it but He has given us HIV for a reason. I don't know that reason but I want to learn. So I take my pills so I can learn from God.

Conceptualizing HIV in this very specific way and locating it in a finite place in her body gives Sammy control of her status. It also frees her from “letting my whole self be HIV-positive.” Learning the biology of HIV has allowed her to separate her sense of personhood from her illness: “HIV is still me but I am more than just HIV-positive.” Faith that God will reveal His purpose for her “stretches me to boost my mind beyond just thoughts about HIV.” Most of my Zimbabwean participants, many of whom also had childhoods of inexplicable illness and public questioning about their bodies, share very similar language and mentality as Sammy. Phrases such as “HIV freed my mind,” and “it is life-enlightening to learn your status” as well as discussions of the relief that came with the ability to place their illness experiences into a comprehensible framework, serve to challenge opinions that learning one's HIV status is experienced only negatively. Using both biological and religious frameworks for understanding their HIV status, my Zimbabwean participants predominantly describe relief, calm and a new sense of purpose in life upon learning their HIV status.

### **Is HIV a blessing from God?**

Both American and Zimbabwean participants pose this question to themselves as they seek to place HIV in a comprehensible and meaningful framework. For some, understanding HIV in terms of God's purpose for their life or as God's consequence for actions that put them at risk for HIV, comforts them. For others, separating God from their HIV status positions Him outside their illness as a Being they can turn to for compassion. For all my participants, God is conceptualized as a loving, healing and compassionate God who, even if He placed HIV on Earth to signal its end, is available to hear their prayers and give them an outlet for their suffering. These outlets are interpreted in the form of support groups, understanding friends and relatives, ARVs, prayer and compassionate pastors.

Twenty-two year old Prince, one of the first members of Nyeredzi Inopenya, is one of several Zimbabwean participants who understand his HIV infection as a blessing from God. Of the nine individuals I had full interviews with in Zimbabwe; six frame HIV as a blessing by describing the opportunities they have received as a result of their positive status. Prince's narrative is demonstrative of their conceptualization of HIV as a religious opportunity. Viewing HIV as his "special path from God" gives Prince a purpose he didn't see himself having before his diagnosis.

Before he knew his status, Prince describes himself as a "fun-loving person enjoying life for myself only. Also, I was a simple prayer kind of person-a lazy prayer person. With HIV, I see the many dimensions of life; like that God didn't just give me life, but gave His only Son for me to live abundantly." Placing his infection inside a Christian moral framework gives him a sense of heavenly purpose and strength that he wants to share with others. He has combined his religious language with the

psychosocial support framework he has learned from Nyeredzi Inopenya to create an image of himself as Jeremiah, humbly fighting HIV and spreading the gospel of safe sex, positive living and thanks to God.

The fear and confusion my participants describe when they first learned their status often disappears as they negotiate systems of meaning and belief systems.

Grace, another founding member of Nyeredzi Inopenya, uses similar language to Prince as she describes the relief and clarity she felt upon placing HIV and her life's events into a meaningful framework. Doing so allowed her to break with a self she describes as "only HIV" to enter a life in which she is "more than just my status." Creating a system of meaning around HIV allows Grace to control her body and thoughts in a way she couldn't before she was diagnosed. Though her HIV is not cured, Grace and several other participants feel healed from the suffocating fear and silence they lived with before (Danforth 1989; Weitz 1991).

Rose Weitz discusses the importance of using frameworks as tools for comprehending the often incomprehensible turns one's life takes with HIV. In her analysis of interviews with HIV-positive Arizonian men and women in the late 1980s, she illustrates the decreased anxiety and stress that accompanies searching for and creating an explanation around acquiring HIV. She states, and many other scholars agree, "simply having an explanation makes it easier to tolerate the illness" (1991:72 see also Danforth 1989, Diedrich 2007, Frank 1995, Kleinman 1988). Regardless of the type of framework individuals draw upon, it is important that they make it their own and that it satisfies their healing needs.

Describing the opportunities Prince has had as a result of his positive status, such as participating in Nyeredzi Inopenya activities, traveling to various functions, receiving counseling, food and clothing, make Prince think "HIV is a blessing in

disguise. I have actually benefited from having HIV. No one would think that that is possible when they get the shock of being positive, but I look at my life and it wouldn't have been possible if I wasn't HIV-positive.” The organization has sponsored a class in NGO management, which he never would have had access to alone; they are even helping him plan his dream organization– he wants to be able to teach rural kids about positive living. Other youth comment that even though they have HIV, now that they have ARVs and education about the disease and positive living, they are “no longer depressed about their status and actually much better off than the rest of Zimbabwe.”

These comments reflect both the importance of psychosocial support for HIV-positive individuals as well as the dire situation of the majority of Zimbabweans. One youth says, “everyone here needs food and counseling. We're the lucky ones. Who would think that the lucky ones are the positive ones?” Some describe feeling guilty about receiving such good care when their neighbors are struggling, Grace, who feels blessed to have “been brought back from death” by Nyeredzi Inopenya is particularly struck by the number of schoolchildren continuing to test positive and the scarce resources which always seem to be dwindling: “the reality is that almost our whole country is positive. Everyone needs the kind of help we get here [at Nyeredzi Inopenya]. But there are only so many dollars.”

This grim analysis turns one towards Maslow's hierarchy of needs among extremely limited resources. Abraham Maslow, a famous psychologist of the 1940s and 50s developed a theory of human motivation, which stated that the driving force of humanity was the actualization of a hierarchy of needs (Simons, Irwin, Drinnien 1987). He believed that needs are prepotent, completely consuming an individual until the need is met, and that these needs are hierarchical in order of fulfillment.



Basic needs such as food, water and shelter must be secured before issues of safety, love, esteem and self-actualization can become a priority. In contexts of extreme poverty and untold need, interventionists are forced to decide who is lowest on Maslow's hierarchy of need. Deciding who is the most needy, and which needs are the most pressing or important to alleviate can be fraught with moral, political and social undertones of human worth and societal value. Robert joins my Zimbabwean participants in recognizing these dilemmas and interpreting his involvement in systems of support as a blessing from God. He apologetically says, "I'm just really thankful that I'm American and that I found out when I was an adult; I just pray and pray for those poor African children." Not knowing I also interviewed Zimbabwean youth, this comment is particularly moving.

### **Ongoing Support through Faith**

Understanding their involvement in Nyeredzi Inopenya as a blessing provides my Zimbabwean participants with a critical source of ongoing psychological support. It provides a framework for answering questions that persistently trouble them such as "why am I [still] here" and "why am I [still] sick?" I have added [still] into these questions to distinguish between the different questions my participants, American and Zimbabwean, ask themselves at different moments. During periods of health, my participants question their future and purpose in life. During illness, they focus on their role in this world and the reason and purpose for their suffering. The participants who accept their HIV status conceptualize HIV and opportunistic infections as trials from God and chances for personal and religious growth. Their faith comforts them and points them towards an answer for their infection. Most describe their purpose on Earth through others—they are heroes who have survived as testimony for living

positively and confidently with HIV.

My participants narrate a process, rather than a moment, in which they came to understand their purpose in life. Some describe an evolving sense of purpose as circumstances in their lives changed. Robert struggled after his family abandoned him and after his parents died: “when I first learned I was HIV-positive, and went through hell and back in the hospital, I knew God had kept me alive for my parents. But after they died, I didn't know why I was here.” Counseling, the strength he gets from his clinical staff and his faith in God, have “shown me that I am here to stop people from killing themselves from depression about HIV. No one should do that. I didn't do that. I can tell people my story so that they come through the shock stronger.” Participating in my interviews was therefore an opportunity for Robert to reaffirm his life's purpose.

Conceptualizing their illness experience through a faith-based lens also influences how my participants understand and structure time. Some participants conceptualize time in several dimensions, making distinctions in time that accompany self-transformations or moments of clarity. The way Grace describes time is representative of several of my participants who see divisions in their lives as a result of their HIV diagnosis. Grace structures time around her HIV diagnosis and then further, around the time she starting “becoming her new self.” She also reflects upon memories and past events differently depending on her health in that past moment. For example, past routine clinic visits carry different weights in their present narration depending on her health at the time of the visit. Tremendous narrative importance was placed around clinic visits that occurred during ill health, even if the result of the visit was inconsequential. Grace narrates that seeing HIV as a work of God has helped her to conceptualize time in the present and future as something that

is possible for her to have. She cites the emphasis Nyeredzi Inopenya makes on positive living as complementing her religious belief that people are put on Earth for a specific reason and should strive to fulfill God's expectations.

### **Negotiating Moral Space**

In addition to using narrative frameworks to assign meaning to life events and a conceptualization of time, several of my participants create moral spaces and spheres in which they physically and symbolically locate different life events in a process of assigning meaning and order to experience. Cathy, Maria and James have all struggled concurrently with HIV and serious drug abuse. Using a Christian framework of struggle, consequence and reward, their faith in God and the possibility of personal improvement with divine assistance has helped them to make sense of their lives and assign meaning to their HIV diagnoses. Their Christian framework is remarkably consistent with the narrative Narcotics Anonymous follows through its Twelve Step program, which Maria and James completed (NA World Services 1988). Additionally, Maria and Cathy have used personal standards of good mothering as a marker of control over their drug habits and their responsibility to God.

These three individuals actively maintain separate moral spheres as a way of organizing their life experience and retaining control of a body and self that have often been servants to addictive narcotics. Each describes a certain type of identity or position that one must occupy to honestly and respectfully enter a church. Cathy describes that she can no longer go to church because "I have to be real. I can't pray and be in the holy place and then come out in the streets. That's not right." Maria describes going to church as "ok only if you are in the right mind. Like you think about God and being holy not about drugs and the streets." These women, like James,

assign opposing moralities to the physical locations of the church and street, enhancing their metaphorical significance as locations with specific conceptualizations of selves and assigned moralities.

A mental separation accompanies the physical distance these participants strive for between what they narrate as two polarized ends of the spectrum of their life experiences. These ends, the world of the street and that of church, carry publicly judged moralities. Life in the street is associated with drugs, prostitution, crime and sin, each of which is decried by their churches. The street is the location of moral decline, a place without control that leads “to places you never wanted to go.”

Though Cathy, Maria and James cannot definitively locate where and when they contracted HIV, each describes the street as a place that makes you “sick” regardless of HIV status. “Sick” implies moral and mental illness as well as physical disease, all of which are publicly judged. Uniting the street and church would unite the sacred with the profane in a way that would breach the boundary actively constructed between street life and the life my participants are trying to live now. For Cathy, who is still struggling with her drug addiction, this boundary is more permeable than she wants it to be. For Maria and James who have more distance from their lives with drugs, the boundary strengthens their resolve to remain clean.

This active maintenance of separate moral spheres illustrates how metaphorically distinct realms act as frameworks for organizing life experience. My participants narrate events that happen “in the street,” “after the street,” “in my life now,” and other such phrases which suggest the power of mental and physical boundaries in the narration and active living of their present and future selves. Importantly, each conceptualizes the beginning of their experience with HIV in the “street.” Associating the root of their experience with HIV with their street life has

allowed Cathy, Maria and James to conceptualize HIV as “a disease anyone can get if you don’t take care.” This reduces feelings of personal guilt and blame as well as the scariness of contracting an incurable progressive disease. For Maria and James, it also leaves available religious frameworks as sources of comfort and respite. They describe God as “caring about HIV,” implying that He will acknowledge that they contracted HIV through sin, but that He won’t “stop loving us.” This is an especially important realization for Maria who suffered many years of depression surrounding her guilt over her contraction of the virus in addition to fierce stigma and discrimination. Maria describes HIV as “something that I did because I looked for it by being on the street.” James and Cathy use similar language of “taking HIV.” Claiming personal responsibility and involvement diminishes the possibility that God sent HIV personally to them as a warning or message. It also diminishes the fear surrounding their diagnosis by allowing them to relate HIV to any other disease “that can be taken.” Maria gives examples of diabetes and asthma, which she sees one being equally susceptible to if one is not careful.

My Zimbabwean participants in contrast, do not position themselves as responsible or at all involved in acquiring HIV. Acquiring HIV through mother-to-child transmission, my Zimbabwean participants attach a different sense of agency to their HIV infections than my Americans participants who acquired HIV through a combination of drug-use and unprotected heterosexual and/or homosexual intercourse. These different positionalities generate different relationships between their sense of self, God and their explanations for HIV's origin.

### **HIV Origin Stories**

Although some of my participants understand their HIV infection as

punishment for personal and societal sins, none conceptualize God as menacing.

Several of my participants, both in Zimbabwe and America, see HIV as a lesson God sent to the world; in Prince's words, "we have gone too far from His ways and He is trying to bring us back." Some point specifically to prostitution and alcohol consumption, others to war and bigotry. For each participant who shared an HIV origin story, they utilized the same framework to explain both generally and specifically why HIV exists and why they have it. It is revealing to note such consistency in frameworks among participants that feel satisfied with the explanations they have, against the difficulty other participants have in explaining HIV specifically and generally.

My Zimbabwean participants conceptualize themselves as innocent victims of disease; they do not see themselves as personally responsible for their infection or for its origin on Earth. Prince's comment on his status is emblematic of my Zimbabwean participants:

I was just born. I played no role but I also can give no blame. HIV is just one of those God-sent diseases for mankind's sins. Not punishing us because look around, there are plenty of disease. Don't dig into that [explanation for HIV]. Leave it to the scientists. God has His ways to make people repent from sins. [With HIV], He's instilling knowledge and wisdom to decrease the impact of sin.

Using a religious framework as an explanation for why they are HIV-positive places my participants' personal suffering into a larger cohort of individuals who turn to God for answers and strength (Plattner 2006). Even participants who describe HIV's origins in biological terms express feeling comfort from this sense of collective identity when they are stigmatized and isolated. Physically coming together as a cohort of HIV-positive youth at Nyeredzi Inopenya events or in a church service provides tangible evidence for this community. The collective is particularly powerful

because it reaches beyond those they know are HIV to all individuals who use prayer for strength and clarity.

Among those that believe HIV was sent by God, several specify that the virus is a sign that the world is ending, Cathy joins many of my Zimbabwean participants in narrating her preparation for “coming to God.” A sense of impending doom creates daily panic and frustration when she feels that her preparation for God is inadequate. Jack also interprets HIV as a biblical sign that the world is ending. Though he shares some of the same fear as Cathy, he has not been paralyzed by it. He believes that God is

Creator of everything under the heavens. Because He loves us, he brought Jesus to die for our sins. A time will come when the sinners will perish versus you which are pure. Diseases will come to signal the end is coming as shown in the Bible. Crime is at its highest; there are wars and diseases we can't understand. This means I have to be prepared—I need to accept the Bible and will be found on the good side of the Lord. This makes me feel scared because most of the time I feel that I do bad things. I think about the world ending everyday but I know God is helping me do good.

Grace also understands HIV as the word of God being fulfilled. However, unlike Jack, her acknowledgment that the world is ending does not scare her. It is just the background state of her life: “I was born with HIV already here in this world.” Her trust in God is unconditional; if she follows His plan for her, she has no reason to fear. She continues,

If you go to the Bible, you will see that there will be diseases that cannot be cured. This is punishment for the world's sins. So the world is coming to an end. It makes me feel nothing because I was born into people talking about it. Everyday you're not sure you'll live but I still plan for the future even if I don't know if it will come. In 1999 I was in grade 4 but already had plans for grade 7. This world ending is just like death—it could happen anytime. Whatever happens, I'll wake up on the other side.

Cathy, Jack and Grace illustrate three different reactions to the same

interpretation of HIV as a biblical sign of the approaching end of the world. Each are important to understand in the context of their treatment and care choices. Cathy has struggled with a cocaine addiction as well as with medication adherence because she sees futility in personal action in the face of God's power. Jack lives with an enormous amount of self-inadequacy that he has not successfully prepared himself for God. This affects his self-esteem and the choices he makes, especially regarding the future. Grace on the other hand, has not let her biblical interpretation of HIV stop her dreams: "everyone in this world has conditions that affect them. And everyone has the same condition that the world will end someday. Mine [HIV] is no different than theirs so none of us should let it affect our lives." This positivist attitude has allowed her to take control of her HIV rather than letting it "consume" her.

Robert conceptualizes HIV in another framework entirely. He believes HIV was a government conspiracy, noting that the sociopolitical environment of the 1970s and 80s, the emergence of "this gay disease" and the homosexual movement for equal rights were too aligned for HIV to have happened any other way. He keeps God separate from his understanding of HIV causality so that he can "look to God for support, not blame." He views HIV as something that happened to him, an external entity that "came to live with me" through no fault of his own. This hands-off rationale fits with the removed nature of germ warfare in a way that may have made accepting a life-threatening diagnosis easier at a time when he had just lost his family and many friends' support. Understanding HIV in terms of personal innocence also frees Robert from the guilt that is often socially pushed onto HIV-positive individuals, especially male homosexuals.

Despite this hands-off rationale towards HIV, Robert adheres to his medication regimes and is very deliberate in learning as much as he can about HIV. In



much the same way as participants who put full trust in God for their physical healing, Robert unconditionally trusts his clinicians. He states that through the most awful bouts of side-effects from medications or procedures, he has stuck to his doctors' orders not only to impress them, but to respect them as much as they have respected him. Importantly, Robert actively incorporates HIV into his visions for the future as much for himself as for his clinicians. Despite the trials he has had to face as a direct result of HIV, he has never viewed his diagnosis as a death sentence. This is particularly impressive when one remembers that Robert was diagnosed in 1997, only 1 year after the discovery of the “cocktail.” In a moment of declaration in our interview Robert proudly shared that he “can stay on pity-potty or get off and fight.” As he continues to work through the changes HIV has brought to his life, he seems determined to stick to this motto, envisioning a future bright with flowers and children playing. Believing God is in his heart, Robert is secure in his life mission of teaching and comforting the newly diagnosed in hopes that they won't have to struggle as hard as he did.

The variety of interpretations and life directions these interpretations lead to suggest the importance of understanding HIV from within HIV-positive individuals' supporting frameworks. From such a perspective, it becomes possible to consider the purpose these HIV origin stories serve for my participants. What purpose or meaning does Robert gain from constructing HIV as a government conspiracy against Haitians and gays? What “work” does Prince's explanation of HIV as God's blessing serve do as he organizes his life experiences? This approach may shed light on treatment and care choices, behavior patterns and life outlook. Acknowledging the different interpretations and ways of assigning meaning to HIV illness experience is a step towards ensuring HIV-positive individuals' concerns and needs are effectively met.

### **Agency within Spiritual Transformation**

An equally informative area to consider in understanding HIV-positive individuals' framing of their experiences is how they position themselves as actors in their lives. James is one of several participants whose narrative illustrates the use of a Christian framework for interpreting life's events. Humility plays a large role in his story of "spiritual transformation" from thirty years of drugs and panhandling to the one he leads now. The influence of Pentecostal spiritual narration and Narcotics Anonymous framing is apparent in the way James organizes his story and understands life events. God, as well as James's sense of individual responsibility, contribute heavily to how he understands his HIV diagnosis and addresses it on a daily basis.

James was diagnosed with HIV in 1985 during a period of incarceration. Driven solely by heroin and unconcerned with the consequences of his actions, his positive diagnosis didn't register as something he should be concerned with. For almost twenty years after his diagnosis, James continued to use drugs, panhandle and live on and off the streets. However, in 2004 James experienced a "spiritual awakening" in which God showed him a better future. This awakening represents a turning point in his life and is the pivot point around which James organizes emotions, experiences and ways of understanding the world. Drawing parallels between himself and Job, James constructs time and morality in two dimensions: before and after his "rebirth." He narratively constructs these portions of his life on polar axes, existing in separate realms, with separate ways of thinking about the body, himself and HIV. In our interview, he positions himself opposite his incarcerated self in a way that reiterates and reinforces the boundary and prevents a return to "sick

thinking.”

Recounting in great detail a process of “spiritual transformation,” James's story emerges as a quest narrative (Frank 1995:115). James shares how several events including getting arrested for drug use, meeting a mentor in jail and relearning skills like paying bills and grocery shopping, capitulated him into a new self. His last incarceration began what Frank calls an “occasion of a journey that becomes a quest” for rebirth and spiritual renewal (1995:115). Through James's “spiritual awakening,” a sense of purpose emerges and he describes himself as “a newborn baby, ready to learn how to make things right” in his life. The dream is that:

One night I was in my cell and I was having all this wicked crazy nightmares. And the nightmare was that the police were chasing me, canine was chasing me, some drug dealers I had ripped off were chasing me, my family was chasing. I can remember running and running and I climbed up this fence and I tripped and I fell. And when I rolled over on my back, I looked up and that whole group of people I just mentioned were standing around me. And I opened my eyes and I could see the walls of the cell but I could see those people too, standing over me. And I could remember closing my eyes and talking to God and saying, ‘God please, if you just take this away from me right now, I won’t turn my back on you again.’ And I closed my eyes, right, and I opened them, right, and they were gone and I can remember getting on my knees and crying like a baby, right, and praying to God at like 3 o’clock in the morning. My cellmate was banging on the door, calling the CO, saying, ‘he’s going crazy.’ It was such a beautiful feeling. And from that point on, peace came over me, you know, I was happy to be locked up, you know. And uh, I just started taking direction and signing up for groups.

Referring to his mentor as “a vessel sent from God,” James gives credit and power to God for the transformation in his life: “I didn’t do this. God did this, ok. Yes I was a willing participant but He led the way.” This is a remarkable shift from the responsibility James claims for his actions before his spiritual awakening. He narrates himself as fully responsible for the years he spent panhandling and engaging in high-risk unprotected sex and drug use. These actions, including getting HIV, are each conceptualized in a negative framework as actions where he was the central actor.

This type of agency separation closely follows the Twelve Steps of Narcotics Anonymous in which addicts are led to take responsibility for their addiction and to surrender themselves to God for renewal and rebirth (NA World Service 1988). The process of his spiritual transformation and the events that precipitated are “the work of God” (bracketed questions are those of the interviewer):

[Can you tell me a little bit more about how you were involved in that change?]

By having an open mind in order to listen to the person that God used as a vessel to come and talk to me, ok. Because, whether we realize it or not, everything we do is a part of God's plan, down to the way we blink our eyes. And He knows what's gonna happen to us before it happens. And sometimes He'll let us go through. You say to yourself, people say to themselves 'God, why is this happening to me?' You think He's supposed to be there to pull you out of the fire before you fall in. But He'll let you fall into the fire for a reason, ok. And I contribute my testimony as similar to Job. Job told the Devil, 'do whatever you want to do to him, but don't take his life.' ok. And that's what happened to me. The Devil did everything he possibly could but he didn't take my life because God had another plan for me. And I was so grateful when He sent that person as a vessel to talk to me, right. Because we want God to come down to talk to us personally, but that's not going to happen. So what He does, is he sends someone else...I knew no matter what I went through, that God was there for me. I knew He had my back. I knew He was gonna see me through.

[How did you know He was going to have your back?]

To keep it simple, because He's God. That's it. There's no more explanation about that. I don't question God. I don't question the Word of God. It is what it is, you know. You can twist it but it's God's word. And just like it applied thousands and thousands of years ago, it applies to people today. Am I perfect, no...but I know right from wrong.

James's spiritual awakening and self-reconceptualization mark a departure from Frank's outline of quest narratives which center on an active narrator, claiming life's interruptions are the grounds for a transformation (1995:134). James indeed takes his last incarceration and awakening dreams as the grounds for a quest but places agency and direction in God. Following NA's framework of submission to a Higher Power in hopes of curing “spiritual sickness,” James's story illustrates the

need to expand Frank's quest model (Frank 1995; NA World Service 1988:91).

Although he may not explicitly claim agency in the way that Frank describes, James does conceptualize himself as involved in his quest for transformation and devotion to God by responding to God's call for change and following the NA Twelve Step Program.

James's word choice resembles language common in Pentecostal narratives of religious rebirth. He describes a “a break with the Devil” as he distanced himself from “being full on into the disease of addiction; it’s almighty if you let it rule you.” This phrase is verbatim from Narcotics Anonymous, which describes addiction as “an incurable, chronic, progressive and fatal disease. Though it is treatable, it is never gone” (NA World Service 1988:7).

James applies this same language to his understanding of HIV as “diabolical: if you let it, HIV can kill you.” HIV “isn’t really an issue” for James perhaps because he has been fortunate not to have suffered from serious opportunistic infections or perhaps as a result of comparison with other life events. In a deeply religious testimonial, using the word “diabolical” for HIV, which James associates with his reckless street life, locates HIV in his past with a past self, in a time and body that he is determined not to revisit. This helps him control his thoughts about his past as well as squelch the possible control HIV could wield over his present. He understands HIV as something he must “keep tabs on” but will not control him unless he lets it. This cognitive awareness helps direct James towards the moral space of Narcotics Anonymous and his Pentecostal Church. He shares that he has almost completed the NA Twelve Step program; “there are just those nagging things that trip me up.” His regular involvement at church, his job and his NA meetings propel him towards “whole acceptance of God. But at the current moment, I'm not all the way there.”

The control James now seeks over his HIV status and division between past and present selves reflects a conceptualization of illness as intrusive. Charmaz divides experiences with, and definitions of, illness into three categories: illness as interruption, intrusive or immersion. James, as well as a few other participants, views illness as intrusive, “tightly packaging the illness and self” (1991:66). He imposes strict routines and checklists on his daily activities and distinctively separates his sense of self into two realms, before and after his spiritual transformation. Thinking about “tomorrow today might ruin how [James] think[s] of today.” This allows him both to control his HIV status as well as limit the possibility of a drug relapse. This constant cognitive awareness, “guarantees” that illness will not seep out of its containers unexpectedly into other realms of James's life (Charmaz 1991:66). This technique is integral to Narcotics Anonymous and Pentecostal frameworks of daily prayer and meditation over life's events and an individual's purposeful movements (NA World Service 1988; Poloma and Green 2010). Unfortunately, these frameworks offer little advice when illness does spill beyond the containers. For James, illness encompasses HIV, his drug addiction and his “sick thinking.” Recognizing and validating the many layers of illness experience and their interactions thus becomes critical to effectively and meaningfully assisting James as he continues to dynamically interact with his past, present and future conceptualizations of the world. It also highlights the importance of considering the religious and spiritual dimensions of illness experience as a source for understanding an individual's response to HIV and the changes it makes in his or her life.

### **Linguistic Shifts**

In addition to considering the narrative trope an individual uses for framing his or her experience with HIV, it is revealing to consider the particular language he or she uses when discussing HIV. Leap suggests that there is “meaning which grows out of the speakers' use of language but also meaning within the structure of language itself” which can turn the flow of discussion in very particular and revealing ways (1990:156). Considering the therapeutic and creative powers of language is therefore an important tool for elucidating how an individual positions him or herself relative to an HIV diagnosis, relationships with family and friends or other important aspects of life. Although I have not extensively examined my participant's language use because most are non-native English speakers, I have analyzed some of my participants' pronoun shifts.

James's descriptions of accepting God and the changes He introduced reveal an interesting linguistic shift as he talks about things he wants, or something he does. As he said, “Because we want God to come down to talk to us...” he switches from using I statements to an inclusive we. He makes other shifts, from “I” to “you” when describing how people remember God only while *they* are in jail, or when *they* blame God for things that have happened, as well as when he is describing how drug addicts may give up drugs but always clutch to something. Upon clarification, James openly admits that he did and wanted all of these things.

Leap illustrates how specific verb and personal pronoun preferences while discussing HIV may be potential clues into how individuals conceptualize HIV and his or her personal relationship to the virus. For example, indirect references, indirect verb and personal pronoun usage may reflect the speaker's conscious decision to

remain distant from HIV. On the other hand, a willingness to use the term HIV or AIDS or active verb phrases such as “I got HIV,” may demonstrate a certain level of success with dealing with HIV's impact on an individual's life (1990:148).

Leap's discussion lends insight into James's linguistic shifts as a potential tool for putting distance between his past and present selves and the mentalities and actions he associates with these two components of his life. Each action James describes as things “you” do is characterized as a fault or something he is ashamed of. Starting a vignette with “I,” James switches tone and personal pronouns as the story reaches the climax of admitting participation in a high-risk or sinful activity. He assumes a mentoring or preaching tone, making hand gestures to demonstrate the incarcerated's earnest prayers or a daily non-drug habit. By not including himself linguistically as a participant in these actions, he perhaps is signaling an incomplete acceptance of the actions he classifies as faults. At other points in the interview, James shares “yeah, I accept that I did a lot of bad stuff. I can't regret it because what good would that do? But I can still wish I didn't do it.” This comment occurs as he discusses his struggles to feel pure at church among those he views as “real good-doers.”

Other shifts occur between “I” and “you” when James describes how conversations with other inmates keep *you* trapped in the “sick thinking” that got *you* in jail in the first place. He gives an example: “you might think 'the cops came at 8 in the mornin last time. So if I sleep until 8:07, I'll be fine. Now that's sick thinking. That's stuck on stupid.” James has a pattern of describing something he classifies as stupid (forgetting about God, thinking coincidental factors will help you avoid jail as opposed to actually changing habits) in the “we,” “you,” or “they.” Either later in the interview or upon clarification, he admits he has done these things. It is puzzling to



put James's open and strong claim of responsibility with these linguistic shifts that seem to evade responsibility or diffuse his own agency. Perhaps, as Leap suggests, these linguistic differences are "the last step of consciousness to change" (1990:156). Pointing out these shifts at the end of our second interview elicited an annoyed but grateful response from James: "You know, talking with you and having you push my buttons a bit about this nitty-gritty stuff has helped me wake up to the work I still have to do. I guess we never really rest doing God's work, do we?" Facilitating this reflection among HIV-positive individuals and others with chronic illness may help them navigate interpretive and linguistic frameworks.

### **Conclusion**

This chapter demonstrates the importance of looking to HIV-positive individuals' belief systems as clues for how they conceptualize themselves, their illness experience and their relationship with God. A large portion of my interviews focused explicitly on questions about God and my participants' conceptualization of HIV within a religious framework. Danforth's description of religion as attempting "to deal with the problem of human suffering by placing it in meaningful contexts in which it can be expressed, understood, and either eased or endured," is correct (1989:510). The participants who use a Christian framework to organize their life experiences describe the relief that occurred as they began placing events, emotions and conceptualizations of the world into an interpretive framework. Their narratives suggest the value in searching for and utilizing narrative tropes of religious or other origins.

One must also consider the negotiation between belief systems that may occur

as individuals try to personalize frameworks to fit their life experiences. Doing so sheds light on how individuals conceptualize themselves and others, a sense of time, and treatment and care choices. The complexity of such an analysis mirrors the complexity of the meaning-making process my participants have engaged in at varying points since their diagnosis. For some, this process has been a constant throughout their life, even before their HIV diagnosis. For others, the move towards self-reflexivity was one that took a much longer time and has occurred only in fits and starts. Looking at the ways participants have framed their illness experience within biomedical, social and religious interpretative frameworks reveals how HIV can be understood on several levels and in both positive and negative terms.

The overarching frameworks from support groups, medical care facilities and religious organizations have influenced my participants' narratives to varying degrees; my participants and I see similarities as well as differences to these master narratives. To learn the full extent and scope of outside frames on my participants' stories would offer insight into the permeability and active dynamics of narrative creation. The degree to which organizations such as medical facilities perceive themselves as having a narrative, or how they understand their narrative relationship to clients, if at all, are important areas for expansion. Analyzing the interactions that may exist between organizations and the narrative elements of an individual's tale would offer the opportunity to more fully explore the inter-relational quality of narrative expression and thus, the potentially inter-relational quality of healing.

**CHAPTER 8**  
**CONCLUSIONS AND EXPANSIONS**

HIV is powerfully connected to many spheres of an individual's life. With tendrils in political, economic, cultural and religious arenas, HIV as a biological disease interacts with HIV as a socially constructed illness (Danforth 1989). These experiences, interactions and arenas of contestation and interpretation can be articulated and shared through stories. Stories foster a process of meaning-making and reflexive contemplation by providing a space for dialogic synthesis of life's events. This created space offers more than just the opportunity for narrative expression; stories are a form of healing.

For my HIV-positive participants in the United States and Zimbabwe, storytelling and listening became healing events. The opportunity to share experiences and emotions that frequently remained closeted became an active healing strategy that complemented their medical treatments. Story-sharing moments helped my participants fit their experiences with HIV into meaningful frameworks (Danforth 1989). Narrative frameworks from Narcotics Anonymous and Nyeredzi Inopenya, as well as Christian and positive living doctrines, helped many of my participants understand HIV as an *aspect* of their life, but not their life. Distinguishing their conceptualization of their physical body with HIV from their personhood was therapeutically healing (Diedrich 2007). This realization was often accompanied by a process of self-transformation, changing the way my participants understood themselves, their world, and their HIV status. Sometimes these conceptual changes were directly associated with HIV, such as suffering from an opportunistic infection; for others, HIV was only indirectly referenced as facilitating these shifts. Understanding the relationship between one's HIV status and one's experience of HIV and its relationships to other spheres of life must therefore be grounded in a multidimensional, qualitative method.

I have employed a synthetic interview style so my participants could decide how our interviews ebbed and flowed around certain topics and events. The methodology of my project reflects how HIV is but one part of an HIV-positive individual's life experience. My focus on experiences with and conceptualization of stigma, community and religion, reflect the intra and interpersonal dimensions of an HIV illness experience. Stories are told to individuals; these individuals are situated within specific cultural and social contexts. These contexts, and the relationships between the individuals and how each approach story-making and sharing profoundly influence a narrative experience. The richly contextual dimensions of HIV illness narratives challenge not only the narrow lens of biomedicine but also the approach to stories as narrative Truth (Walley 1997).

My participants share that their experience with HIV is rarely, if ever, mediated through a biomedical lens. Rather, when they think about HIV, they think about church services, basketball games, family dinners, the latest town gossip and experiences of God. They also think about the relationship between the virus and their self-conceptualization, and how these emotions relate to their involvement in communities, their conceptualization of time and the future, and their understanding of HIV as a global epidemic. Their stories offer insight into the lived experience of a virus too often associated with medical jargon, and statistical trends. Sharing their stories reminds the world that *people* are tellers of tales and that tales are important sources of expertise.

Writing this thesis is a process of sharing my participants' voices. As a witness, facilitator and co-constructor of their stories, I have stepped back from the immediacy of our shared narrative space to look at the underlying structures and dimensions that influence their tales. I have demonstrated the necessity of a

multidimensional approach to understanding the HIV epidemic. Narrative offers clinicians, staff members, family and friends the opportunity to understand HIV in its ever-changing relationships with the many spheres of an individual's life. Medical discourse, and government and non-governmental organizations must be informed by this dynamic conceptualization of HIV to effectively offer care, healing and support to HIV-positive individuals.

### **Contemplating Narrative**

At the same time that illness narratives should become a more prominent tool in understanding the complexities of living with HIV, one should also be wary about the anthropology's often unquestioned reliance on narrative as an expression form. As medical anthropology puts increasing emphasis on narrative as an important avenue through which to learn about the beliefs, perceptions, actions and experiences of healers, the ill and their families, Mattingly (1998) asks,

Are some ways of defining narrative better than others? Do we need to define a story in culturally specific ways? The notion of narrative may ring suspiciously of an ethnocentric universalism, without sufficient attention to the cultural differences which render both terms of the equation, "story" and "experience," open to cultural variation. The very notion that narrative is iconic, which is part of a traditional Western view, is challenged by studies of dramatic forms in cultures where narrative or dramatic structure is significantly different (1998:9).

Mattingly's comments provide an important critique to my assumptions about the universality of narrative as a tool for articulating illness experiences as well as my assumption that narrative is capable of capturing or "tapping" the experience of suffering (Wikan 2000:218).

Wikan also points out that illness narratives need not be about illness at all, but may be either the background or foreground to life's other tales. At times, illness

may only be a vehicle through which to relay life's other traumas, joys or revelations. Perhaps I was so focused on eliciting stories of illness and healing, thickly described, that I have missed the point of my participants' stories. Though I explicitly structured our interviews so as to discuss HIV in conjunction to other aspects of life beyond the biomedical, I may not have fully acknowledged the full variety of ways in which illness interacted with my participants' lives. Further, I may have over zealously connected illness to arenas of their lives. Perhaps the tales that I dismissed as exaggerations or fabrications held important information about my participants' conceptualization of HIV. Therefore, in future work, I would like to return to those tales as important sources of challenge to normative illness narratives (Kleinman 1988). I should also problematize the view that narrative is a natural, even inevitable, form with which to come to grips with life-altering illness.

I now approach narrative analysis with more trepidation than I did at the beginning of my investigation. Though I stand behind my statements that narrative can offer important therapeutic powers as a process of meaning-assignment and organization, I am wary of the overemphasis on narrative in academic analysis (Mattingly 1998; Mattingly and Garro 2000; Wikan 2000). Narrative analysis does provide researchers with a way to understand how personal and cultural constructions of illness become stabilized, reified and socially embodied through stories told to oneself and others. However, as Laurence Kirmayer writes “narratives are not the only constituents of experience. Indeed, in acute illness, narratives are often fragmentary or undeveloped; where narratives are most coherent, they also may be formulaic and distant from sufferers' experience” (2000:153). The two sides of this narrative spectrum were illustrated with Cathy's often incoherent narrative and perhaps a too “clean” version of Maria's suffering as she narrated through the

Narcotics Anonymous framework.

Kirmayer focuses on metaphors and action-schemas as more accessible to those in acute sickness than the “more elaborate stories of origins, motives, obstacles and change” (2000:155). Though none of my participants were interviewed during periods of acute ill health, it would be important to investigate how their narrative experiences and comfort with narrative expression fluctuate with physical and emotional health. Kirmayer and Wikan's critiques of illness narratives point to the danger of overemphasizing this form of expression; I would like to pursue these critiques in depth and return to my participants more knowledgeable of other forms of expression.

### **“My illness and me” and the Importance of Terminology**

Wikan critiques academic construction of illness narratives as falsely individualistic, about “my illness and me,” rather than the web of social relations into which an illness falls (2000:218). Based on ethnographic research about illness experiences in Egypt, Oman, Bali, Bhutan and Norway, she claims that situating illness narratives as about “my illness and me,” wipes out relationships and social settings, “partly misconstruing the source of suffering,” and more dangerously, hindering researchers from ever comprehending what illness truly meant to the individual (Wikan 2000:217).

Wikan's remedy for the misconstruction of illness experience is observation.

She relates:

Had you been there with me when it [sickness] happened, or in the first few months after it happened, you would have had another basis on which to judge my illness story. You would have seen and sensed how my illness affected me, that would fill in, support, or undermine the snippets of story that



I am giving you. You would have been able to make your own observations.....If you had seen me and talked with me at the time when I was sick, and for some time afterward, you would have had a reference point, a context, for my story. Better still, if you had met and talked with persons close to me who would be willing to tell *their* stories” (2000:220-1).

Anthropology must address the preponderant place of self-narrative in anthropological analysis currently with the incorporation of observation as a tool for making sense of a person's experience. She argues that particularly in narrative analysis, in which the teller can “tell you anything [she] wants,” the anthropologist must anchor his or her analysis in real-life events “and also to offer resistance to a person's telling-it-as-it-was” (Wikan 2000:221). The idea of “attending to a person's world” makes inherent sense as I try to fill in the gaps in my participants' narratives and understand what their narratives' are all about. Though I spent several months in Zimbabwe and interned briefly at the American clinic, I do not have specific observation of my participants' local worlds, nor was I present for any periods of illness about which I am in part concerned. Complementing future interviews with more specific observation would allow me to “better get at a person's experience with illness” (Wikan 2000:221).

Just as Kirmayer questions the validity of considering narration as fully representative of an illness experience (2000:153), Wikan calls into question the very terminology of illness narratives:

I find it difficult to believe that I need 'narrative' to comprehend people or their world. To be frank, I am always suspicious when I encounter the concept. I wonder what it is going to deliver that “story” could not. And I am often supported in my conviction that the emperor has no clothes (2000:217).

Wikan describes “story” as experience-near, “probably in every language, whereas ‘narrative’ may be so only among (middle-class?) educated Americans and European intellectuals” (2000:227). Stories keep us grounded; there is no way to miss

the lived experience. Narrative, Wikan argues, falsely assigns privileged access to lived experience by making the value judgment that stories must be analyzed and transformed to be understood as “real.” She concludes her argument against narrative by saying, “I have no need for 'narrative' to tell you my story. All it does for me is create an impression of something fancy – narrative analysis sounds better than story analysis” (2000: 228).

Such a powerful argument to cast off the jargon-filled narrative analysis resonates with me as I struggle through the texts of narrative analysis and narrative ethics. Wikan's critique against narrative has given me a moment's pause in the appropriateness of focusing on the “illness narratives” of my participants'; I have also done a double-take about the casualness with which I first used the words “story” and “narrative.” Though Wikan's argument correctly points to the overabundance of narrative jargon, narrative analysis still has an important role in situating stories within their larger structural contexts. Doing so allows one to understand the linkages stories provide between personal experience and cultural meaning. Furthermore, narrative analysis highlights the mediation between particularities and generalities not only between one individual and his or her cultural context, but between larger groups of individuals and national and international patterns, trends and forces. Without the anchorage between my participants' vignettes and their local moral worlds, I would be hard pressed to understand the significance of my participants' stories.

Including Wikan's argument in my conclusion illustrates the dynamism surrounding my conceptualization of stories, my role in sharing them and the implications of my constructions of my participants' stories. Mattingly and Garro's work, *Narrative and the Cultural Construction of Illness and Healing* (2000), of

which Wikan's argument is a part, has shaken the foundations on which I thought my thesis was grounded. I realize now the limits I have placed on my analysis of stories by focusing only on the said. The power of silence tells us that not all can be said. Exploring the counterplay between silence and narrative is a way to enhance my understanding of lived predicaments. Recognizing that silence speaks invites questions about who speaks. Where are the silences? What might they imply about my participants, their social location, and/or larger sociocultural elements?

Finally, I now understand that my emphasis on creating a safe therapeutic space for sharing private thoughts is a cultural value, one with a time and place location that might not hold true for my participants. This relates to why I expected and got long histories from my American participants and only five sentences from some Zimbabweans. The difference may reflect shared social norms about storytelling (especially with a stranger), who tells stories and what constitutes a story.

Stories circulate and I have become a vector in their circulation. One story is that stories are therapeutic. This resonated with me as a way of understanding traumatic events from participants as well as the everydayness of their lives. This is one way of thinking about stories and perhaps there are other ways. My thesis is therefore a story of stories, all of which have particular social locations. Most notably, my thesis is situated within my cultural understanding of story creation and sharing as valued, dialogic and an important resource of understanding life experiences.

Other areas for explanation include deliberately focusing on the connection between my participants' understanding of HIV, their role in acquiring the virus and their medical and behavioral choices. Such an investigation could inform healthcare policy and education targeting HIV-related behavior by offering vector-specific analysis of life with HIV. Exploring in more detail narrative frameworks and the

relationships my participants' stories have with other types of storytelling would lend insight into the dynamics between personal stories and larger frameworks. It would also invite questions about how individuals learn or absorb narrative skills and the ways in which they are culturally embedded.

This thesis is but the beginning of a long path towards understanding HIV and the people it infects and affects. It is about the complexities of lived experience and the ease and difficulties of communicating these experiences through stories. May it stand as an important perspective on the HIV epidemic as embodied by my participants in the United States and Zimbabwe. Most importantly, may it stimulate others to think critically about the ways HIV is understood, approached and enacted.

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