

**A Question of Life, A Sentence of Death: Analysis of the
Empowerment Discourse for HIV/AIDS in Guatemala City**

A thesis presented by

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In this thesis, I examine the ways in which the term “empowerment” (*empoderamiento*) is conceptualized and utilized by various actors in the HIV/AIDS community in Guatemala City. My desire to explore this theme stems from the participant-observation I conducted in a Médecins Sans Frontières HIV/AIDS clinic from March-August 2004. In my thesis I analyze the various discourses emerging around this word, its evolution/development in different spheres and people, and its deployment and appropriation by various individuals. Utilizing interview data from fieldwork conducted in December 2005, I use two analytical methodologies to investigate the discourses that healthcare providers and patients present regarding the notion of “empowerment.” The first analysis uses a coding model both to characterize the nature of the discourses, uncovering trends between patients and providers, and to compare these discourses to the First World’s articulation of the word empowerment (using World Bank’s definition). The second analysis utilizes a case study of a patient/provider to explore the complexities of adopting a First World discourse. Here I demonstrate that attempts to “localize” the concept of empowerment is limited to translating the word linguistically and to using local people to promote its use. I argue that attempts to promote First World discourses indeed fail to instill a true local empowerment because the underlying ideological presuppositions in the term “empowerment” leaves no room for local understandings. Such a pattern proves to be unsustainable and ineffective to promote true grassroots empowerment. Hence in this thesis I propose that the World Bank changes its current day definition of empowerment in order to frame development programs directly from local people’s epistemology.

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Dedication

A todas y todos los que Trabajamos para Vivir y Respirar en nuestra Vida individual y colectiva.
A la gente de Guatemala cuyas mentes, corazones y cuerpos verdaderamente nos tocan y guían hacia donde deberíamos estar.

*To all of us who Work to Live and Breathe in our individual and collective Life.
To the people of Guatemala whose minds, hearts and bodies truly touch and guide where it is We need to be.*

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A mi familia escogida. Esto es para ti.

Este trabajo realmente es un Trabajo. Lo que se toca en estas paginas es mas grande que podemos imaginar...pero allí estamos soñándolo cada día, viviendo y realizándolo en milagros diarios.

*My gratitude is to life, which has given me so much.
And my gratitude is to the person who brought me into the world, and to the one who keeps guiding and supporting me unconditionally. My mother, MY Professor, my colleague, my inspiration.*

I am grateful for my mentor Reyes. For her push, model and dedication to the processes of empowerment. I keep learning the lessons she has taught me. And there is more wood for this fire.

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To my chosen Family. This is for you.

This work really is Work. What is touched on in these pages is bigger than what we can imagine...but there we are dreaming it each day, living and realizing it in daily miracles.



Don't you know
They're talkin' bout a revolution
It sounds like a whisper
Poor people gonna rise up
And get their share
Poor people gonna rise up
And take what's theirs

Don't you know
You better run, run, run, run...
Oh I said you better run, run, run, run...

Finally the tables are starting to turn
Talkin' about a revolution
Finally the tables are starting to turn
Talking bout a revolution

-Tracy Chapman 1988

CHAPTER 1

FIELDWORK NARRATIVE

Introduced to AIDS in the USA

The first conscious personal contact I had with HIV/AIDS was when I was 15 years old. I met Bob at an outdoor church for the homeless, during the days in which he walked around on the Boston Common with a cane in one hand, and a little piece of paper with numbers in the other. Each week Bob reported to me how his numbers were doing. At the time I knew they had to do with his medical state, and I now realize that these numbers were his viral load and T-cell count. I knew Bob for about two years, speaking with him outdoors at church, taking his portrait, visiting him in the hospital, in a hospice, and speaking at his funeral.

Navigating Central America

After my sophomore year at Haverford, I decided to take Deans Leave and with the support of the Anthropology department's Lafer-Scher internship, I bought a one-way ticket to Costa Rica in October 2004. Here, I conducted participant-observation in a variety of healthcare settings, and after two months, I decided to visit a home for HIV/AIDS. Upon entering the home I was taken back by the fluid and dynamic family of HIV positive people working in the home, caring for each other in all stages of life, including those in their terminal stage of AIDS. Immediately I felt drawn to this disease, identity, and community. I wanted to explore this strong feeling I had in the presence of others. But how?

I traveled up to Guatemala City by bus with my backpack and the address of an old woman with whom I could stay for several days. While I was here, I looked up the addresses

of HIV/AIDS organizations in the phone book and half cautious, half oblivious, walked around Guatemala City, saying I wanted to volunteer at an organization. Without knowing what I was doing, that day was my first exposure to the HIV/AIDS NGO scene in Guatemala. People were friendly, informative, and quiet, but oftentimes did not know what to do with me, and thus gave me vague answers. I knocked on the black iron door of Médecins Sans Frontières (MSF) clinic, and was bluntly told in the doorway that they take “no volunteers—ever.” I retreated and kept walking. After a week I was fortunate to find permanent housing for the year in a house with 5 international and Guatemalan women, working in different areas of the country. It is here that I met my mentor Reyes, a Barcelonan nurse and social worker, who worked at the very HIV/AIDS MSF clinic that rejected me earlier.

In the following two weeks I spoke with Reyes every afternoon and evening about her experiences in the clinic, the patients, the stories, the climate, and the HIV/AIDS “scene” in Guatemala. Soon she set me up to volunteer with an HIV/AIDS home in Guatemala City. Here I worked in conjunction with the director to begin all kinds of activities for the patients, talking and cooking with the people in the home, and generally a part of the home’s life. Each day I would take field notes about my experiences, what people were talking about, etc. After about a month of working there, the home went bankrupt and it was time for me to leave.

MSF Clinic

In about a month’s time, in March 2004 I began to hang out with Reyes in the MSF HIV/AIDS clinic. Speaking with the head of the clinic, I gained permission to sit in the waiting room, the adherence/education and social work consultations, and later to the nurse

and physician consultations. Here I would take field notes about everything I was seeing and hearing, from the different cases patients presented to the doctors, to the inter-relationships and dynamics between healthcare providers in the clinic. After about a month of this, I coordinated with the two educators to conduct my own discussion group in the waiting room. Here, with a group of about 25 patients, I began to ask about ideas that I had been reading about in several medical anthropology texts, namely Kleinman's *The Illness Narratives* (1988) and Rappaport's *Testing Women Testing the Fetus* (1999). In addition to observing the different parts of the clinic, each day I asked people about their illness, stories of diagnosis, goals in life, visualizations of HIV inside their bodies, and anything else that presented itself. I wanted the conversations to be fluid and indeed use the reflection time *for* the patients. I would start off many conversations stating, "In the waiting room, we are all talking with each other or thinking. I would like us to open up the conversations and speak as a group in order to share with each other the processes that we are going through. What are we thinking about? What was your story of diagnosis like? Each of us has one. How has your life changed? How have you been treated by people in the hospitals and by your family?" The discussions ranged from complete silence, to an intense discussion. While the meetings were not support groups, and while I was not a therapist, I observed that these discussions often appeared to be therapeutic for people. Some days I conducted open-ended interviews with people about the same topics and tape-recorded these with their verbal consent. Thus, for about two months, between observing the various healthcare providers in their consultations with patients and facilitating these discussions, I gained a critical "cultural intimacy" with the HIV/AIDS culture in Guatemala.

After about 2 months, my role in the clinic began to change from the described reflexive engagement about the lived experience and meaning of life for HIV positive

people, to a more politically active leadership role. Over the next 3 months I began the “Patient Empowerment Project” which later turned into the organization “Grupo Solidaridad Positiva” (GSP; Positive Solidarity Group). The premise of the project was based on the fact that the MSF clinic was a temporary 5 year project whose goal was to establish an AIDS treatment program which would later be assumed by the government, and that the true responsibility to provide life-sustaining antiretroviral (ARV) medication lay on the Guatemalan government. Hence, the project’s goal was to mobilize patients in order to obtain ARV medication from the Guatemalan government. In order to attain this goal, there needed to be an empowerment process among the patients.

This empowerment project used the Freire-inspired methodology of “reflection-action” (1970). In the waiting room we continued to reflect on the value of life as a positive person, and make the connection that this “consciousness-raising” about living as positive people required action: initiating patient-led political incidence. Thus, while reflecting with different cohorts of patients in the waiting room about the meaning of a positive life, we also began to talk about how citizenry and participation in the state through the tax system operates. Explaining how the system operates clarified to patients that they were not organizing themselves to “ask” the government for medication, but that they were “demanding” their human right to treatment. Time was running out: MSF was going to leave in a year, and there was a need for the patients to participate in facilitating this “handing over” process. The Patient Empowerment Project emerged, and began mobilizing patients. I worked as one of the main facilitators, calling and leading meetings, organizing patients, creating a mission statement, and planning presentations for hundreds of patients to be informed about their collective process. For about three months I emphasized the *participant* in participant-observation, and simultaneously kept taking field notes.

PAPER OUTLINE

In my senior thesis, I will investigate how the term “empowerment” (*empoderamiento*) is conceptualized and utilized by various actors in the HIV/AIDS community in Guatemala City. My desire to explore this theme stems from the above-described participant-observation I conducted in an MSF clinic in Guatemala City from March-August 2004. I observed this word “empowerment” floating through many areas of the clinic including in nursing, the doctor patient consultation, social work, education/adherence consultations, in the waiting room, and ultimately in the Empowerment project meetings. The term itself oftentimes seemed to be unclear or incomprehensible, and I perceived the word to have different meanings for different people in the clinic. During my volunteer and research work in the clinic, I sensed a tension between how the MSF patients and staff perceived and used the term in the particular context of HIV/AIDS in Guatemala City. Thus, in my thesis I would like to closely analyze (1) the various discourses emerging around this word, (2) its evolution/development in different spheres and people, and (3) its deployment and appropriation by various individuals.

I aim to do this by critically investigating how this concept of “empowerment” is framed by:

- MSF through the World Bank
- Healthcare providers in MSF clinic and in other NGOs
- HIV positive patients (half of whom receive MSF services)

The World Bank (WB) is one of the leading importers of the word empowerment into many areas of the world, and thus I will use their framing of the word “empowerment” to analyze its usage in the local context of the HIV/AIDS community in Guatemala City. Because the World Bank stresses the importance of measuring, understanding, and defining the characteristics of empowerment, I conduct a structured analysis of 22 interviews with healthcare providers and patients in order to look at how people define and characterize the word “empowerment” in general, and in relation to the World Bank’s definition. Based on this analysis I argue that while both patients and healthcare providers describe aspects of empowerment that are similar to those described by the World Bank, the providers’ concept of empowerment is more closely aligned to that of the World Bank than those of patients. However, such an analysis of definitions is insufficient to understand how these discourses are implicated into people’s everyday life. Hence, in this thesis I will use a second methodology of discourse analysis in order to unpack the definition of one informant’s conception of empowerment in order to demonstrate how such First World discourses are realized and played out in local contexts. Using this case study, I will demonstrate that attempts to “localize” the concept of empowerment is limited to translating the word linguistically and to using local people to promote its use. I will argue that these attempts fail to instill a true local empowerment because there is no consideration or addressing of the underlying ideological presuppositions that the term “empowerment” entails (such as western pedagogical models), and hence there is no room for local understandings. Thus, as local activists deploy this term, what results is a fragmentation between local people, in which the activist believes the “other” is unable to comprehend or listen to what they are telling them about the First World concept of empowerment. Such a pattern proves to be unsustainable and ineffective to promote true grassroots empowerment. This implies that

the current day World Bank model must change in a way that enables the word/notion of empowerment to be redeployed in local contexts, answering to a variety of issues implicated in the lives of people. Hence, I suggest that empowerment should be framed directly from the social actions and worldviews of local people, using their own cultural understandings of what it means to be a social subject.

In this chapter I have described my own narrative of working in the field and briefly presents my data collection, two main methodological approaches used to analyze data, and my two main arguments for each analysis. Chapter Two provides the basic context for HIV/AIDS in Guatemala, describes the methodologies used to analyze my data (including the process of collection and the problems with the analysis), and presents the chosen theoretical framework to look at “empowerment” in my chosen field site. Chapter Three presents an “interview analysis” in which I use coded interviews to make claims about how patients and providers characterize, conceptualize and utilize the word “empowerment” in general, and specifically in relation to the World Bank’s definition. Chapter Four presents a “discourse analysis” in which I analyze a case study so as to illustrate how First World discourses of empowerment can promote fragmentation in local settings, when local people assume them. Chapter 5 concludes by discussing the two methods of analysis and making general concluding remarks about these methods and their implications for HIV/AIDS in Guatemala and First World development projects.

CHAPTER 2

GUATEMALA CONTEXT

Basic Demographic Information

With about 400 km of ocean coastline and roughly about the size of Tennessee, The Republic of Guatemala is located in Central America bordering Honduras, El Salvador, Mexico and Belize. The country's diverse geography includes both a tropical climate in the lowlands and a cool climate in the highlands. Guatemala's mainly mountainous terrain, costal plains and rolling plateaus produces various natural resources such as petroleum, nickel, rare woods, fish, chicle and hydropower. In 2001, only 12.54% of this land was arable, 5.03% had permanent crops. The government of the Republic of Guatemala is a constitutional democratic republic comprised of 22 departments. Since January of 2004, the chief of state is President Oscar Jose Rafael Berger Perdomo who serves also as head of government (CIA World Factbook). Approximately 40-65% of this population is Maya (Amerindian), over 40% ladinos (of 'Latin' culture, speaking Spanish and wearing Western clothes though they may be part or full Maya), 5% white, 2% black, and 3.9% other mixed race or Chinese. (Hutchison, 1200) Among the population about 60% speak Spanish, and 40% speak Amerindian languages; there are 23 officially recognized Amerindian languages that include Quiche, Cakchiquel, Kekchi, Mam, Garifuna, and Xinca. The religious practices are that of Roman Catholicism, Protestantism and indigenous Mayan beliefs.

The population is fairly young; the following gives the distribution of the population according to age group. In 2005 42.4% are 0-14 years, 54.2% are 15-64 years, and only 3.3% were 65 years and over in 2004. Total life expectancy at birth 2005 estimate is at 65.19 years (CIA World Factbook). In the 2004 approximately 56% of the population lives in poverty;

one in five people live in extreme poverty. Infant mortality is 39/1,000 live births (one of the worst in the region), and maternal mortality also yields extremely high numbers of 153 per 100,000 births (CIPE). Currently Guatemala has the highest rate of malnutrition with approximately 15% of the total population suffering from acute malnutrition in 2002, and with 47% of the total population had chronic malnutrition in 1998/9. Chronic malnutrition currently affects approximately 47% percent of children under five (World Food Programme). Due to disparities in education across gender lines females had a literacy rate of 63.3% whereas men had a 78% literacy rate in 2003 (literacy is defined as people age 15 and over can read and write; no language is specified).

Political Context

On December 29, 1996 President Álvaro Arzú officially ended a bloody 36- year civil war by signing the Peace Accords. Throughout these years, 150,000 lives were taken, 50,000 people had “disappeared” and some 1 million turned into refugees in this small country. A significant part of the Peace Accords entailed investigating about human rights violations through a Truth Commission, which was to be overseen by MINUGUA (the United Nations mission in Guatemala) in order to recognize indigenous identity, and to promote the socio-economic development for all Guatemalans. Follow-through on these accords however, has been slow, where voting turnout for the indigenous population was about 18%--a “collective rejection that underlined the deep-rooted animosity felt by most indigenous people towards a political system that had exploited them for centuries.” Many officers who committed atrocities avoided persecution, and in 1998 only 2 days after publishing human rights investigation for the killings, Bishop Juan Gerardi was murdered. Surfacing Guatemala’s fragility, the murder was followed by vigils and a seemingly

“paralyzed” government (Stewart 2002:434). During this time, crime rate skyrocketed, theft, robberies, drug and gang-related murders increased, and in 1997 Guatemala had the 4th largest incidence of kidnappings in the world. The Policia Nacional Civil (PNC) was instilled as a new law and order force, and individuals of this force soon became the perpetrators of corruption.

Presently, Guatemala’s situation is grim. By 2001 MINUGUA reported that only 36% of the government’s commitments were met. Guatemala’s economic industries are mostly foreign-owned, and most of the work available is unskilled work in garment and textile factories earning about \$3-4 daily. In 2001, over 100,000 Guatemalans (mostly women) worked in these sweatshops. Currently there is “Maya cultural revival” with schools educating Maya children in their own language. The revival also increases the number of indigenous writers and journalists. Courses are taught at the university level, and ladino university students are asserting their Maya heritage and mixed-race identity. Still however, institutionalized violence, discrimination and racism are rampant. In general the Peace accords have been a “bitter disappointment” for many Guatemalans (Stewart 2002:435) where random acts of violence and criminality are accompanied by a dysfunctional justice system. There are very few economic opportunities, and living standards are low with substandard healthcare and educational opportunities; many have fled to the United States illegally in search for opportunities.

Although people around the world are fighting to transform “HIV/AIDS = death” to “HIV/AIDS is a chronic disease,” for too many young and old people, a positive HIV diagnosis is still viewed as a death sentence. In 2003 Médecins Sans Frontières (MSF) estimated that 100,000 people in Guatemala are infected with HIV/AIDS (MSF 2003 International Activity Report), where national sources estimate HIV prevalence rate to be

1.1% and with 5,800 deaths recorded at this time (CIA World Factbook). Specifically, the prevalence rate for men who have sex with men (MSM) is disproportionately high approximately 11.5% of MSM are HIV/AIDS positive (this is the highest rate of any risk group) (CIA World Factbook 2003; UNAIDS 2003)¹. Guatemala's label as a "low prevalence" country deceives the reality of this fast spreading epidemic².

One study entitled, "The emergence of AIDS in Guatemala: inpatient experience at the Hospital General San Juan de Dios" briefly gives a picture of the epidemic through a few statistics (representing actual bodies) in Guatemala City's General Hospital where between 1999 and 2000 (18 months) data was collected. The study found only 12.5% patients had been diagnosed with HIV infection before 1999, yet nearly all had symptomatic AIDS. This figure indicates that most people were diagnosed once they were already in the AIDS stage of their infection. This is particularly shocking because it takes 8-10 years for an HIV infection to develop into symptomatic AIDS; it implies that 87.5% of patients were infected with HIV for 8-10 years without knowing their diagnosis. Furthermore, 60.3% of the patients were diagnosed with HIV infection during their hospitalization. Once they were hospitalized, the mean length of hospitalization for HIV-positive patients was 17 days. Of those who were in the hospital, approximately 23.7% of the patients died during their

¹ Generally, healthcare figures in Guatemala (particularly for HIV/AIDS) under-represent the actual prevalence rates.

² It takes approximately 8-10 years from when a person is infected with HIV for their immune system to go so far down that they develop "full blown" or symptomatic AIDS. Because of this "window period" or "latency period," many people may be asymptomatic and are unaware of their HIV diagnosis until 8-10 years after infection until they develop AIDS (and even then many die without knowing they had AIDS). In the meantime, for almost a decade, these individuals may unknowingly transmit HIV to others and re-infect themselves (speeding up the process of developing symptomatic AIDS). Those who are then infected by HIV are also likely be asymptomatic for another 8-10 years until they too develop AIDS. Thus, while Guatemalans themselves and the international community may view an estimated 1.1% prevalence rate in Guatemala to not be "high risk" compared to prevalence rates up to 37.3% in Botswana (CIA World Factbook), several healthcare providers in Guatemala have warned me that Guatemala "looks like what sub-Saharan Africa looked like just a little while ago."

hospitalization—a percentage that is double the mortality of non-HIV patients.³ Though Guatemala is currently considered a “low prevalence rate,” in reality the data suggest that the prevalence rate “probably represents a picture of the epidemic ten years ago,” where such figures give a “frightening warning “ of what will probably explode very soon, suggesting advance warnings of trends in the future (CIA World Factbook; Samayoa 2003:813). Hence in such a context there is a large need for preventative measures, including HIV/AIDS education. Five major health concerns for People living with HIV/AIDS (PLWHA) in Guatemala include: a curative (rather than preventative) approach to healthcare, limited access to healthcare services, a centralized healthcare system, a lack of education and high stigma.

In general, these low/under estimated numbers and the outdated material (much of the above statistics being from 1999) and lack of studies strongly reflects the unwillingness of the Government to recognize the growing prevalence of HIV/AIDS (as this would imply public healthcare expenditures the government may not be prepared to spend). It seems as though not collecting data seems purposeful and useful to validate ignoring the issue. As I have listed all of the statistics I could find on this topic, it should be noted that there is very little information about any socio-cultural characteristics of the HIV positive population such as “social class” or “income structure.” Perhaps these topics are not of importance to those institutions who do collect information such as UNAIDS or the Ministry of Health, or perhaps collecting such data would reveal a correlation between socio-cultural factors and HIV status, thus revealing how the healthcare system is badly structured for the majority of people receiving positive HIV tests; hence, not collecting such socio-cultural data may be to purposefully ignore such potential revelations.

³ Of the 227 patients who were discharged, 208 were discharged home, however a number of people went home “in order to die.”

METHODOLOGY

Returning to the Field

Back at Haverford my junior year I decided that it was important for me to have continuity with Grupo Solidaridad Positiva (GSP) and to formalize my data collection. Though I had taken field notes and conducted open-ended interviews, I decided to conduct more structured interviews with both healthcare providers and patients. Through support from the Center for Peace and Global Citizenship, I returned to Guatemala for 3 weeks in which I conducted 31 interviews, all of which were conducted in Spanish (with the exception of one), and all digitally recorded on my iPod. I filled out a “contact sheet” for each interviewee in which I asked basic demographic questions and several questions about participation in the healthcare system (see Appendix A). While the majority of the interviews were conducted in inside the NGO buildings, some were conducted in the apartment in which I was staying as well as in public restaurants. For each interview I tried to provide a setting that was closed and confidential; however the strained circumstances under which I was to meet people did not always allow an ideal setting.

The interviews lasted anywhere from 1-2 hours and covered a variety of topics, namely: illness narratives, visualization of the disease, knowledge/relationship to treatment, alternative treatments, adherence, attitudes towards HIV/AIDS institutions, knowledge about the healthcare system, opinions about the rights and obligations of a patient, and about the word “empowerment” itself (see Appendix B). I tried to follow the general order of topics, but oftentimes would steer off topic, or change the order so as to maintain the integrity and flow of the conversation. I did not know exactly what aspect of HIV/AIDS I

would be writing about, and hence the breadth of the interview topics reflects such questions. I began to transcribe the interviews myself while in Guatemala.

It is important to note that while the main purpose of my return to Guatemala was to formalize my research, I was also returning to see old colleagues, and to see how GSP was doing. Because I had so actively participated in initiating and running GSP, as a researcher I was received extremely well by most participants, whether I had personally worked with them or not. My deep connection with GSP brought a critical legitimacy to my presence in Guatemala once again, and in asking so many probing questions. In fact, it might be that because I was so involved in the empowerment process, even the questions I was asking about illness narratives, or adherence were seen by my informants to be instrumental in the grassroots empowerment movement still taking place. Generally speaking, and particularly among the patients, there seemed to be a lot of trust regarding the reason as to why I was collecting data about these specific topics. Particularly in the last question “What would you like to tell people about HIV/AIDS in Guatemala?” I felt like people were looking to me to help carry their voices elsewhere. For the interviews, I not only spoke with people in the MSF clinic, but also branched to other MSF clinics and NGOs that I had heard of (and perhaps visited in my first days), but that I was not formally associated with. The fact that I had worked with MSF, and started GSP was enough legitimacy for people to open doors to me and to allow me to ask almost any questions I wanted to.⁴

⁴ Despite the general welcome into the HIV/AIDS community, the one place that refused my presence in their space was in the MSF clinic itself. After I had left in August 2004, a new head of the clinic came, and refused to bend any rules for me to be present in the clinic, as it is “orders from France that there are to be no volunteers.” After many discussions between providers who knew me and the head of the clinic, she firmly stood her ground, and I was essentially banned from the clinic! However, despite this resistance, I did go back to the clinic into the waiting room and through the secretary got several phone numbers in order to make interview appointments with healthcare providers and patients outside the clinic. This experience reflects the rigid bureaucracy within which MSF operates: they were not flexible enough to welcome back a young woman who actually *started* a group (GSP) that was up and running in the clinic! Needless to say, this non-reception was extremely disappointing both to me and from MSF staff who had worked with me.

The interviewing process was intense: it was an exercise in which questions that had once been out of my own “curiosity” or asked in order to further the empowerment process, had become more formal with an academic drive and framing⁵. I felt awkward about this research in a place that had always been a predominantly activist site, and hence I “downplayed” the research emphasis during my interviews. I did this by very consciously disregarding or talking about how I did not like to use the tape recorder, not looking at my interview sheet very much, and generally rolling my eyes and making side comments when going through the technical components of the interview, so as to show that it was not something I was comfortable with⁶. Such attempts to make the conversations informal are evident in my conversational language use throughout the interview, and with various actions throughout the process. For further discussion of this negotiating process, see my paper “Context, Frame, Footing and Discourse: Analysis of an Interview in Guatemala City.”

Upon my return to Haverford in my junior spring I conducted an independent study in which I dedicated myself to transcribing my data, and in which I began to use and analyze the data in a paper “Applying Bourdieu’s Theory to HIV/AIDS positive women in Guatemala.” Here I extensively analyzed an interview with a Guatemalan psychologist at MSF about empowering women and applied academic theory to my findings. This exercise proved to be very helpful in learning how to look through and write about my data.

Because of the quality of some of the recordings, and the time consuming nature of transcription in general, even after the semester was over I still had some transcriptions to be

⁵ These questions went through many drafts, first starting at Haverford, revised with Professor Porter at Bryn Mawr, and then revised a third time with Reyes on site in Guatemala. In the actual interviews however, I did not adhere to a set format, and allowed my interviews to be somewhat unstructured and open.

⁶ Having conducted more research this project, I realize that this was unnecessary; however it was very much a part of my research experience in Guatemala.

done. Using the Mellon Mays Undergraduate Fellowship yearly stipend, I hired a Chilean anthropologist in Cambridge, MA to finish the transcriptions. I have read through the transcription material I am using for this thesis in order to check the form and verify its accuracy. I have 963 pages of transcription material total, single space (this transcription material comes from my second trip to Guatemala, and does not include the first set of interviews I conducted while leading the discussion groups).

Processing Data

I entered the cover sheets into the computer using Microsoft Word, and printed out data sheets for each interview including basic demographic information. After much reflection about the extensive work I did in Guatemala, looking at and collecting data about everything from illness narratives to treatment in the healthcare system, I decided that I needed to limit the scope of my analysis and decided to focus on the notion of empowerment—one of the strongest overriding themes that I had worked with. Hence, I conducted a “search” for the word “empowerment” in each of the 22 documents, and printed out a separate document for each interview, each which included each time the word “empowerment” was mentioned, as well as the text around the word. For each interview, these “empowerment-documents” (E-docs) are anywhere from 1-6 pages long (single space, in Spanish).

After getting this material together, I read each of these new E-docs, and created another document, a “use of empowerment” sheet (Use-E sheet); this sheet describes in my own words how the word empowerment was used each time it was mentioned. These Use-E sheets proved to be useful to look at the different themes that were surfacing in the interviews without reading through the entire E-docs. Because the Use-E sheets were in

English, I was able to look across interviews somewhat more easily, and come up with a coding scheme. In time, I developed a coding model, which delineated a number of themes and sub-themes. With this coding model, I then went back into the original Spanish E-Docs and filled in the coding model with relevant material from the E-Docs. However, because the E-Docs were in Spanish, I was not able to cut and paste this material, and hence translated most of the E-Docs into English while coding the interviews. I translated word for word into the coding model, and hence did not use my own words when coding the transcriptions. I did a trial run of this first coding model for 10 interviews. Looking at the interviews it was evident that there were too many categories and sub categories to analyze, and thus revised my coding model, creating new one with only four major categories (see Appendix D). I used this new coding model to re-code the 10 trial run interviews and the remaining 12, yielding a total of 22 coded interviews (see Appendix C for interviewee breakdown).

I used these new coding models to look for major similarities and differences between patients and providers, noting the variation between trends. I also compared patients and providers conceptualization of the word empowerment with the one described by the World Bank.

In conjunction to this interview analysis, I conduct a close reading and “discourse analysis” for one of the interviews in order to show how a different analytical methodology may yield different outcomes for certain data. Such outcomes indeed imply different conclusions regarding the topic of empowerment.

Methodology Discussion

At first I was hesitant to look across patients and providers in attempt to gage a “definition” of empowerment, a set of words to “delimi[t] or describ[e] the meaning of a concept or term by stating the essential properties of the entities or objects denoted by that concept or term” (Wilkepedia 2005). Based on my fieldwork experience, people did not seem to frame the word empowerment in terms of a “theoretical definition,” and I was worried that attempting to extract a construction of such an expansive word would be too biased on my part for indeed, “theoretical definitions of the same term often contradict each other depending on whose theory is being used as the basis” (Wilkepedia 2005). However, the reason that I decided to focus on extracting these definitions from informants stems from the fact that in leading empowerment theory, these definitions are deemed important to articulate “rationality”. Indeed, one of the guiding words for empowerment from the World Bank document entitled, “*Measuring Empowerment: Cross-Disciplinary Perspectives* (Narayan 2005),” is the word “measuring,” thus implying set parameters, definitions and characteristics of “empowerment” rather than examples of empowerment in practice without the word itself. As such, Narayan states that in order to measure and monitor empowerment, one must clearly define the concept and framework which connects empowerment to “improve development outcomes and identifies determinants of empowerment itself” (Narayan 2005: 4). It is precisely because the WB claims such a definition is critical, that this thesis focused on these definitions in the interviews themselves, and specifically in the Interview Analysis in Chapter 3.

Though I have decided to analyze my data by using a coding model, I have encountered many limitations, problems and gaps while coding the data.

Problems with Interview Analysis

The most evident problem with my coding format is that I am forced to fragment people's words and sentences from their conversational context into a coding scheme. Not only am I extracting words out of the greater response of a person, but also by coding them I am not accounting for the question asked, what came before the question, the general tone of the interview, or any external factors such as location, etc. Hence, because these words are decontextualized and fragmented, I might give a greater emphasis on something that was meant a side comment, or that generally was not intended to be given the meaning I apply to it.

I have limited the text that I am analyzing to areas where the word “empowerment” as such is mentioned (in the E-doc), and I am leaving the rest of the interview text out. This is problematic firstly, because there are other words that are similar to empowerment that are used such as “concientización” (consciousness-raising), “capacitación” (capacity-building) or “poder” (power) that I did not code for, and are not part of the analysis. Hence, there may be entire discussions and descriptions of these words that I am missing because I am generally looking at about 1/10 of the interview—usually the tail end of it—when I ask questions about empowerment (see Appendix B for interview topics). However, in reading documents about the concept of empowerment (by influencing organizations such as the World Bank), I have realized these local uses/ variations of the word empowerment are often not valued as much as the word “empowerment” itself. Because of the emphasis in defining and measuring this word, I have remained focused on looking for the word itself. As these words are aimed to be applied globally with universal definitions, there is little effort to value the local uses of these words or understandings. Secondly, in my methodology, I record the

definition of empowerment directly, but I do not look back to the beginning part of the interview to look for aspects to support the given definition. Thus, for example, if a respondent defines empowerment in terms of adherence to medication, I do not go back to other parts in the interview where he mentions or describes adherence. I believe that the analysis could have been richer if I had taken the individual's "definitions" of empowerment, and used these definitions to go back to each interview to look for the description and details of these characteristics in other parts of our conversation.

Because interviews are open ended, and oftentimes respondents speak for a long time on a topic, it is difficult to delineate when it is that they are defining/speaking about the word empowerment, or when they are speaking about the context of Guatemala generally. Hence, for many of the "definitions" (particularly the functional ones), I use my own interpretation to decide when a person is describing something that is a part of their larger understanding/definition of empowerment, or when they are merely describing a contextual situation in Guatemala.

While I have chosen to focus this thesis on empowerment, I did not know what I was going to write about when I initially conducted the interviews. Hence, with many of my informants, there is extensive conversation about other topics; because of this I did not deepen my exploration of the topic of empowerment. Thus, particularly for my Interview Analysis in Chapter 3, I utilize any information I gleaned prior to establishing my focus.

In coding I have confronted the problem of what I should do when a person describes empowerment in a narrow and specific way, yet throughout the interview the person refers to processes the World Bank would regard as empowering (but the individual does not regard them as such). For example, if a person describes empowerment in terms of adherence to medication, but throughout the interview he talks about the importance of

access to information between citizens and the government (as the WB describes in their definitions)—what do I do with these descriptions if they are not labeled as “empowerment” by the interviewee? Because I cannot go back to the interviews and ask, “by talking about this, were you referring to empowerment?” in this thesis, I have decided to leave out anything that is not directly articulated as the definition of empowerment itself by informants. The assumptions and inferences about what is and is not empowerment in a discussion are not for me to make, and I have decided to focus on a text that is directly talking about empowerment to gauge any understanding of the concept.

Furthermore when I code for different categories/subcategories within the E-doc, I look for whether a subcategory was mentioned at all and did not look at the extent to which a single informant mentioned it. Thus, in Chapter 3 when mentioning quantitative numbers regarding “how many times [a subcategory] was mentioned,” numbers can be deceiving. For example, an informant can have a short abstract definition of empowerment, but multiple long functional ones throughout the interview, yet I will quantitatively I count this individual as having “both abstract and functional definitions,” even though it may have been predominantly functional. This problem is addressed in Chapter 3 when analyzing specific data.

Lastly, the number of interviews analyzed (22) are definitely not enough to make any statistically relevant claims, and at times I am not sure if the numbers are high enough to make any general significant claims. When the numerical outcomes within categories/subcategories are high, low, or in the middle, it is hard to know whether the same outcome/pattern would occur if there were a larger sample. Thus, due to the limited amount of quantitative information, Chapter 4 provides a supplementary methodology presenting a mini-ethnographic case study for one of the interviewees themselves; this methodology aims

to extend beyond drawing conclusions from quantitative data by exploring the broader contexts in which individuals are situated.

THEORETICAL FRAMEWORK

There is extensive literature about the word “empowerment,” spanning from “patient empowerment,” “educational empowerment” to “women’s empowerment.” All of these concepts have their genealogy in the developmentalist discourses of International Financial Institutions like the World Bank and reflect worldviews imported from the First World to other parts of the world. It is in this broader sense that I will use the concept of empowerment in this thesis.

Choosing a Compatible Theoretical Framework

As an international humanitarian aid organization, Médecins Sans Frontières (MSF) provides “emergency medical assistance to populations in danger” and whose objective is to “rebuil[d] health structures to acceptable levels” (MSF 2005). Although MSF refers to the word “empowerment” in several documents, articles, reports and statements, the organization is not specific about what they mean by the word. For example, in an online search for the word “empowerment” on the MSF website, 3 articles appear, each of which use the term only once in the text, and on the topic of AIDS: “lack of empowerment of women” is listed among other economic and social factors which make nations vulnerable to HIV, “a sense of empowerment among NGOs” as a product of the struggle in Thailand to produce cheap ddI, and “the empowerment of women to say no” as an ideal (2000, 2000, 2001 MSF Article). MSF derives its usage of the term “empowerment” from International

Financial Institutions such as the World Bank (WB), an institution that has historically utilized the term since the 1960s; hence I will use the World Bank's broader formative framework of the term "empowerment" in order to analyze data regarding MSF and other HIV/AIDS NGOs in Guatemala City.

This thesis will use an empowerment framework from another transnational resource for developing countries: the World Bank (WB). The WB's mission is that of "global poverty reduction and the improvement of living standards" by bringing financial and technical assistance to developing countries (World Bank 2005). While Both MSF and the WB appear to be two unrelated organizations, they both share in their international work in developing countries, and in terms of assistance (MSF with medical assistance and the WB in terms of financial and technical assistance). Hence, for the sake of this thesis, I believe it is appropriate to use the World Bank's concept of the word "empowerment" as a lens by which to look the use of the word "empowerment" by HIV/AIDS providers and patients in Guatemala City.

World Bank Framework for Empowerment

The World Bank has produced two extensive books which delineate the term "empowerment," and even attempt to measure it: Deepa Narayan's *Empowerment and Poverty Reduction: a Sourcebook* (2002) and *Measuring Empowerment: Cross-Disciplinary Perspectives* (2005). These volumes suggest that empowerment involves several dimensions. In the first book Narayan defines empowerment as, "the expansion of assets and capabilities of poor people to participate in, negotiate with, influence, control and hold accountable institutions that affect their lives" (Narayan 2002: xix). Such resources and decisions include on the one hand *opportunity factors*: the informal and formal rules/norms of the institutional, social and political

contexts in which individuals are located; and on the other hand *agency factors*: individual and collective assets and capabilities permitting agents to pursue their interests. The Bank's delineation and utilization of these terms illustrate their engagement in the ongoing debate of structure and agency in development⁷. Moreover, Narayan highlights four key elements as factors which are considered to be "almost always present when empowerment efforts are successful": (1) *access to information*, flowing from citizens to government and visa versa; (2) *inclusion/participation*, treating poor people as co-producers; (3) *accountability*, reinforcing accountability for state officials, employees, employers and politicians; and (4) *local organizational capacity*, the ability of people to work, organize and mobilize resources together (Narayan 2002: xix-xx). While these four elements are separately delineated in the chapter, Narayan notes that they are "closely intertwined and act in synergy" (Narayan 2002: xix).

In her chapter on "What Is Empowerment?" Narayan describes empowerment as having both an *intrinsic* and *instrumental* value, which she cites as relevant at the individual and collective level, and from the economic, social, or political level. As such the intrinsic significance of empowerment is "valued for its own sake" whereas its instrumental importance is viewed to have "potentia[l] [...] importance for its direct and indirect impacts on other aspects of development." (Narayan 2005: 40). In terms of its implementation, Narayan asserts that some people may be inactive in empowerment efforts due to a lack of institutional mechanisms which require accountability, or because the "cost" of action is too high for an individual (Narayan 2003: 18).

⁷ Economist and philosopher Amartya Sen has engaged in this debate by addressing the centrality of individual agency in the world's deprivations including poverty, oppression, hunger, and violation of political freedoms and basic liberties. He explains the "deep complementarity" that exists between individual agency and social arrangements, whereby the force of such arrangements may determine the "extent and reach of individual freedom" (Sen 1999:xii). Thus, many development theorists who follow Sen, currently reject policies which regard people as "passive recipients of aid," and instead support policies that conceptualize people as "active agents" who are to control their individual lives (Koggel 2005).

Moreover, while Narayan delineates these various elements, she briefly mentions that there is “no single [empowerment] model,” and that the definitions of empowerment are “embedded in local value and belief systems,” (Narayan 2003: 14) where an empowering approach to development will recognize and value identities including “changes in beliefs, mindsets, and behavior” (Narayan 2003: 17). Here, an empowering approach is conceived to build on the strengths of poor people in terms of their “knowledge, skills, values, initiative and motivation to solve problems, manage resources and rise out of poverty. It treats poor people as worth of honor, respect and dignity.” (Narayan 2003: 17). However, while in *theory* the WB’s approach appears to incorporate a kind of “cultural relativism” to notions of empowerment in their specific contexts, this thesis seeks to explore what happens in *practice*: are First world definitions and approaches to empowerment, as conceived in already established development structures (such as the WB) actually flexible enough to work compatibly with how local people make meaning in their lives?

In *Measuring Empowerment: Cross-Disciplinary Perspectives*, the second work on empowerment commissioned by the World Bank, 27 researchers and practitioners (in economics, political science, sociology, psychology, anthropology and demography) outline conceptual frameworks to monitor and evaluate programs that are based in empowerment approaches. Here Narayan defines empowerment as, “refer[ing] broadly to the expansion of freedom of choice and action to shape one’s life. It implies control over resources and decisions” (Narayan 2005:4). She states that in order to measure and monitor empowerment, one must clearly define the concept and framework which connects empowerment to “improve development outcomes and identifies determinants of empowerment itself” (Narayan 2005:4). This need for this clear definition is precisely what informs my decision to compare WB theoretical definitions with how people in a local context define

empowerment. It is precisely because the WB claims such a definition to be critical, that this thesis focuses on these definitions in the “Interview Analysis” in Chapter 3.

While the above demarcates Narayan’s perspective and definition of the concept in *Measuring Empowerment*, the book is a compendium of many other authors who contribute additional dimensions to the word, in specific contexts and in using specific terms. For example, Karen Oppenheim Mason analyzes the definition and determinants of empowerment, specifically looking at the concept as applied to women in their familial and household context. Using a five-country comparative study, Mason argues that women’s empowerment is multidimensional, relational and cultural. It deals with the relations between individuals and the communities of shared beliefs, values and norms; it cannot be conceived through only individual traits (such as wages and education), but it must be understood through the “shared cultural consensus about who has the right to power and resources” (Mason 2005; Narayan 2005:27). One may observe that Mason’s definitions share components of Narayan’s earlier definition (such as is cultural and multidimensional traits), but becomes specified to the particular situation of women, and in the sense that it is relational. However, though Mason focuses on the relational nature, this approach to empowerment is being supported by the WB, as it is published in their book, and thus contributes to their own working definition of this word. This work on the relational aspects of empowerment by Mason is not exclusive to her own understanding, but is also central to Christine Koggel’s argument. In her paper she claims that the term empowerment explains the “fundamentally relational nature of agency,” as opposed to the individualized approach (Koggel 2005:1-2).

CHAPTER 3

INTERVIEW ANALYSIS

This chapter analyzes the components of interviews conducted about empowerment. I describe the sample size analyzed, and delineate several similarities and differences that I find between providers and patients, illustrating these points with textual examples. Lastly, I briefly discuss the general similarities and differences that these data present in comparison particular aspects of the World Bank's definition. I provide data in support of the conclusion that providers present a closer empowerment discourse to the World Bank definition than do patients. For a description and discussion of the research methodology, see "Returning to the Field" in Chapter 2.

Due to the time consuming process of transcribing and the limited availability of transcribers, out of the 31 interviews conducted, I analyze 22 of them. As mentioned in the Chapter 2, I look at transcription material that contains the word "empowerment" directly in the text (New E-Docs), and do not refer to other parts of the interview that may have similar word or descriptions. The 22 interviews are divided into 10 healthcare providers and 12 patients. Of the 12 patients, 5 of them also identified themselves as healthcare providers. However, because most of the healthcare provision provided by these 5 individuals is educational (usually peer education), and because most of them became involved with HIV healthcare provision due to their diagnosis, I will treat them as patients for most of the

analysis (however in the examples I will note that they are “provider patients”)⁸. Of these 12 patients, 2 are female and 10 are male, of which 7 males identify as homosexual. Out of the 10 healthcare providers there are 6 females and 4 males, of which two males identify as homosexual and one woman as bisexual. For a complete chart of interviewee information, see Appendix C.

As mentioned in the Methods chapter, the New E-Doc categories I developed are:

- 1) Definition of Empowerment
- 2) Feelings about Empowerment
- 3) Application of the concept of empowerment to adjust to HIV
- 4) World view of empowerment

I make several major claims pertaining to these categories and their subcategories with regard to similarities and differences among patients and providers. These claims are illustrated with textual examples from the transcriptions.

Patients and Providers: Similarities

Similarity A:

Both providers and patients have similar conceptualizations about the nature of the word empowerment. The notion of “external/collective” involves the notion of

⁸ The assumption that most HIV positive healthcare providers are educators due to their HIV status is based on other parts of these interviews not explored in the thesis as well as from my fieldwork experience working with several of HIV positive providers. I have observed that oftentimes entering into HIV-related work as an HIV positive provider is frequently part of the HIV positive person’s “illness narrative” and is very much informed by their experience of living with HIV/AIDS.

empowerment as a force coming from the outside the individual (for example, by a physician or by the government) and/or something that is communally acquired in a group. The notion of “internal/individual” is based in idea that empowerment comes from within a person and/or that empowerment is based in one person and not a shared process with other people. 9/10 providers and 11/12⁹ patients characterized empowerment as “external/collective” and 8/10 providers and 9/12 patients characterized the word as “internal/individual,” thus favoring an external understanding slightly (but perhaps not significantly). It is interesting that although internal/external and collective/individual appear to be opposite constructions, both characteristics were used to describe empowerment about equally. However, because these data represent the total number of times such empowerment characteristics were mentioned (in the E-Docs), it is not clear if the two conceptualizations always coincided in the same interviews or not, and whether one characterization was dominant over another (meaning there may have been some interviews that had more collective/external data, and some which had more internal/individual data). The example below illustrates how both conceptualizations exist in a single definition (internal/individual concepts are in bold and external/collective concepts are underlined).

*To put **my knowledge** very well into practice because that is going to help a lot of people. Effects, **I know** there will be many problems behind us, but **I know I can confront them because I know the truth that I carry**—which is the truth that many people have to know: to **inform oneself**. Even the children because **in principal I would like them to know also**. (#2 patient homosexual male)*

Similarity B:

Both providers and patients cite “knowledge of HIV/AIDS” as important to empowerment. This “knowledge of HIV/AIDS” as comprehending the biomedical model in relation to HIV (awareness that HIV is virus, etc.) is mentioned by 6/10 providers and 7/12

⁹ Throughout the document the format “11/12” is meant to be read “eleven out of twelve.”

patients. However, it is interesting that while this biomedical knowledge is stressed, adherence to ARV medication is only mentioned by one provider and by one patient. This seems to imply that providers and patients focus on building a basic understanding of their biomedical situation before using this knowledge to interact in the situation with alternative actions/solutions (such as adhering to antiretroviral treatment)¹⁰. The examples below demonstrate a provider's and patient's approach towards promoting "knowledge of HIV/AIDS" in relation to empowerment.

Empowerment is a person who is well, who knows how to assimilate well with what they have. Meaning if that you have to know what you have...but you are not going to give it to anyone by only talking to or looking at someone or giving them a hug. (#6, provider P: female)

I think it is a way to empower also. Only with the act of talking about the ways of ... how to transmit HIV... how it is not transmitted, [is] already empowering someone. You are already empowering because the people then do not self-stigmatize or self-discriminate or its more difficult that discrimination falls on them, direct discrimination from other people. (#28 provider female)

Empowerment is the knowledge of knowing that the virus exists, knowing that the virus can be treated. And definitely it is the knowledge of person who lives with HIV to know what they live.... I have to know what I have and go to the doctor, and the doctor will tell me what it is I have...empowerment is[...] knowledge of how the virus develops, how to treat people who live with the virus and how I relate to the virus. (#22 patient male)

Similarity C:

In general not many patients cited "coping with HIV" as an important element to empowerment. In the coding scheme, "coping with HIV" is defined as referring to various feelings/attitudes that individuals have towards the HIV including the subcategories:

"accepting it," "normalizing the disease," viewing it as a "chronic illness" or believing "a person's attitude towards HIV will affect how the person experiences the disease."

¹⁰ However, perhaps it is the case in other countries that patients already have a higher level of basic healthcare education and hence many people already have a basic biomedical understanding of HIV/AIDS; thus, perhaps empowerment in these countries does not focus on building/attaining "knowledge of HIV/AIDS" but instead empowerment processes focus on introducing the next stage of "coping with HIV" such as adherence to treatment.

Of all the patients, these “coping with HIV” subcategories were mentioned very little, whereby “accepting it” occurred the most (5/12), and with the rest of the subcategories mentioned above even less (1/12, 2/12, 3/12 respectively). Hence, for patients, these notions were not crucial in defining empowerment. However, although this subcategory was not mentioned very much in the context of defining empowerment, it might be that these ideas are prevalent for patients in other aspects of their lives. From my extensive participant-observation fieldwork (including extensive conversations with patients), there does seem to be a notion that HIV should be regarded as normal, chronic and accepted. However, these attitudes were not surfaced in this part of the interview and thus while they might be part of patient’s outlook on the disease, these “coping with HIV” categories are disassociated with the notion of empowerment. The following examples demonstrate how providers and patients articulate various “coping with HIV” subcategories in relation to empowerment.

While I deny what I have, while I don't accept it, I will not be empowered. (#15 provider patient homosexual male)

[Empowerment means to] accept it in a positive way...accept that it is not something mortal, but something chronic. (#5 provider patient homosexual male)

For me it means to accept, in reality...that you accept what my diagnosis is, and that you can confront it before others. (#14 patient female).

I realized that there also exists many who do not want to accept their situation and so they live badly. And they have the opportunity to live well but they don't accept.” (#1 patient homosexual male)

Providers only cited the sub-categories of “coping with HIV” once besides regarding it as a “chronic” disease, cited 3 times. This is a very small number considering the fact that (as mentioned in the next chapter), the notion of HIV as a “chronic” disease is directly related to a First World discourse on HIV/AIDS. Hence, although providers are more likely to have

access to education and information, and are more likely to articulate such First World discourses, they still do not cite these “coping with HIV” categories as part of the process of empowerment. These data are surprising, and perhaps explanations could be similar to that of the above described patients: perhaps providers do adhere to the notions of “coping with HIV,” but they fail to cite these in the specific context of talking about empowerment. The example below demonstrates a provider who does articulate some of the “coping with HIV” categories in the context of empowerment.

I don't see a difference between this disease and diabetes—for me this is a chronic disease. (#3 provider bisexual female).

Similarity D:

In general, half of the patients and providers use the term PLWHA (person living with HIV/AIDS) when describing empowerment. The concept of a PLWHA attempts to emphasize the *person* rather than the disease itself; furthermore, the term PLWHA connects an individual person to a national and international community of people with HIV/AIDS by identifying them as a PLWHA. It appears to be important for 6/12 patients and 4/10 providers to use the term PLWHA when articulating the concept empowerment. However, for those who do not mention PLWHAs in the data set, it is not necessary to mention the concept of a PLWHA when talking about empowerment. Hence, because about half of the patient and provider informants do not use the concept PLWHA, it does not appear to be an essential part of patient and provider understanding/description of empowerment. The examples below depict how providers and patients do refer to PLWHAs.

The PLWHAs in Guatemala... (#2 patient homosexual male)

[Empowerment] is a word I did not know before, until now in the process of being seropositive...it is a new word I learned through my diagnosis also. (#1 patient homosexual male).

With PLWHAs you have to try to make them not afraid (#8 provider male)

Similarity E:

Half of the providers and patients demonstrated some sort of “attitude” towards empowerment (5/6 provider and 6/12 Px). This outlook is almost always positive. Demonstrating this “attitude” was not directly addressed in the interview, but was demonstrated at some point in the interview. The following shows examples of this attitude.

The experience of empowerment for me has been sometimes very fun. (#15 provider patient homosexual male)

It is a word that I like. It is a word I like to use too...it is nice/pretty. (#1 patient homosexual)

As such I tell you [empowerment] is a very very difficult job. It is difficult, but not impossible. (#8 provider male).

Patients and Providers: Differences

Difference A:

All providers and patients (except for one in each category) used abstract definitions to describe empowerment. “Abstract” definitions refer to ways of describing empowerment in which an informant provides a theoretical conceptualization of the word empowerment; the definition is not grounded in any personal examples. “Functional” definitions refer to ways of describing empowerment in which an informant uses a lived example of a person/people in order to illustrate the term. In my coding scheme I divide functional definitions as either using their own life (“self”) or if they use another person’s example (“other”) to illustrate the term empowerment. 9/10 providers and 11/12 patients used abstract definitions. However, for all of the patients, the abstract definitions were much shorter than their functional definitions. Patients tended to favor the use of both “self” and

“other” functional definitions when describing empowerment: 11/12 used self-functional definitions and 7/12 used other-functional definitions to define empowerment. Though there is a difference between these two numbers, these data may be insufficient to conclude whether or not patients necessarily use self-functional definitions more than other-functional definitions. The following example shows how one patient’s description of empowerment includes a brief abstract definition and a lengthy self-functional definition. Included is also an example of another patient’s other-functional definition.

Abstract: *[Empowerment is] to know my rights...to know my rights and obligations that the country, that the state has with me.*

Functional (self): *[[my diagnosis]] in part was well, a benefit, because at least...it tried to...overcome this of... alcoholism... and not taking care of myself because when I would sometimes go to parties in different places, and there [through the diagnosis] I changed, my way of living, my way of life. In a certain way my life turned a lot a lot...definitely in a big way...With respect to empowerment I have see that well, in my home at least, I know it, what I can do and what I cant do. But there are people who still at these levels are still ignorant about what is AIDS. There are many of us who we don't know it because not only within other patients, but outside the people too have discrimination against us, because they are not educated. Empowerment means more than anything to have rights and obligations that the state has with me...rights, me as a citizen, the right to life and the right to medication and services. Meaning medical treatment from the state for the simple fact of being a Guatemalan citizen, right? Because as a citizen I pay my taxes and whatever else that I do and in the end, however it is, I am contributing so that the country progresses. And so it is part of the Guatemalan country that I have the right that the state gives me services, right? That is in the Political Constitution and also in the Human Rights that every Guatemalan citizen has the right to life, to education to medical services, and finally to treatments as a Guatemalan citizen. Meaning that for me, and that is what we want the other people to know, that we all have the right that the state gives us our medication for free.*

Other: *[My 9-year-old granddaughter knows what HIV is] Perfectly. She does know. She is as empowered as I am [she laughs]...each workshop that I [go to] she says to me, “look mom, did you bring reading material?” “Yes, here it is...now that I have brought it, now you read it. (#6 provider patient female)*

In contrast, most of the providers (8/10) had long abstract definitions and shorter functional definitions; providers tended to favor the use of abstract definitions when describing empowerment. When providers did use functional definitions however, 3/10 were self-functional, and 5/10 were other-functional. The examples below present two abstract, two self-functional and one other-functional definitions of empowerment by providers. Note

how the longer abstract definition describes empowerment in a very detailed way (including specific empowerment actions/activities/understandings, and delineating the difference between patient and provider empowerment).

Provider Abstract: *I understand empowerment in a general way...like a word derived from power, right? That's how I see it, empowerment. And so I think that it is an acquired capacity that each person has to make a situation manageable. (#28 provider female)*

Provider Abstract: *Empowerment of a patient I would define as the capacity of the patient to provide themselves with ... special self-care to be able to favor a healthy state meaning the acquisition of a healthy state: exclusive use of condoms, eating without fat, yea a hipofat diet...a comprehension more or less what a CD4 is what are defenses and viral load, a bit of those four aspects. That is what I would call the empowerment of a PLWHA. Empowerment also at the level of their rights that they keep taking care of themselves, as well as others with all the rights that the Guatemalan constitution gives us with a chronic disease...to know their rights, to have the capacity and the want/desire to defend them, I think that is the most difficult maybe. That is what I would call the empowerment of the patient. Empowerment of a healthcare provider entails the acquisition of the technical knowledge of the attention to PLWHAs, the comprehension that it is an infection, an chronic disease, yes, the same as other diseases and well not to stigmatize PLWHAS...the capacity to give information about rights and to support PLWHAs, at least to refer them to places where there is legal resources for PLWHAs. (#29 provider homosexual male)*

Self-functional: *In terms of the empowerment of the doctor, I think that it is this process that we are in, that I am having also. (#27 provider female)*

Self-functional: *As part of the [MSF] team I am empowered with regards to my profession, what I do here. Meaning I am clear about and assume my role here. (#10 provider female)*

Other-functional: *Empowerment that the woman is having about certain rights that have...been reflected on and products of this [...] consciousness that they were infected by their husbands because socially they permitted [their husbands] to have a promiscuous life. (#10 provider female)*

Hence, although quantitatively there appeared to be a close number of both providers and patients using abstract definitions, it is clear from these data that patients mention abstract definitions but predominantly utilize self-functional definitions (as well as some other-functional definitions), whereas providers predominantly use abstract definitions to define empowerment and do not often use functional definitions.

What could account for this difference? Perhaps it is the case that some degree of abstract definitions are found in both populations because Guatemala, located in the Americas, is indeed a Western society, in which there exists an emphasis on being able to abstract and define certain concepts. This tendency to label and define is tied to the Western First World educational system. Hence, because providers are more likely to have had extensive exposure to education (including higher education), they are more likely to regurgitate definitions in the way in which they were educated/ trained/schooled. In contrast, the high usage of self-functional definitions by patients may be attributed to not having too much exposure to Western models of education, and to their socialization in an oral society whereby concepts are understood by using functional examples. Furthermore, such functional definitions may be attributed to their own HIV/AIDS education background. Because peer education is so widely used with HIV/AIDS, it is possible that patients model their definitions of the word empowerment after how peer educators explained it to them. As discussed in the following chapter, peer education in “Social Learning Theory” claims that people may “serve as models of human behavior” (UNAIDS citing Bandura 1986). Hence, similar to how HIV/AIDS peer educators use their own life experiences to demonstrate what empowerment is, the patients may do the same when responding to my own inquiries about empowerment.

Difference B:

Few patients and more providers mention “stigma” when talking about empowerment. AIDS-related stigma entails acting out marked prejudices associated with a particular person, quality or condition. Only 2/12 patients mention stigma as a factor in empowerment (implying the concept of stigma but not always using the word), whereas

6/10 providers mention it. Perhaps just as mentioned below in Difference F where patients may have lived the civil war too closely to talk about it, patients may also live HIV-related stigma too closely to articulate this as part of an empowerment process. Furthermore, only 3 patients mention rights as a factor in Empowerment whereas 8/10 providers mention this. As mentioned above with the term “chronic disease” in Similarity C, the notions of rights (human, state, citizen, PLWHA rights) are part of a western First World discourse. Because providers are more likely to be repeatedly exposed to this discourse through their education and situatedness as active professionals, this may be the reason they mention rights more than patients do. The lower level of education that patients receive is likely to be a factor in their low usage of the word “rights.” The first example below demonstrates the concept of stigma for a patient, whereas the second example demonstrates the concept of rights for a provider.

But there are people who still at these levels are still ignorant about what AIDS is. There are many of us who don't know it because not only within other patients but outside the people too have discrimination against us, because they are not educated. (#23 patient male)

Empowerment also is that people have the conditions and capacities to demand their rights. Not just saying, “yes, yes, I am [HIV positive],” and well, that's it. No. It also implies to execute actions, also implies demanding. [An empowered woman may say] simply and sincerely, “put it [the condom] on” in other words, “these are your rights. If you want things, well you also have to help me because I am no more going to be assuming all of the responsibility of the house” for example. (#10 provider female)

Difference C:

More providers than patients refer to “self-limits” in attaining empowerment. This term “self-limits” refers to a person’s restriction on attaining empowerment because of their own internal self/processes (for example, a PLWHA’s self-stigmatization would be a self-limit by inhibiting their own ability to become empowered). Whereas 6/10 providers refer to possible “self-limits” in attaining empowerment, only 2/12 patients mention this. Yet, all of

the providers who cite a self-limit, refer to PLWHA self-limits and not to their own potential self-limits (as providers) in being empowered. Thus, perhaps because providers refer to “others” self-limit, it is easier for them to express this than patients themselves. Perhaps too, it is harder for patients to see their own self-limit because they are living it themselves. The example below demonstrates the facility in which one provider expresses this.

The frequent cause of discrimination is by the person themselves. (#21 provider male).

In perceiving a “structural limit” as an outside force (such as the dysfunctional healthcare system, lack of medication, one’s immediate family) impeding empowerment, there is a slight raise from the self-limit for patients where 4 patients mention a structural-limit as opposed to 2 patients for a self-limit. However, providers maintain the same ratio with 6/10 perceiving structural limitations to empowerment. This example illustrates the kinds of structural limitations some providers think about.

The people in the social security don’t have support groups. It takes a lot to get to them. And so for the same, they are not organized because they are not empowered. That is the problem.... that there are rumors, always. It is always like that, I feel that in whatever place this exists. (#9 provider Px male homosexual)

Difference D:

More providers mentioned “political incidence” when describing empowerment than did patients. This term is directly translated from Spanish and refers to the way in which people involve and participate in political activities. 5/10 providers and only patients 3/12 mention this. Such a difference might occur because providers have had more exposure to political incidence. Perhaps however, both providers and patients are exposed to political incidence equally, but providers have the tools (through higher education) to name it as political incidence, whereas patients do not have the tools/vocabulary to articulate it as such. The low number of patients citing political incidence as part of empowerment is interesting

when seeing how most patients (11/12) view empowerment as external/collective that implies group mobilization. This example shows how a provider briefly describes an example of political incidence he was involved in.

[Interviewee's role as a psychologist, running groups for HIV positive people (with alcohol problems) who are going to take/already taking ARVs]. The project has been growing, and other necessities arose. And one of them was to empower people, right? The PLWHAs. And well, this other responsibility came to me and that is what we have been doing, right? To try to organize people so that they demand from the government their medications. (#8 provider male)

Difference E:

The providers tend to speak about empowerment specifically referring to Guatemala, whereas patients focus on other parts of the world. 6/10 providers speak about Guatemala whereas only 2/12 patients refer to their own country. In contrast, about the same number of patients and providers speak about empowerment in the world (4/12 patients and 3/10 providers). It seems that for each group there is a notion of empowerment in the world, implying that for several people empowerment in Guatemala is more largely situated/participating in processes involving people in other parts of the world. The following three examples demonstrate different perspectives about empowerment in Guatemala and in other parts in the world (Spain) by different healthcare providers.

Because it is their rights, and our right as people, citizens, to be worried so that they also demand their rights. And that the state, the government here in the constitution it says that it is the duty to watch over the rights of citizens, however they [the state] are the ones that violate the rights of citizens. And so that is what we want, we are so that this does not happen in Guatemala. (# 21 provider, male)

Perhaps the word empowerment, for... "Empowerment" as they say in the United States, goes a little further than knowledge. But in the case of PLWHAs in Guatemala, the word empowerment is in the condition of knowing what their situation is, what is it that affects them, what are their risks, their pros and cons, in relation to adherence... we believe that for the case of Guatemala, it is the first step, so that they are trained to this condition to get to know themselves... Many of our PLWHAs think that there is a discriminatory and stigmatizing process because of cultural processes in Guatemala. Why? Because in Guatemala if you are a PLWHA, if you are a man, you are a homosexual; if you are a woman, you are a prostitute. And so this is how the self-esteem comes down. (#25 provider, homosexual, male)

In Spain I cannot say that we are 100% good [in terms of empowerment], but what I can say is that there does exist a state of well being, there does exist a formation that is really at all levels. We are talking about a cultural level that demands rights from healthcare personal. They are very clear that they cannot be badly treated, that they have to have their medication on time. They know it. And if they don't know it, there is a union, there are organizations, there is a Ministry of Health that supports them, that avails them. There are organizations that are very very very strong, that have contacts at the international level. We are talking about a very elevated development.

Difference F:

There is very little mentioning of the civil war and genocide in Guatemala. In total this was only mentioned twice by providers, and zero times by patients. Perhaps this was not mentioned very much by either population because of how recently the civil war and genocide had taken place (the peace accords were signed in 1996), and because of how government oppression is consistently experienced by Guatemalans every day. The constant strain of working and/or living under an oppressive government/country is great, and articulating such individual and collective repression may have been too difficult for people to express. However, the two providers (a nurse/social worker and a psychologist) who did speak to the genocide both had higher education, were better off socioeconomically, and in fact the nurse is a foreigner from Spain; hence the two were perhaps a bit more removed from the war than the majority of patients and/or providers who may be in a socioeconomic status or situated/positioned in ways that made them more likely to be affected by the war. The distance these two healthcare providers might have experienced may have afforded them more freedom to talk about something that was so intensely destructive and repressive to so many people. It is not always easy for the survivors of repression to talk about their repression upfront, as oftentimes there are few linguistic tools to do this in the aftermath. Hence, it may be easier for these very few healthcare providers to introduce this element to

the understanding of empowerment because of their particular more removed situation.¹¹

The below examples present their thoughts.

And furthermore, when you speak about empowerment, when you speak about participating in this, participation in what, it gives them fear for the 36 years of war that they have lived here in Guatemala. If you demand in whatever moment they will treat you as a guerilla. If you try to demand your rights, like people now, they will be discriminated because of the same, because of demanding their rights as such. In any given moment they have to know that the government can give the medication. (#8 provider male).

Basically there is a history of terror in Guatemala, we cannot forget there were 36 years of war, 36 years of conflict and people are afraid. And that is manifested in education, in health, in the family, in a person themselves, and so that people are terrified. And so they don't want to go further. (#3 provider bisexual female)

Patient/Provider Responses as Compared to the World Bank Discourse

As mentioned in Chapter 1, according to the World Bank the four key elements considered to be “almost always present when empowerment efforts are successful” and which are “closely intertwined and act in synergy” (Narayan 2002: xix-xx, xix) consist of:

- (1) Access to information, flowing from citizens to government and visa versa;
- (2) Inclusion/participation, treating poor people as co-producers;
- (3) Accountability, reinforcing accountability for state officials, employees, employers and politicians;
- (4) Local organizational capacity, the ability of people to work, organize and mobilize resources together

General Conclusions for All Participants

According to the above analysis, all four elements are mentioned either by healthcare providers or patients within the 22 interviews analyzed. Hence, in this project's sample there

¹¹ These claims are speculative, and could be completely wrong.

exists a collective notion of empowerment that does adhere to the World Bank's definition. However, in each individual interview it was infrequent (for both providers or patients) to articulate all 4 aspects mentioned by the World Bank. Oftentimes an individual presented certain elements pertaining to the World Bank definition, yet because their definitions were rooted to their own particular situation, their articulation of the word/concept empowerment referred to their localized experience.

The first two elements "access to information" and "inclusion/participation" were mentioned in the interviews, but the nature of these elements do not match that of the World Bank's understanding. In general, access to information was not spoken about in terms of "citizen and government flow of information," but rather was mentioned in the context of information about the biomedical model of HIV/AIDS, and sometimes about the knowledge of what "rights" or "empowerment" is; there was no mentioning of information as flowing from the government to citizens. Likewise, the inclusion/participation mentioned was not specific to seeing "poor people as co-producers." Participation was directed at HIV positive people and those who support them, and there was little mention of poverty and no conversation about "production"; instead providers and patients mentioned participation/involvement in consciousness raising and in participating in social movements pertaining to bettering the lives of PLWHAs. It seems that perhaps the World Bank used the word "production" because in general the organization has economic oriented objectives, and hence interviews did not yield this kind of definition.

Despite these variations on the first two elements, the nature of the second two key elements, "accountability" and "local organizational capacity" as described by the World Bank matched well with what was articulated by patients and providers. In general,

accountability mentioned in the interviews did include “state officials, employees, employers and politicians,” as articulated by the World Bank, and also included everyday citizens.

Likewise the local organizational capacity of people did include the “understanding of the ability of people to work, organize and mobilize resources together.” It is significant that these two elements conceived in large organizations such as the World Bank are on-target with what happens on the ground. Such similarities may demonstrate the “trickle down effect,” where aspects of these large First World discourses indeed do appear and manifest themselves in local settings.

Specific Conclusions for Patients and Providers

The following summarizes the similarities and differences discussed in this chapter. After each similarity/difference I will briefly mention how the claim may/may not adhere to the World Bank’s (WB) definition (parts #1-4 above) of empowerment. The findings below illustrate that although in the “similarities” category both patients and providers adhere to WB notions of empowerment, in the “differences” category, only providers adhere to the WB’s definition. Within this category there are various ways in which providers adhere to the WB definition, and the provider’s alignment with the WB’s definition appears to be consistent; thus, I conclude that providers have a closer definition of empowerment to the World Bank than patients do.

Similarities of Patients/ Providers in Relation to WB Concept of Empowerment

Both providers and patients:

→ Have similar conceptualizations about the nature of the word empowerment where they both characterize it as “external/collective” and “internal/individual.”

The notion of an external/collective view of empowerment adheres to WB #4 definition as an external nature could encompass factors such as “local organizational capacity, the ability of people to work, organize and mobilize resources together”. Each part of these descriptions deal with an individual dealing with /negotiating with their outside world, and thus empowerment has to do with an “external/collective” interaction. Furthermore, patients’ and providers’ idea that empowerment is “internal/individual” adheres to the WB #1 definition whereby an individual and internal understanding of empowerment could entail an individual’s “access to information” as articulated by #1 WB.

→ Cite “knowledge of HIV/AIDS” as important to empowerment.

This component of empowerment also coincides with the WB #1 claim that empowerment deals with “access to information,” in this case to HIV/AIDS. Indeed as the WB articulates, knowledge about HIV/AIDS can may in fact flow specifically “from citizens to government” through public health educational interventions, for instance.

→ Half of patients and providers use the term/have a concept of a person living with HIV/AIDS (PLWHA).

Using the concept of a PLWHA adheres to WB #2 definition in that the term PLWHA builds the construction of an HIV positive person that “includes” them as people, allowing

them to legitimately “participate” in society, and incorporates the notion of “people as co-producers.” This notion of production combats the social death promoted from stigma, and instead refers positively to HIV positive people’s production in society (though the term PLWHA does not necessarily include poverty as indicated in the WB definition).

→ Half of patients and providers demonstrated some sort of attitude (mostly positive) towards empowerment.

Positive attitudes about the word empowerment adheres to WB #4 definition whereby such an attitude will help foment “local organizational capacity, the ability of people to work, organize and mobilize resources together.”

→ Mention the subcategory “Coping with HIV” very little.

If the notion of coping with HIV had been mentioned more, it would have adhered to the WB #4 definition in that normalizing HIV or viewing as a chronic disease, would have enabled people to “work, organize and mobilize” because they would not have been stagnant and immobilized with self-stigma, depression, etc. However, because “coping with HIV” was mentioned very little, as a group neither patients nor providers adhere to this notion supported by the WB.

Differences Between Patients/Providers in Relation to WB Concept of Empowerment

→ All providers and patients (except for one in each category) used an abstract definition to describe empowerment. However, for all of the patients, abstract definitions were much

shorter than their functional definitions, whereas for providers abstract definitions were longer and functional definitions were shorter.

Regarding abstract definitions, providers adhere to the #1 WB definition of empowerment involving “access to information, flowing from citizens to government and visa versa.” The fact that providers articulate educational/schooling-oriented abstract definitions demonstrates their exposure and access to information. Furthermore, the ability to produce abstract definitions will allow such information from higher institutions such as the government to reach them as citizens.

→ Only 2/12 patients mention stigma as a factor in empowerment (implying the concept of stigma but not always using the word), whereas 6/10 providers mention it.

Regarding notions of stigma, the providers adhere to the #2 WB definition of empowerment involving “inclusion/participation.” This term involves the act of incorporating many people into a movement through their partaking in variety of activities. This view of including people through participation is a topic touched upon when talking about stigma. In addressing stigma, the providers refer to how the force does not allow inclusion/participation in neither day to day activities with others nor in political incidence. Hence, the provider’s talk about stigma adheres to this component of the WB definition that involves inclusion/participation.

→ Only 3 patients mention rights as a factor in empowerment whereas 8/10 providers mention this.

Regarding rights, providers adhere to the #1 WB definition because rights has to do with “access to information” from “citizens to government and visa versa”; the notion of rights deals with this interchange between individual and state directly.

→Whereas 6/10 providers refer to possible self-limits in attaining empowerment, only 2/12 patients mention this. In perceiving a structural limit as impeding empowerment, there is a slight raise from the self-limit for patients where 4 patients mention a structural-limit as opposed to 2 patients for a self-limit. However, providers maintain the same ratio with 6/10 perceiving structural limitations to empowerment.

Regarding both self and structural limits, providers adhere to the #4 WB definition for empowerment. These limits deal with the ability of both individual and collective people “to work, organize and mobilize resources together,” and also deals with “local organizational capacity”. Hence, as more providers articulated these self and structural limits, they adhere to the WB #4 definition of empowerment.

→Providers mentioned more instances of political incidence (5/10) when describing empowerment than did patients (3/12).

Regarding political incidence, providers adhere to the #2 and #4 WB definition for empowerment. Political incidence includes the #2 notion of “inclusion/ participation” with people coming together to intercede collectively, and also incorporates #4 notion of “local

organizational capacity, the ability of people to work, organize and mobilize resources together”—critical factors for political incidence to take place.

→The providers tend to speak about empowerment specifically referring to Guatemala, whereas patients focus on other parts of the world.

This concept does not appear to adhere to any of the described WB definitions of empowerment.

→There is very little mentioning of the civil war and genocide in Guatemala.

While there is very little mentioning of the genocide, the two times it is mentioned by providers, adheres to the WB #3 definition that pertains to “accountability, reinforcing accountability for state officials, employees, employers and politicians.” Providers mentioning of the civil war and genocide is brought up to speak of the culture of repression in Guatemala, and also to point to the government/state responsibility to take a role in empowerment.

CHAPTER 4:

DISCOURSE ANALYSIS

We may observe from the previous chapter that there are a variety of ways in which differently situated people express their understanding of the word and concept “empowerment.” For both patients and providers, some notions converge with those articulated by the World Bank, and some diverge from this First World discourse. However, it is often the case that institutions such as the World Bank place a great emphasis on the positive effects of having their supposed universal discourse reach people around the globe. In this chapter, I will challenge this idea that a First World discourse is positive for all people situated in their local settings by conducting a discourse analysis of an HIV positive person; the analysis aims to illustrate the kinds of fragmentation that can occur within local settings when First World discourses (such as that of empowerment or HIV/AIDS education) are assumed by local people.

Utilizing a Discourse Analysis and a Theoretical Framework

By “discourse analysis,” I do not refer to the way in which people communicate (such as in “conversation analysis”), but rather I refer to the “specific ways of speaking about things which have acquired a largely habitual and taken-for-granted character” (Crossley 2005:60-61). Within the field, discourse analysts may choose to work generally in order to “demonstrate the existence of common patterns of language across numerous texts”; the previous chapter uses this approach for the various interviews through the coding model. In contrast, this chapter takes a different analytical approach by looking at “speech in

action, teasing out the various techniques of sense-making it entails” (Crossley 2005:61). Such “sense-making” within discourses will vary in size from small scales, to those that are all encompassing. For example, a given speech text can be understood as providing explanations for the way people behave, or it can be seen to fully constitute the person itself. In this thesis I will use the latter definition by utilizing a Foucauldian approach towards discourse to analyze a specific interview mentioned in the previous chapter.

Usually seen as a post-structuralist using a social constructivist approach, Michel Foucault examines how bodies are controlled by discourse (one of the most important concepts in his work) (Shilling 1993:64). In his view, “the body is not only given meaning by discourse, but is wholly constituted by discourse” wherein the body is “produced by and existing in discourse.” As opposed to a naturalist approach where natural biological differences determine the capabilities of people, (Shilling 1993:69) Foucault believes the biological body to disappear, and instead becomes a “socially constructed product which is infinitely malleable and highly unstable.” (Shilling 1993:65) Yet, within this invisibility, Foucault believes the body to be not only the central point of discourse, but as “constitut[ing] *the* link between daily practices...and the large scale organization of power on the other” (Shilling 1993:66 citing Dreyfus and Ranibow 1983). Such interconnection produces a “ ‘mindful body’ ” (Shilling 1993:67) which is comprised not only of flesh, but is defined through “its possession of consciousness, intentions and language” and controlled through “surveillance and stimulation” (Shilling 1993:67).

Foucault’s notion of discourse is primarily concerned with language in which its “unity” involves the “interplay of the rules that define the transformations of these different objects, their non-identity through time, the break produced in them, the internal discontinuity that suspends their permanence” (Foucault 1970: 32-33). In this sense,

discourses are the “sets of deep principles incorporating specific grids of meaning which underpin, generate and establish relations between all that can be seen, thought and said” (Shilling 1993:66 citing Dreyfus and Ranibow 1983; Foucault 1974). The First World discourse on empowerment with HIV/AIDS is an example of such guiding principals, establishing not only the mindset of people, but also their relations to others. Yet, according to Crossley, one of the “key critical imports” to understand discourse involves “the assumption that those who partake in it are largely unaware of the system of conventions they habitually use and are perhaps also unaware of specific consequences that their way of speaking may have.” Thus, because of the speaker’s unawareness, the analysis which “unearths and ‘deconstructs’” the system brings a “potentially liberatory value” (Crossley 2005:61). It is my aim in the following analysis to begin to surface and articulate the processes that may or may not reside in the consciousness of the interviewee. However, it is not for me, an external being, to bring a person into consciousness; according to Crossley, social agents are indeed flexible, containing the ability to recognize that their thoughts and outlook on the world has been learned from a social structure (including that of discourse) (Crossley 2005:61).

Case study

Edgar is a 43 year-old gay man living with AIDS for the past 5 years (at the time of the interview) in Guatemala City. The same day we met, I interviewed Edgar about his life and his thoughts on a variety of topics concerning HIV/AIDS (see Appendix B). Yet, all throughout the interview, one of the most prominent recurring themes was Edgar’s articulation of both an educational discourse on HIV/AIDS and a First World discourse on this matter. By educational discourse I refer to the western focus on cognition, which uses

the schooling model of knowledge acquisition to import or receive information, instead of shared learning; by First World discourse I refer to an individually focused improvement of the individual, rather than a collective and communal approach (a component heavily promoted by disseminators of the First World discourse, such as the World Bank). Looking at the entire interview, at first I identified 9 times that an educational discourse was mentioned, and 16 times a First World HIV discourse was surfaced, and noted their close proximity to each other. Yet looking more closely at the specific instances of these discourses, all of the educational discourses included components of the First World discourse, and almost all of the First World discourse mentioned were framed in an educative genre. The overlap between the two discourses demonstrated how integral one discourse is to the other, and how it is difficult to delineate where one ends and the other begins.

Such overlap may be accounted for by a number of reasons. Firstly, Edgar had previously been a primary school teacher and thus has assumed an educative role for much of his work. However, while acknowledging and being mindful of the effect his profession has on his presented discourses, much of the education imparted in the interviews appears to retain a very strong First World discursive element to it.

There are people who receive medications in the Social Security [hospital] and sell them [...] to have money because they have 4, 6 children and they have to give food... I don't know. In my way of thinking, I say, "I would take the medication, I would get well, and I would start to work." But many people don't think that. Only, "ah, I am sick..." I have heard many, "I am sick." And [they] ask, "What do you have?" "I have AIDS." "You AIDS? That is a lie, AIDS is the people who are lying in bed, with tuberculosis, bronquitis, a pneumonia... and all the diseases. But you don't have AIDS." "Yes, I have AIDS." "No" they tell me, "That is a lie. You are a carrier of the virus." [cough] But that is the mentality of the people, no? It cannot be changed, but sometimes I would like to transmit to people that it is not a situation of death, this. It is a disease like whichever. [...] Yes, it is what I think. It is a disease like whichever one. I take care of myself, I will live many years—until where it is possible. But, if I don't take care of myself I will die of whatever disease. Not from being a carrier of the virus.

This last aspect of HIV/AIDS being a disease “like whichever one” directly coincides with the First World notion that “AIDS is no longer viewed as an apocalyptic threat, but rather as another chronic disease” (Barbour and Huby: 2). Not only does Edgar assume this chronic disease approach himself, but he would like to “transmit” it to people, undoing their notion of what it means to have AIDS. This notion of extending knowledge and teaching others is central in the First World model of peer education. Such a model is used in many areas of public health (including nutrition, or substance abuse), but “stands out” in global efforts to further the process and impact of HIV/AIDS prevention, care, and support (UNAIDS: 6).

Peer Educational Theory

Peer education is a widely used concept implying “an approach, a communication channel, a methodology, a philosophy, and a strategy” which usually involves using members of a specific group in order to “effect change among other members of the same group” (UNAIDS: 5). In the interview Edgar refers to several different audiences he targets when promoting an educational discourse including his gay male friends, people in the waiting room he encounters, his family, and the general public. Hence, in each different sphere he is to a different degree a “member” of the group whether it is through sexual orientation, HIV status, kinship, gender, nationality, etc. The change effected by peer educators is often used at the individual level, modifying people’s knowledge, attitudes, beliefs or behaviors, but may also effect change at the group or level of society, by “modifying norms and stimulating collective action” leading to both program and policy changes (UNAIDS: 6). Edgar addresses such individual behaviors several times, by using his own life as an example; for instance, when advising people not to drink alcohol and to modify their nightlife behavior he

says, “Yes, [take my suggestions], really...because by doing that *I* changed my life a lot.”

Such instances of using his own model adheres to the behavioral theories in peer education such as “Social Learning Theory” which asserts that people can “serve as models of human behavior” and that certain people are able to elicit specific behavioral changes from certain individuals, “based on the individual’s value and interpretation system” (UNAIDS citing Bandura 1986). Though Edgar is confronted by people who have different values and interpretation systems, his shared “memberships” of several groups (described above) provide him with similar terms with several people, thus allowing him a sphere of influence to effect change.

However, while peer education is a model that is disseminated and picked up by individuals such as Edgar, the model is not detached from the content. Booklets and papers describing peer education for HIV/AIDS not only include a skeleton of a model, but also entail the content of the AIDS education itself. Hence, if the peer education model is articulated in the First World and exported to developing countries such as Guatemala, the First World discourse surrounding HIV/AIDS will also be imported. For example in another First World text called *Teaching AIDS*, peer education programs are described as being “able to give HIV and AIDS a human face to boost the audience’s empathy, understanding, and acceptance of those infected with HIV or living with AIDS” (Tonks 1996: 98). The above excerpt demonstrates how Edgar assumes this role of using his own face to educate people by undoing the disbelief that someone with his good physical appearance has AIDS by declaring, “Yes, I have AIDS.” Such a presentation both signals Edgar and the HIV positive person’s situatedness established in interaction, and also “forms part of the message communicated”; hence, the peer education model to frame education in

other parts of the world actually carries messages in its form including overarching First World discourses such as HIV/AIDS conceived as a chronic disease.

The discourses presented by Edgar do not only entail such HIV discourses specifically, but also carry First World queer discourses. For example when speaking to his gay male friends who were dying from AIDS about going to the Hospice to get treatment, Edgar articulates the famous slogan “Silence = Death” which ACT UP created at beginning of the epidemic in 1987 to make criminal actions against gay people visible. He recounts his experience,

Because I had two friends, very very good friends and they resulted infected after me. And I [said], “Ok guys the opportunity has arrived in that you need to confront life. Let’s go I will take you...” “No, we don’t want to. They are going to discover us, they are going to know that we are what we are...” “What does that matter to you, if your life is more important?” They did not want to. They died.

Crimp and Rolston (1990) described the slogan “Silence=Death” stating it ‘declare[d] that silence about the oppression and annihilation of gay people, then and now, must be broken as a matter of our survival’ (Myrick 1996:60). In his own way Edgar adhered to this notion that if his friends were to be silent, they would die, and that only through breaking that silence through “confront[ing] life” by means of “discovery” (disclosure of their positive status and homosexual orientation), would they survive. Within this discourse, Edgar related this notion of visibility to the word “empowerment” stating that the word has to do with being able to “comport before all of society,” hence as visible gay and HIV positive people seeing care and treatment. He told this to them by referring to their actual lives being at stake when they did not want to come out; in this experience, Edgar attested to the lived truth of this slogan: silence did equal death.

Yet, while Edgar lives out, presents and embodies these discourses, what are the shortcomings and costs of assuming such knowledge? Though the extent of this may never be known, it appears in this last example of assuming the “Silence=Death” discourse, Edgar’s belief that only care through visibility will save a person, he in fact negates the “cultural intimacy” he actually shares with his HIV positive male Guatemalan gay friends. Edgar stopped trying to help his friends after their response, “we don’t want to [go]”; according to the information presented, there were no other ways in which he attempted to understand his friends’ words, and he simply used their negative expressions to outline their doom, “They did not want to. They died.” The First World discourse stripped Edgar of his ability to speak his local language with his friends on this subject matter—he did not unpack *why* they were ashamed to come out as being “what they were,” and was unwilling to listen to the words, explanations or models of understanding his friends had; he interpreted their words as ineffective. After the above statement, I attempted to clarify his explanation,

[Was] the reason [they refused going to the hospice] so that people wouldn't know they were homosexuals?

Yes. That was the strongest reason they had. “But what does it matter if you both are free to make your life, be happy?” But no, they did not want to. I tried to bring them here to the hospice. And they accepted once when they were very bad. But after that they did not want to come, [they said/implied] that it “made them ashamed that everyone knew where they were coming from, they knew this place was for those sick with AIDS.” Many prejudices, many prejudices. I think also that it was little preparation... little acceptance for themselves that made them act this way. Because for me, I do not care. If they tell me “ah, you have AIDS” at first I thought, “ay, it is a disease for homosexuals.” But now I realize that no. And now I know that I am not more or less than anybody. I am a person like everyone. I want to live and that is the most important, I do not care.

By framing his friend’s decision to not participate in the hospice as due to the possibility of making their homosexuality visible as the “the strongest reason they had,” Edgar implies that his friends in fact lacked reason. He engages in this irrationality by trying to question and undo their logic, asking “but what does it matter...?” in attempting to question their premise

abstractly, without listening closely to what they were communicating to him. We can see his inability to listen when he does not recount their response, but informs us curtly, “but no, they did not want to.” Perhaps his friends did give a verbal explanation, perhaps they were silent, or perhaps they had previously already stated the significance of this situation. Yet, whatever was said or unsaid, Edgar presents their reply as negating his own suggestion, informing us, “but no, they did not want to.” Though it is impossible to gather such knowledge from this interview, it is possible that earlier in his life (before assuming this First World discourse), Edgar would have understood from his own lived experience what his friends were going through, comprehending their frame of mind and non-budging attitude. Yet the discourse within Edgar is truly all encompassing, and his connection with his friends has become fragmented, with no room in his mind to make the two stances compatible. Their connection is severed at a fundamental level, and their misunderstanding reached the point of their ultimate departure: the death of both friends. Indeed, the abruptness with which Edgar narrates the whole story in several sentences, informing us simply in the end that “They died.” demonstrates how this is the conclusion he has made, without questioning as to what brought them to this, besides the concrete fact that they verbally refused to go to the hospice. Indeed, Edgar was confined by the all encompassing First World discourse, and disabled to use tools he might have once had: to genuinely connect with his dying friends.

The above excerpt illustrates how Edgar operates with an Enlightenment approach towards behavior, which assumes that with correct information, a person will act wisely. Within this mindset, one of the major tools utilized to change people is that of disseminating knowledge. However, the above case clearly shows that this is a dangerous assumption: in many cultures, and for many people throughout the world, knowledge acquisition is *not* enough to change behavior. This is simply and dramatically demonstrated with the booming

global pandemic of HIV/AIDS; many people know how HIV is transmitted and have received basic education, yet this information is not enough to change behavior, as it intends to, and the pandemic grows. Thus, in this grounded example, although these two men know their fatal condition, and have been informed about a hospice that would help them recuperate physically, they still refuse treatment. Although Edgar is a gay man with AIDS in Guatemala himself, under his First World mindset, such a response is illogical. Searching for a logical model with which to contrast their irrationality, Edgar looks to his own learned attitude which simply “does not care” about AIDS/homosexuality stereotypes because he is fueled with the knowledge that he is a “person like everyone.” Edgar repeatedly uses his own example demonstrating his conception of a lived experience of empowerment stating later, “I am not ashamed to say it, that I am seropositive, now it also does not make me ashamed to say that I am homosexual but that this has helped me accept myself, accept the disease to know my limitations as seropositive.” Tapping into this kind of universal equalizing epistemology is quite appealing to Edgar, as it may be for many people. Yet, while he may take on universalistic ideas within this discourse, it denies him the local understandings of people he may have once understood.

As he assumes such a strong First World discourse, Edgar has lost touch with the ways in which his friends make meaning in their own lives, and indeed how they create their own identities in the world. Based on how Edgar recounts his friend’s words, it appears that they have a highly relational way of being in the world: keeping others in mind, worrying what people think of them, and concerned about visibility and shame. Yet, although Edgar *is* local in terms of sharing characteristics with these men, his point of reference to make sense in the world is now altered, and he can only see and speak from within his individualistic oriented discourse, nothing else.

We can see that there is no room to consider any other views by the way in which Edgar dismisses his friend's responses using short sentences, informing me several times that (from his point of view) they did not "want to" use/hear/understand the knowledge he offered them. For example, even after Edgar recounts his friend's explanation that they would not take his advice to go to the hospice because of the "shame" of being associated with AIDS, Edgar cannot receive what his friends are saying, and thus comments by oversimplifying the situation his friends communicate by stating, "many prejudices. Many prejudices." In this comment, Edgar seems to agree the World Bank's view that sometimes a person may not participate in empowerment efforts because the "cost" of action is too high for an individual (Narayan 2003:18). In many ways, at this point Edgar is not able to see how his friends make meaning in the world, and thus does not understand how going to the hospice for them means something very different than for himself. His friends have a different perspective in which going to a hospice entails a relational weight (one involving more than just themselves, but the gaze of others), while Edgar seems to view it as an individual action. Whereas Edgar invests in himself, his friends seem to invest in small-scale networks in which their grassroots level deeply defines their identity and concept of themselves. Edgar's assumed First World attitude "are you with me or without me?" does not leave much room for negotiation. Either his friends were with him and his ideas, or against him. In this case, the incompatibility was too great and they missed each other. Thus, fully assuming the First World discourse, Edgar perceived his friends' death as individual "failures" to a system he presented, as the discourse stripped him of any capacity or room to recognize any other "large scale organization of power" or contextual forces that indeed largely contributed to the bodily death of his friends (Shilling 1993:66 citing Dreyfus and Ranibow 1983).

Discussion of Two Sets of Analysis

If we were to use the first set of tools in the “Interview Analysis” Chapter 3, in Edgar’s case we would learn that empowerment is a word he learned “through [his] diagnosis” and at a workshop in the hospice and code his interview using this bit of information. Furthermore, based on the interview it would be possible to gauge his definition of the word empowerment,

“I think the word empowerment has to do with everything, because in my way of thinking being seropositive does not only mean that I have to take the medication, but that I have to have an empowerment of the sickness to be able to comport before all of society...I am not ashamed to say it, that I am seropositive, now it also does not make me ashamed to say that I am homosexual but that this has helped me accept myself, accept the disease to know my limitations as seropositive. And so empowerment for me means everything.”

Although this definition of empowerment is legitimate for Edgar as an individual, until his interactions with other local people are fully investigated, we cannot see what effect or non-effect these definitions have in local contexts. Hence, this “Discourse Analysis” chapter allows a fuller approach in which we may see how these understandings of empowerment (of being able to “comport before all of society” without shame of HIV diagnosis or sexual orientation), are not compatible with how local people manage their lives or understand their place in the world relative to other people. We may observe how this First World discourse, and the discourse on empowerment specifically, alienates Edgar from the very people that are meant to be brought together by this seemingly universal and cohesive model. A word that is meant to bring cohesion is in fact destructive.

Edgar’s example teaches us that even though there may be observed similarities between people, they may not be unified in their understanding about fundamental principals. Hence, when looking at the findings in Chapter 3 pointing to patients and

providers with similar conceptualizations about the nature of the word empowerment (as external/collective and internal/individual, see Similarity A), we must use caution. A similar scenario to the one that Edgar presents indeed may unfold itself for many other patients and providers. While each interviewee is exposed to the HIV/AIDS discursive world (either by being HIV positive or working in the field), and although in Chapter 3 there are similar conceptualizations of empowerment among providers and patients in the sphere of HIV/AIDS work, when providers and patients are in their own local sphere they may have contrasting and unbending views about the meaning and implications of the word empowerment. Within their families, workspace and community in general, the interviewees' views described in Chapter 3 may clash within their spheres of influence and hence isolate them from their own familiar contexts. It may be that such clashing views are more prevalent for providers because findings in Chapter 3 point to their closer alignment with the First World discourse (see *Specific Conclusions for Patients and Providers*); yet this fragmentation may also occur even for those patients who are not completely aligned with the First World discourse but who still use the concept of empowerment. Hence, because everyone interviewed in Chapter 3 had some sense of the word empowerment, just as in Edgar's case, their discursive understandings may actually sever profound connections they have in their own local contexts and relationships.

A Hybrid Model that Would Work?

The World Bank mentions that there is “no single model” for empowerment, and that indeed its definitions are “embedded in local value and belief systems” (Narayan 2003: 14). According to this approach to empowerment, it is beneficial for local people to create the definition of this word themselves. However, in the above example, we can see that in fact when local understandings of a situation are presented, they are incompatible with the

already prescribed structure of the First World discourse as presented by Edgar. Such a discourse approaches people as complete individuals requiring the tools of empowerment (or any discourse) to be repaired, rather than as individuals who seek seeing themselves and approaching their world in terms of relationships. Thus, although the World Bank gives the impression that the definition of empowerment should be made local, it envisions local people merely adopting an already formulated and structured word. Edgar has little flexibility in regards to changing his understanding of the word, so much so that he cannot even hear other people's model of understanding their own situation. As mentioned previously, Edgar's example may typify how other patients interact with their local contexts once internalizing elements of the First World discourse on empowerment. Hence while discourse analysis probes one example of a patient who is also a healthcare provider (as an educator), such analysis opens up the possibility that this kind of fragmentation may occur with many of the providers and patients interviewed in Chapter 3 when they bring words such as empowerment into their local context. Indeed, the World Bank makes the definition of empowerment "local" by educating local people, instead of allowing their definition to be dictated by the way that the local people live and approach their own lives.

I suggest that if the World Bank were serious about making the word empowerment local for other people, they would reinforce conceptual schemes and realities that already exist, rather than offering something radically different. If there were true commitment to making the word empowerment local to the context of Guatemala, there would have existed a flexibility in Edgar's approach to not only recognize, but to live in the cultural intimacy he has with his gay positive friends, and to understand and connect with their relational nature navigating their identities and life (concepts of relationality in empowerment are mentioned in Chapter 2 with both Mason and Koggel's work). Indeed Edgar does adhere to the World

Bank's understanding of empowerment. Based on his abstract and functional definitions, Edgar defines empowerment as "[the ability] to live with the medication in the hours you have to do it," informing people what the word empowerment means, and "ha[ving] to do with everything." Based on these views Edgar adheres to all 4 of the WB factors to empowerment: #1 WB where "access to information" is critical in medication adherence, #2 and #3 WB definitions where the "inclusion/participation" of other PLWHAs in learning about empowerment is important, and #4 WB where "local organizational capacity" will enable a collective group to work together to achieve "everything". However, while Edgar's discourse on empowerment matches that of the WB very well, still all four of these factors do not allow him to speak eye to eye with his friends. There is no true engagement in their thought process, and all attempts of peer education outreach fail: his presented knowledge does not alter their behavior (see *Peer Educational Theory* in Chapter 4 for a brief discussion on Enlightenment thought). In order for an intervention to really function, one must seek these local understandings. In fact oftentimes it is not even a question of seeking out these understandings—Edgar's friends told him upfront why they would not go to the hospice! It was Edgar's imported strict First World definition that did not allow these words to register.

If however, these empowerment projects were to truly adopt and make their own conceptualizations local (without being reprimanded), definitions for empowerment could have some longevity and sustainability to them. Notions of empowerment are not sustainable when they are simply translated into another language in a certain part of the globe. There needs to be a more whole and integral understanding of the notion of empowerment to make it sustainable for and from the local context truly recognizing "changes in beliefs, mindsets, and behavior" (Narayan 2003: 14, 17) as the WB articulates, but does not practice. For, although local people are used as agents to disseminate a

message, the local people lose their own literacy in their native language. This loss is exacerbated by the fact that the local people misunderstand this loss, or may not realize that they lost it altogether, “unaware of specific consequences” this loss may have (Crossley 2005:61). The case study of Edgar in this chapter extracts one of the interviews coded and described in the quantitative analysis in Chapter 3, and qualifies these numbers with how elements of these discourses play out in a specific situation. Hence, looking closely at how these interactions play out for Edgar (a person adhering to the WB discourse) allows us to challenge the supposed encouraging numbers of people reciting the WB discourse; instead, the discourse analysis allows us to look deeply at situatedness of local actors in dialogue, and to look directly at the real life and death implications of importing these discourses.

CHAPTER 5:

CONCLUSION

In this chapter I will first discuss the two methods of analysis used to look at the discourses of empowerment and their interaction, and secondly I will make general concluding remarks about the two methods used in this thesis and their implications for HIV/AIDS in Guatemala and First World development projects in general.

Based on this analysis I argue that while both patients and healthcare providers describe aspects of empowerment that are similar to each other, the provider's concept of empowerment is more closely aligned to that of the World Bank than those of patients. However, such an analysis of definitions is insufficient to understand how these discourses are implicated into people's everyday life. Hence, in this thesis I will use a second methodology of discourse analysis in order to unpack the definition of one informant's conception of empowerment in order to demonstrate how such First World discourses are realized and played out in local contexts.

Interview Analysis

As it is oftentimes the case in social science research, an academic seeks to extract "findings" from her/his data. As a student of anthropology who has invested much time exploring in her field site, obtaining such "findings" from my data was appealing, and hence I embraced a methodology that would make my qualitative field work quantitative in a way that could draw "conclusions" from lived conversations transformed into transcription "data."

After analyzing the interviews from 22 patients and providers living or working with HIV/AIDS in Guatemala City, I concluded that while some providers and patients have

similar conceptualizations of the word empowerment, they also have differing understandings of this word in various points. Furthermore, I concluded that providers have a closer articulation of the concept “empowerment” to the World Bank than do patients. Both findings are significant, as they challenge assumptions regarding the sharedness and direct transfer of discourses between people in the same environment.

Due to the fact that both healthcare providers and patients operate within a similar healthcare system and are often in the same medical spheres, there exists the assumption that both groups share the same definition of empowerment. My data challenges this assumption by demonstrating that while indeed providers and patients have some overlapping similarities in conceptualizing empowerment, they have many differing conceptualizations as well. These differences fall along the lines of how providers and patients describe empowerment abstractly/functionally, and in relation to stigma, rights, self/structural limits, political incidence, the country of Guatemala and its genocide/civil war (see Chapter 3 *Differences between Patients/Providers in relation to WB concept of empowerment*). Furthermore, in relation to the World Bank’s definition, providers have an alignment closer to the World Bank than do patients. The disjuncture between patients and providers may stem from larger gaps between these two populations such as difference in age, gender, sex, education, ect¹². Yet, what are the implications of such findings for HIV/AIDS in Guatemala?

In general, it is important to know which discourses are being articulated by whom because oftentimes resources, including financial resources for NGOs and government programs, indeed depend on whether or not constituents, participants or recipients in development projects articulate the discourses present in the beneficiary’s mission statement.

¹² Unfortunately due to the small sample size and limited skills to analyze the data, I was unable to look across such factors to see if any of them are indeed related to how people understand empowerment; such a study would be beneficial for future research, as it would help facilitate an understanding of what factors contribute to influence how people conceptualize empowerment.

Hence, as “empowerment” is currently a popular “buzz word” (Koggel 2005), it is important for the recipients of development funding and programs from the First World to articulate the discourse of their benefactor, including that of “empowerment.” Furthermore, articulating this discourse is not only important on this large scale of group/project support, but also being fluent in this discourse may affect people on an individual level, determining for example whether or not a patient may be included in a support group, or may be referred to receive treatment. Though confining, the closed way in which I conducted the interview analysis (exclusively looking at the discourse of “empowerment”) indeed was conducted in order to highlight the way in which the First and Third World development projects operate in most of the world: if the discourse is not present, then the entire project or person may lose legitimacy and thus may not be supported in development efforts.

Discourse Analysis

The previously described tool of analysis is meant to analyze questions of development in a similar way to which development programs operate: using a narrow specific definition of a certain discourse and seeing where people fit within these. Such a functional way of handling development is problematic, as it does not address the specific needs or orientations of the people the programs claim to assist. Thus, in conjunction to analyzing the situation of discourse with HIV/AIDS in Guatemala using a methodology similar to how the system operates, by incorporating a “discourse analysis” of one interview, I attempt to include a more integral approach to look at people’s lived experiences and how these interact with imported First World discourses.

The analysis of Edgar’s First World peer educative discourse in Chapter 4 provides an example of an embodied discourse, surfacing the shortcomings of promoting the usages

of First World discourses. For example, while the First World discourse of “HIV is a chronic disease” may appear to enlighten people by reducing HIV-related stigma by creating a broader view of such a narrowly viewed disease, this discourse in fact may limit one’s perception of their own local models of explanations, hence isolating them from own communities. Hence, on the interpersonal level, such discourses may do a disservice to the relationships established in local contexts; in this case, such a discourse seemed to displace Edgar as a local Guatemalan gay man into a non-local way of thinking, thus isolating him from what was happening “on the ground” in his community and with his peers. Such isolation implies that if the WB aims to promote a sustainable usage of the term “empowerment,” the institution needs to re-orient their articulation of its definition in a manner that will work with and affirm the ways in which local people create meaning in their lives rather than imposing a way in which meaning “ought” to be made by people around the globe. While it seems as though the First World discourse intends to bring him closer to his friends in the form of “educational outreach” through peer education, the discourse does not leave enough room for Edgar to actually receive his friends’ knowledge schemas or experience; such interactive frames indeed lacked *interaction* as he was not able to probe into the actual content of his what his friends were saying, and instead seemed to frame their “inaction” as a their own “failure” to listen to him and help themselves.

Edgar’s privileging of verbal articulation and reception of the First World discourse over his friends presented orientation is problematic, as it isolates him from his peers. It seems that even if Edgar had wanted to create a hybrid understanding of empowerment, tapping into his understandings of the local gay Guatemalan culture in order to connect with his friends, he was not able to. Sustainable discourses need to enable people like Edgar begin processes of empowerment while remaining a genuine included member of their local

community. The analysis in Chapter 4 demonstrates that in order for empowerment projects/movements to have this quality of sustainability, those disseminating the information (such as the WB) need to meet people where they are. “Meeting them” in this way does not mean that institutions should gain a “cultural intimacy” in order to take local people out of their own orientations by acculturating them into an alternative discourse. On the contrary, the analysis promotes the dire need of First World development institutions to base their development programs in local epistemologies and articulations of the problem in order to promote projects that are truly grassroots, fomenting positive change for communities in their own terms.

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Appendix A: Contact Sheet

All questions were read out loud to interviewees, and I filled them out myself (with the exception of two physicians who filled it out themselves).

No.

Date/time:

Place:

circle: Provider/patient

Maintain name confidential? Yes/no

Name:

Age:

Sex:

Birthplace:

Where live:

Religion:

Frequency of practice religion:

several times a week, every 15 days, each month, once year, never

Level of education:

primary school, “básico”, high school, technical school, diplomado, university

Sexual orientation:

heterosexual, homosexual (or men sex with men), transgender, bisexual, no response

Marital status:

married, united, boyfriend/girlfriend, single, widow, separated

No. children:

Occupation (if not working, previous occupation):

Level of income:

high, medium, low

Income source:

own, pension, work, partner, family

HIV status:

+, -, no response

Years living with HIV:

You know about HIV/AIDS through:

reviews, pamphlets, television, radio, people talking, school

Where have you received or currently receive medical attention services and what type?

Since your diagnosis, what people or organizations have you consulted or have given you advice?

Do you know about your legal rights to receive treatment and an appropriate medical attention?

Appendix B: Interview Topic Guide

The following are rough translations of my own guides to the interviews and do not represent the exact questions themselves, or all the themes covered in the interviews.

Healthcare Provider Interview

History of working with HIV/AIDS

- What is your role here (details? How much time with Px?)
- How did you begin to work with HIV? Why?

Knowledge of HIV

- What did you know about HIV before and after working with the disease?
- What aspects of your job/experience have caught your attention?
- What have you learned from the experience?
- How do you learn, at the medical level, with patients?
- What kind of information on the patient would you like to have that you don't

have?

- What have the patients given you?
 - You to the patients?
- What does this work mean for you?

Abilities

Attitudes

Vision of the disease

- How do patients understand or explain the HIV?
- How do your patients/clients visualize HIV?
- Models of explanation (do models change? Why? What influences this?)
- Is HIV/AIDS perceived as individualized or communal disease?
- Is HIV/AIDS approached as individualized or communal?

Knowledge of Treatment

- Do patients have trust in the ARV treatment?
- How do they feel towards the treatment?
- What does the treatment mean for them?
- Problems in treatment?

Healthcare/Treatment Alternatives

- What alternatives/complimentary health or healing are there?
 - Religion
 - Complimentary medicine
 - Natural/traditional medicine
 - General care (ex. hygiene, nutrition)

Adherence

- +/- Factors
- Problems?
- what are "good" patients?
- Rare cases of patients?

Evaluation of the Institution [wherever they are working]

- How would you evaluate the level of information, attention and care?
- The resources available?
- Differences between organizations at the level of attention?
- Can your “commitments to your work” be fulfilled in this institution?
- What value does your work add to others?
- How is healthcare “integral” or not? What could work better?
- To what capacity can you disseminate your knowledge?
 - Can you learn from others?
- How your relationship is to the patients in this setting? Obstructions?

Knowledge of the healthcare system

- How is the healthcare system structured? Organized?
- Rights and duties of the patients? Of the providers?
- Are these rights and duties fulfilled? How and why?

Empowerment/Rights and Obligations of Providers and Patients

- What does it mean to be empowered as a provider? As a patient?
- How does one obtain empowerment?
- What consequences does empowerment have in your life?
- Do you know other people who have demanded their rights? How did it go?
- How do you see empowerment in other countries?

Conclusion

- What are your goals in life? In your professional career?
- What message would you like to give others about HIV/AIDS in your country?

Other themes: stigma, discrimination, and “emotional drainage”

Person Living With HIV/AIDS (PLWHA) Interview

History of infection

- Story of diagnosis?
- Information about HIV before diagnosed
- Different key actors in your life
 - Family
 - Organizations/institutions
 - Religion
- Other ways of taking care of oneself
- Where did/do you look for help? Advice?

Vision of the Disease

- Why are you HIV positive?
- Models of explanation? How do you understand it?
- Do you/how do you visualize HIV?
- What influences images of HIV?

-Have they changed? Why?

Knowledge of treatment

- Trust in ARV treatment?
- How did you feel before treatment? Now?
- What does treatment mean for you?
- Problems you have with it?

Complimentary Care

- Religion
- Complimentary medicine (natural/traditional medicine)?
- Medicinal plants, “hueseros”, “curanderos,” healthcare promoters?
- General care (nutrition, hygiene, exercise, toxic habits)?

Adherence

- +/- Factors
- What is difficult about being adherent?

Evaluation of the Institution [where interview is]

- How would you evaluate the:
 - Attention and information given?
 - Relationships with the personal (doctors, therapists, nurses...)
 - Resources
- What differences are there between organizations at the level of attention?

Knowledge of the Healthcare System

- What do you know about how the health care system is structured? Organized?
- Rights, duties and obligations of patients? Healthcare providers? government?
 - Are these fulfilled? Why?
- What are the rights to health?
 - How do you know them/not know them?
- How do you demand them?
- Do you know other people who have demanded their rights? How did it go?

Empowerment of Patients

- What is “empowerment”?
 - In what context have you heard this word?
- How do you obtain empowerment?
- What consequences does it has in you life?
- Similar experiences?
- How do you see empowerment in other countries?

Conclusion

- Goals in your life?
- What message would you like to give about HIV/AIDS in your country?

Appendix C: Interviewee Breakdown

No.	Provider/Patient	Where	HIV Status	Sex	Age
1	Patient	JSJ	+	M	43
2	Patient	JSJ	+	M	28
3	Provider	MSF-Fr	-	F	32
4	Patient	GN	+	M	22
5	Patient Provider	GN MSF-FR	+	M	21
6	Patient y Provider	MSF-Sw	+	F	58
7	Provider	MSF-Sw	-	F	37
8	Provider	MSF-Fr	-	M	27
9	Patient y Provider	RNPVVS	+	M	28
10	Provider	MSF-Fr	-	F	46
11	Patient	MA (MSF-Fr)	+	M	25
12	?	?	?	?	?
13	Patient	MSF-Fr	+	F	28
14	Patient Provider	GN	+	F	36
15	Patient Provider	GN	+	M	56
16	Patient	PA (MSF-Fr)	+	M	45
17	Patient	MA (MSF-Sw)	+	M	33
18	Patient	MA	+	M	26
19	Provider	MA	-	F	38
20	Patient	MA	+	M	36
21	Volunteer	MSF-Fr	-	M	19
22	Patient	MSF-Fr	+	M	31
23	Patient	MSF-Fr	+	M	32
24	Patient	MSF-Fr	+	M	23
25	Provider	GP	-	M	42
26	Provider	MSF-Sw	-	F	32
27	Provider	JSJ	-	F	48
28	Provider	MSF-Fr	-	F	37
29	Provider	MSF-Fr	-	M	36
30	Provider	GP	-	F	28
31	Provider	MA	-	F	38

NGOS

MA: Marco Antonio

PA: Pastoral Social

JSJ: Jospicio San Jose

RNPVVS: Red Nacional de PVVS

GP: Gente Positiva

MSF-Fr: MSF clinic French section clinic “Yaloc”)

GN: Gente Nueva

MSF-Sw: MSF clinic Swiss section clinic at Roosevelt Hospital

Note: Parentheses indicate interview took place in NGO but patient receives medication from MSF (ex. GP (MSF-Fr))

Appendix D: NEW E-Doc Coding Model

1) Definition of Empowerment

Do they have a definition?

Abstract

Functional

SELF

OTHER

Internal?

External?

Collective?

Individual?

2) Feelings about Empowerment

Attitude/value to word Emp

Perceived limitations

Self-limit

Structural limit

3) Application of the concept of empowerment to adjust to HIV

Coping with HIV

Normalize the disease

Redefine as CHRONIC DISEASE

How you FEEL about HIV affects how you ARE and HOW YOU EXPERIENCE

IT

Accept it (no denial)

Knowledge of HIV/AIDS

Adherence

Stigma

PLWHA (concept of this)

Rights (know or mention)

Political incidence

Mentioned?

Give examples they know?

4) world view of empowerment

Mention Emp specific to Guatemala?

Mention civil war/recent genocide?

Mention Emp in USA/other places?

Appendix E: Quantitative Results

	Providers	Patients + Providers	Patients	Patients + Providers
Total	10	12	7	5
M	4	10	7	3
F	6	2	0	2
Homo (male)	3 (1biF)	7	4	3
Abstract?	9	11	7	4
Functional (self)	3	11	7	4
Functional (other)	5	7	2	5
Internal/individual	8	9	4	5
External/collective	9	11	6	5
Any attitude demonstrated?	5	6	3	3
Self-limit	6	2	1	1
Structural limit	6	4	1	3
Normalize?	1	1	0	1
Chronic?	3	2	0	2
Feel/experience	1	3	1	2
Accept it	1	5	2	3
Knowledge HIV/AIDS	6	7	4	3
Adherence	1	1	1	0
Stigma	6	2	1	1
PLWHA	4	6	5	1
Rights	8	3	2	1
Political incidence	5	3	2	1
World view-Guatemala	6	2	2	0
Civil war/genocide Guatemala	2	0	0	0
World view-USA other	3	4	2	2

Appendix F: Images of HIV/AIDS in Guatemala



(Above) Guatemala City at twilight. (Below) The entrance to MSF Clinic (French Section) Zone 1, Guatemala City.





Patients waiting to be called for appointments in the waiting room at the MSF clinic. It is in this waiting room that I conducted the reflection group discussions, and where organizing for the Patient Empowerment Project began.



(Above and Below) Most of the MSF staff including: the head of the clinic, 3 physicians, 2 psychologists, 2 educators, one nurse, social worker, maintenance worker and secretary. In the entire team there are only 3 ex-patriots (foreign MSF volunteers), and the rest of the staff is local Guatemalan staff. (Above) Almost all of the clinic's staff is gathered here when I called a meeting to clarify the mission of the Empowerment Project.





(Left) Conducting participant-observation with my mentor Reyes. (Right) Talking with the educator about the waiting room discussion groups and how to best plan the Empowerment Group's meetings. (Bottom) At work writing the Empowerment group's mission statement in the MSF clinic.





MSF nurse and physician at work in patient consultations.



(Top) An all-patient gathering (approximately 200 people) to talk about the “Patient Empowerment Project”. Up front stand volunteers to become part of the core group to continue organizing events for all of the patients (approximately 1000). (Left) Reyes listening to speakers at the meeting. (Right) The beginning core group of Grupo Solidaridad Positiva (GSP) meets for the first time after the meeting.



QuickTime™ and a
TIFF (Uncompressed) decompressor
are needed to see this picture.

(Top) Current day waiting room in the MSF clinic. The previous clinic was too small for the growing patient population, and the new space has worked very well. (Left) Billboard in waiting room explaining the Patient Empowerment Project. (Right) Demonstrators in a public march for HIV/AIDS awareness.

ECONOMÍA
BM pide atención
al campo /10

EL MUNDO
Portugal llora a
sor Lucía /20

CULTURA
Lágrimas negras
de Bebo /25

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EL FRG INSISTE EN GRAVAR EL BUNKER

El mayor obstáculo de la Gana para conseguir la revaluación del impuesto a los combustibles. NACIONALES [3]



**EL DIVORCIO
Y EL NIÑO**
Qué hacer para
evitar dolor a sus
hijos a la hora de la
separación.
AUTOAYUDA / 31

Tipo de Cambio
Compra
7.72011
Venta
7.74299
No hables
por correo electrónico



EXIGIR LA VIDA
Pacientes con VIH/Sida manifestaron ayer
con el rostro cubierto en favor del uso de
medicamentos originales en el tratamiento
de su enfermedad. Su demanda se dirige a las
autoridades de Salud Pública. COMUNIDAD / 8

Grupo Solidaridad Positiva (GSP) makes the front page of the national newspaper in a protest demanding their life-sustaining antiretroviral medication from the Guatemalan government.