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AIDS – A Social Disease

A Minor Field Study of Women with HIV/AIDS in Nicaragua

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List of abbreviations

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ABC	Abstinence, be faithful, use condoms
AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
ASONVIHSIDA	Asociación Nicaraguense que viven con VIH/SIDA/ Nicaraguan association for people living with HIV/AIDS
CEPRESI	Centro para la educación y prevención del sida/ Centre of education and prevention of AIDS
HIV	Human immunodeficiency virus
INHIJAMBIA	Heroic and winning woman (in Nahualt)
ICW	International Community of Women
LIC	Low-income Countries
MDGs	Millennium Development Goals
MINSA	Ministerio de Salud Republica de Nicaragua/ Ministry of Health
MFS	Minor Field Study
NGO	Non-Governmental Organization
PAHO	Pan-American Health Organization
Sida	Swedish International Development Agency
STD/STI	Sexually transmitted disease/Sexually transmitted infection
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
UNGAS	United Nations General Assembly
UNFPA	United Nations Population Fund
USAID	US Agency for International Development
WHO	World Health Organization

1. Introduction and Purpose

More than 40 million people suffer from HIV/AIDS all over the world and experts are estimating it to be 100 million in 2010. The most afflicted areas are Africa and Latin America. In 2006, an estimated 2.9 million people died worldwide of AIDS and more than 25 million people have died of AIDS since its appearance in 1981. The escalating risk in developing countries is especially evident among young women and girls who constitute 64% of the total number of young people living with HIV/ AIDS (Avert A). Women are highly prioritized and categorized as a vulnerable group in the Millennium Development Goals that needs to be targeted (MDGs 2007).

But HIV/AIDS is not to be looked upon as an entirely medical problem as will be explained throughout this thesis. In Nicaragua it is indeed a social disease as well due to social and cultural factors as will be discussed in this thesis. Nicaragua is an interesting case when studying HIV/AIDS because it is the Central American country with the lowest number of official reported cases. However there are thought to be several explanations for this. Experts believe that the official low number of HIV/AIDS might be caused by underestimated, under-diagnosed or even falsified reporting due to the heavy social stigma it possesses (UNAIDS A). Among other explanations are that the Catholic Church does not allow sexual education at school and therefore unawareness about the disease is high due to failures to recognize the signs of the disease. Other likely reasons are that Nicaraguan people do not have a tradition for getting tested - and a lot of people seem to fear the health clinics due to lack of confidentiality and cultures of discrimination (Envio A).

Cultures of HIV/AIDS related stigma and discrimination are considered hard to kill due to the many myths attached. International donors in the country merely support HIV/AIDS preventive programs because prevention is seen to be more sustainable and economic feasible than treating people already afflicted by the disease. In this way stigmatisation and discrimination get neglected even though they are among the severe psychological side effects of the disease (Avert A). As people living with HIV/AIDS are ignored in Nicaragua by both the local and international community the only support group for women with HIV/AIDS has to use creative methods to attract donor money. The women living with HIV/AIDS have to learn how to be victims of a social disease and how to represent themselves as such. The association strives to empower the women through different group activities but is doubtful whether the women are empowered or actually disempowered.

This leads to the purpose of this MFS project which is to reveal how and why women create identities of stigma and victimization when hit by the social disease AIDS. This paper will investigate mechanisms of stigma and discrimination in relation to HIV/AIDS in Nicaragua seen from the affected women's point of view. Further the focus will be on the empowering or disempowering activities at a support group centre for women living with HIV/AIDS.

Field work conducted at the organization ASONVIHSIDA and its support group for women with HIV/AIDS, ICW, will be the basis of this thesis. The women's narratives will be used to explain how HIV/AIDS is perceived by one group within the Nicaraguan society as well as discussing mechanisms for discrimination and stigmatization. It is important to understand the mechanisms leading to stigmatization of HIV positive women in order to successfully combat the disease and the discrimination. This can only be done with an analysis of the Nicaraguan culture and the societal mechanisms these women are living in. The women's stories and feelings of suffering and victimization will be analyzed and especially how the stories are used to achieve empowerment and secondary gains such as money, but also to reveal how the women merely are pieces in the development game.

Phenomenological I will look at how feelings of stigma and discrimination appear among women with HIV/AIDS in Nicaragua and further how they deal with these experiences. I have emphasized a focus on the Nicaraguan society and especially how the Catholic Church respond to the disease as the church plays a big part in the women's lives. The women are very bond to their religion and find it difficult to both listen to the church and be a part of the association for people living with HIV/AIDS working with a different agenda than the church. I state that all agencies have their own agenda – hidden or not. From the women's narratives and observations I will analyze the below *how*, *what* and *in what way* questions in depth.

My main research questions are as follows:

- How come HIV/AIDS among young women are escalating in Nicaragua?
- What impact do different agents in the Nicaraguan society have on the diseased women?
- What are the women's experiences of discrimination and stigma?
- How do the women cope with these experiences?
- How do the women use their feelings of stigma and for what gains?
- In what ways are the women with HIV/AIDS empowered or disempowered?

It is my intention to demonstrate that these women are influenced in different directions by powerful agents in society and that the support group for women with HIV/AIDS has hidden agendas as well. For this reason merely looking at women and AIDS from a health perspective is not enough – an analysis of the cultural causes and effects of the epidemic has to be taken into consideration as well.

2. Organization of thesis

I will now give an overview of the thesis and briefly describe the content of each chapter to highlight the flow of thoughts connecting the chapters together. Further I will draw attention to the key problems addressed in the chapters.

This thesis is organized into 11 chapters with the first two giving an introduction of the thesis and the last two with summary and conclusions and lastly references. From *Chapters 3* to *5* I describe how I carried out my field work using a triangulation of methods. In the same chapter I introduce background information on HIV/AIDS so readers understand the basic epidemiology of this disease. This chapter also gives background information on the history of Nicaragua and the development of HIV/AIDS in Nicaragua. I argue that even though there is a law against discrimination it hasn't been implemented yet and unawareness about it is high. I briefly discuss the different theories chosen such as from medical anthropology, stigma/discrimination/deviance theories and empowerment theories.

Leaving the introductory chapters we move on to *Chapter 6* to *10* which are based on empirical data from my fieldwork. Cultural understandings of HIV/AIDS is discussed in *Chapter 6* focusing especially at the role of the Catholic Church as a moral dictator and the blame of a deadly culture of unprotected sex which is also believed to be due to a strong machismo culture. It further highlights how women are seen as victims by international agencies. In *Chapter 7* we will hear the voices of the women through phenomenological small stories. This chapter describes the women's fear and ignorance. It includes an observation showing how women living in the street have knowledge about HIV/AIDS and how to prevent it but that housewives are rather ignorant about the disease when contracting it. It further shows the anxiety the women have when revealing their status. It reveals how the women experience prejudice and what they refer to as stigmatization and discrimination at health clinics.

Chapter 8 analyzes how the women experience stigma and discrimination and in what way it occurs. I have labeled stigmatized and deviant behavior in two different tables in order to understand why infected women in Nicaragua have these strong and negative experiences. I show how the women cope with the disease and what mechanisms they use to hide it. The last section of this chapter illustrates how the women change social networks as a surviving mechanism that leads to *Chapter 9.* This chapter describes how the women find a new social network which they refer to as *a family* in the support groups. It discusses the way they use their voice of victimization and stigmatization as a tool to be empowered and to stay inside the new circle. It further reveals how there exist a hierarchy of power inside the supporting circles. In the summary and conclusions I draw attention on why the women with HIV/ADS are stigmatized and how they survive in the support groups. I conclude that the women do feel empowered even though they have no real choice than staying inside the supporting circle. It further stresses how they might risk losing this form of empowerment and their newborn identity.

2.1. Methodological approach

Empirical evidence for the case study was collected during the course of my 3 months field placement in the capital of Nicaragua with a local association for women living with HIV/AIDS called ASONVIHSIDA and ICW in 2006 and included participant observations, interviews with the key informants at NGOs and qualitative interviews with women with HIV/AIDS. For my anthropological field work I have used a small tape-recorder and later transcribed the information with help from a local Nicaraguan woman as some of the women had a dialect I found it difficult to understand. In the initial phase I tried to conduct some of the interviews through e-mail, but as the offices and organisations have limited Internet access and lack a tradition of using the internet, the majority of the interviews and conversations were conducted in person. This thesis will mainly be based on my in-depth and semi-structured interviews with women with HIV/AIDS and observations of activities at ICW and a workshop for young women living in the street (Patton 2002: 339-422).

As mentioned my field work was conducted at Nicaragua's only support group for women with HIV/AIDS, called ASONVIHSIDA and at ICW - a network for women with AIDS which can be found in several countries. ICW was established in 1992 in order to reduce the isolation of HIV positive women and overcome stigma through outreach networking, skill sharing, and peer-support and information exchange. The network is run entirely for and by women with HIV/AIDS and has reached more than one hundred countries (Feldman 2002). ICW and ASONVIHSIDA are entirely funded by international donors.

At ICW I found most of my respondents. The in-depth and semi-structured interviews were phenomenological directed to understand the psychological problems Nicaraguan women experience when afflicted with HIV/AIDS such as stigma and discrimination and also what support they receive. In many ways the women themselves formed a lot of the questions fundamental for this thesis because I started with informal conversations and open-ended questions. Later the research questions were constructed from the women's narratives to hermeneutically understand the social reality surrounding AIDS as facts cannot be disconnected from the social context that gives them meaning. To simplify, basically narrative is a text which describes sequences of real events and often referred to as *story* (Patton 2002: 116)**.** I would have liked to talk to past members of ICW but it was not possible to find old members.

At the initial phase, I started in an informal way asking to the women's problems and attitudes while staying at the centre. I was particularly interested in experiences of stigma and discrimination and to see whether the women were empowered. After a week of observing and at the same time being visible at the center the women began trusting me more and more. It took time to convince them that I was not a potential donor which could influence the direction of my purpose. At times it was difficult to explain my purpose at the centre, as several women thought I worked for the Swedish or Danish government and was there to help them fight discrimination while others thought I was a representative of an organization donating money. Some saw me as a psychologist while others thought I was a Ph.D student. I used a lot of time to explain to them that I was a student doing research on the HIV/AIDS situation in Nicaragua for my thesis (Bryman 2004: 26, Patton 2002: 72). However, when the women began asking me about my purpose the contact was created and I could start arranging personal interviews.

During my field work I was based in the capital Managua where many NGOs and the Danish and Swedish embassies have their headquarters and where each of my 20 interviews with the women was conducted from April to June 2006. I went to ASONVIHSIDA three times a week after 12.00 o'clock because most of the women arrived at that time and I stayed until 18.00 when the office closed. As the interviewed women came from all parts of Nicaragua and especially from rural and isolated areas many of them only visited the centre once or twice a month and therefore most of my interviews were with women living near the capital. The good thing was that I could have many informal conversations with these women. However one limitation is that I have not focused on what area the women come from and taken this into consideration in my analysis.

Each interview lasted from 20 minutes to 1 hour depending on how talkative the women where and how easy it was for them to talk about sensitive subjects such as their stigma and discrimination experiences. I always started up with the same questions related to their attitudes, opinions and beliefs in a kind of broad way for later directing them into more sensitive areas such as experiences of stigma and discrimination after being diagnosed HIV-positive. Some of the interviews I made open-ended so the women could freely talk about issues necessary for them and then I formulated the questions to their needs (Patton 2002: 553). This was a helpful method as I came about to change my original aim of focus. I found out that focusing on stigma and discrimination was extremely interesting in this social setting. The first week I changed my focus a lot until I finally had a more clear aim with my questions which in addition gave me more intensive replies from the women. Even though my research developed into a sensitive subject most of the women were happy to tell me about their experiences.

I told the women that I would switch off my tape recorder whenever wanted, but I encouraged them to tell me what they felt comfortable in sharing with me. I also notified that I could always delete things they later might regret. Most of the interviews where recorded and no more than two women wanted to do the interviews without using a tape recorder. As a rule, I took notes at the same time to ensure that I got all information down (Bryman 2004: 108, Patton 2002: 383).

As my questions focused on the women's feelings, I had to be careful how to formulate them. I intended to make them clear but also open so the women could respond in their own way. My questions often started with *who, where, what, when* and later *how do you feel about…? What is your opinion of…? What do you think of…? You said that…but what do you mean about…*? This was in order to direct the questions into sensitive areas. Finally, I always asked if there was anything more they wanted to add or say. I carefully avoided dichotomous questions leading to yes and no answers and had only a few of these (Patton 2002: 348-382).

I did a whole day observation during a support group meeting for women at ASONVIHSIDA and another observation at an HIV/AIDS preventive course run by the local organization Inhijambia - a Nicaraguan NGO working with young women living in the streets. I used these two observations to see the differences between the two groups if any. I further attended several support group meetings where I strived to be as neutral as possible not to disturb or make the women feel uncomfortable with my presence.

I conducted semi-structured interviews and discussions with different NGO health staff working with HIV/AIDS at different levels. This was done in order to understand the general obstacles with HIV/AIDS preventive work in Nicaragua and the situation especially with women with HIV/AIDS. A "snowball" recruitment method was used to reach institutions and individuals and all contacted organizations where asked to provide additional contacts (Patton 2002: 236). Approximately half of all the contacted organizations provided information for this review and I interviewed representatives at UNICEF, UNFPA, International Children Solidarity, the Danish Embassy and several local NGOs working with gender issues and HIV/AIDS. Thus, I only considered a few number of these interviews to be relevant for the focus of this paper.

However, the comprehensiveness of this review has been limited by difficulties obtaining a response from contacted organizations. In the initial phase of my field work I wanted to interview doctors at hospitals to understand stigma among AIDS patients, but as there had been a long ongoing strike among doctors and nurses, and most of the hospitals were closed during my stay, it was impossible to do research in this area. Therefore my original focus on stigmatization of people with HIV/AIDS at hospitals had to be changed to stigmatization of women based on my field work at a support group (Alvesson et al 1994).

My data for this thesis is mostly collected through observations and individual interviews. Additional data consists of various forms of documentation such as data from the anthropological courses at Lund University and data gathered from different NGO archives as well as articles found through the internet. The Danish Embassy has supported me with some necessary material concerning HIV/AIDS in Nicaragua as well as other educative materials for my thesis.

In this paper I want to give voice to the infected women and analyze their phenomenological, individual and feeling-based experiences. From my interviews I further want to give the reader an in-depth understanding of the HIV/AIDS situation and its psychological side effects and especially how it is handled in Nicaragua. My intention has been to take a neutral point of view when analyzing the interviews. Though, according to Dr. Michael Quinn Patton and experts in methodology: “Neutrality does not mean detachment” (Patton 2002: 50). I aim not to get too involved which might cloud my judgments, and also not to be too distant which could reduce my understanding. This is always a crucial but difficult balance to find.

2.2. Ethical considerations

At times it was very difficult talking with the women about emotional matters such as personal experiences of discrimination, hence the center psychologist offered the women to come to her office after my interviews if necessary. Most of the women left me with the impression that they were content of giving voice to their stories.

In general, the women and the managers of ASONVIHSIDA assured me that they wanted to participate in the interviews in order to spread light over the difficult situations. The majority of the women had told their stories many times before at support group meetings while just a few women were still inexperienced in this and felt it emotionally difficult to disclose their stories in details.

Even though ICW is a network for women living with HIV/AIDS, ASONVIHSIDA hosts both diseased men and women with HIV/AIDS. I interviewed about 10 men because they did not understand why I only targeted the women. Their stories were very insightful but still I have chosen only to focus on women with HIV/AIDS in this paper.

All respondents are anonymous and I have changed their names with the aim of protecting the women. Only some NGO staff and the directors at ASONVIHSIDA and ICW have their real names. Through this paper I will mostly refer to my respondents as one anonymous group named: *the women.*

4. Information on Nicaragua and HIV/AIDS

4.1. What are HIV and AIDS?

The human immunodeficiency virus (HIV) is a virus that infects cells in the human immune system and breaks it down. Years can pass without people knowing they are infected with the virus since in the early stages of the infection there are hardly any signs of the contraction. When the immune system turns weaker the person will be more susceptible of contracting so-called opportunistic diseases whereas the most common are tuberculosis, pneumonia, fungal diseases such as candida and viral diseases such as herpes. It is often from the opportunistic diseases people will die.

HIV is transmitted through unprotected sexual intercourse, transfusion of contaminated blood, sharing of contaminated needles and of mother to child when breastfeeding. Antiretroviral therapy (ART) usually consists of three different ARV because of the possibility of drug resistant.

The most advanced stage of HIV is called acquired immunodeficiency virus (AIDS). It can take years and normally between 10-15 years before a person develops AIDS. However, in Low Income Countries (LIC) where poor people have limited access to proper treatment such as antiretroviral (ARV) and with poor nutrition and hygiene AIDS is seen to develop faster than in other countries. There is still no cure for AIDS and ARV only prolongs people's lives by slowing down the process. It is therefore believed that preventing the disease is the only thing that works at this stage. Thus many international organizations such as WHO are continuously working to find a cure for the deadly disease (WHO A).

In this thesis I have combined the words HIV and AIDS. I have not focused on the different levels of development of the disease as it is not important for my thesis. I will therefore only use the term HIV/AIDS or separately, but without emphasizing on the medical difference. Most of the women interviewed have a very developed HIV.

4.2. History of Nicaragua

Nicaragua is geographically the largest country in Central America but the least populated. However, it has the highest population growth rates in the Americas. The 5.4 million inhabitants consist of more than 70% Mestizos and about 9% are of African origin. A small amount of people are Europeans and a minority is indigenous. Spanish is the official language and at the Atlantic coast languages such as Miscito, Sumo and English are spoken. About 85% of the population is Catholic and 15% is Protestant (Brown 1997, WHO B).

The history is characterized by dramatic changes. Nicaragua has hosted a revolution which abolished 42 years of brutal dictatorship, 11 years of civil war, a prolonged American trade blockade, natural disasters and a young democracy restricted by an enormous debt, corruption and abuse of power. All these factors have contributed to leaving Nicaragua as the poorest country on the American continent.

Before the Spaniard’s arrival in the 1500th century the country was inhabited by indigenous people of e.g. the Nicarao tribe of hunters and gatherers who lived in the far-reaching forests in the eastern part of Nicaragua and at the Pacific cost. Before the 1700th century the indigenous people exercised great resistance against the intrusion of the Spaniard but were almost wiped out by wars, diseases and slavery (Brown 1997: 97-112).

In 2002, Bolaños took over the presidential post from Arnoldo Alemán who the following year was sentenced to 20 years in prison for severe corruption. Family members and close associates were also accused for corruption. Bolaños governmental programme includes democracy, attraction of foreign investments and the fight against corruption.

The problems are still enormous as about half of the 5.4 million inhabitants live in poverty. More than 40% of the Nicaraguan population lives in the countryside and among them 800.000 live in extreme poverty on the level of starvation. More than 30% of the population is illiterate and many children never go to school and the schools lack quality of education and basic facilities. During the last decade Nicaragua has been ranked at one of the top countries at the poverty index and therefore it is a high prioritized country for official Swedish and Danish support (UM A).

Democracy, human rights and freedom of expression is guaranteed by law but still there continuous to be numerous reports telling other stories within the young Nicaraguan democracy. The rising level of crime is often related to drug trafficking and paramilitary counting demobilized members of the Sandinistas and Contras.

4.3. Development of HIV/AIDS in Nicaragua

The first incidence of HIV/AIDS was registered in 1987 among commercial sex workers (WHO C). This made the Nicaraguan government require mandatory AIDS testing of this high risk groups as well as men who have sex with men. Even though Nicaragua does not appear as a severe high risk zone compared to other countries, experts believe that the official low number of diseased is due to a government not wanting to face the problem. But it is also due to a country with a history of economic and political instability (Matute et al 2008: 107).

In 2006, UNAIDS reported 7.300 HIV/AIDS cases in Nicaragua (UNAIDS B). A low number when compared to its neighbors Honduras, with the highest incidence in Central America, reported 63,000 cases in 2005 and El Salvador, reported 36,000 cases **(**Avert D). According to the National Health Plan (Plan Nacional de Salud) from the Ministry of Health in Nicaragua (MINSA) the number of HIV/AIDS cases has increased by 24%

over the last 3 years but many NGOs believe that the number is many times larger (Simonsen 2006).

Unprotected heterosexual contact constitutes for about 91% of the registered cases in Nicaragua (Matute et al 2008: 105). Although the number of reported cases is relatively low, the number of HIV/AIDS cases is raising among young females where married young women and young girls as opposed to represent the greatest risk group. This is thought to be a combination of reasons such as unawareness of the epidemic and the "machismo" culture where men have several sexual partners (Helman 2001). USAID estimates that over 60 % of people living with HIV/AIDS in Nicaragua are females from 15 to 34 years old. Health care personal have seen an increase in the mortality since 2005 (Matute et al 2008: 105).

UNICEF and other NGOs working with HIV/AIDS campaigns in Nicaragua believe that the rising tendency among housewives is due to assumed cultural factors and maybe also caused by false categorization. When women are tested for HIV/AIDS they need to be placed in a certain category either as "sex workers" or "housewives". Discrimination and stigmatization in Nicaragua is believed to thrive well and cause when commercial sex workers want to be registered as housewives (Meeting with UNICEF 16.05.06).

In October 1996, Law 238 – Law of Promotion, Protection and Defence of Human Rights in the Face of HIV/AIDS - was passed by the Government of Nicaragua through the MINSA and revised in November 1999. The law was proposed as a response to the increase in the number of people affected by HIV/AIDS and the principle objective of this law is to provide legal protection to all people living with HIV/AIDS and promote social solidarity while eliminating the discrimination against these people. However, the law has yet to be implemented and in many ways law 238 still has no effect on the Nicaraguan society. Instead it seems like there exits a battle between clerical morality and international human rights in Nicaragua (Moustgaard 2004, USAID A, UNDP and UNAIDS 2001).

The Nicaraguan government still lack a strong HIV/AIDS policy and people affected by HIV/AIDS are struggling for medicine, treatment and especially how to manage experiences of stigma and discrimination. Nicaragua does not have a flattering history when it comes to ratify conventions - either explicitly or by extension - prohibiting discrimination against people with HIV/AIDS or any other disease such as tuberculosis. The women's stories show that what a nation internationally agrees on and how it domestically acts do not always coincide. Another problem is that human rights questions are often mirrored as western liberal concepts and in that way suppressed.

The Nicaraguan Government has acknowledged that HIV/AIDS is a problem and the Prevention of Control of HIV/AIDS and Sexually Transmitted Infections was established in 1998. However, national expenditures on health have declined during the last couple of years (USAID A). Matute et al (2008) who has conducted a study of the spread of the virus from a clinical perspective in 2008 writes: *HIV/AIDS in Nicaragua is in a nascent stage…Education of the population is in an urgent need to increase HIV/AIDS-related knowledge, change attitudes, and increase safer sex practice in the community* (Matute el al 2008: 106).

This chapter has outlined HIV/AIDS in a Nicaraguan context and how it has spread in this country as well as how it was first handled by the government. This leads me to discuss the chosen theories for my thesis.

5. Theoretical framework

The following chapter will introduce the theoretical framework used for analyzing the empirical results. The chosen theories are from social anthropology and especially from the field of medical anthropology. This was to understand the cultural factors of HIV/AIDS in Nicaragua in my arguments that HIV/AIDS in Nicaragua has to be analysed in its own cultural context. Furthermore, I have used different theories on stigma, deviance and empowerment in my analysis. The theories were carefully selected to make my arguments stronger. Stigmatization and discrimination in relation to

HIV/AIDS in Nicaragua which have the main focus of this thesis have been discussed and analysed using different theories from the sociological and socio-psychological field to understand why this occur in Nicaragua and how the women cope with these feelings. Empowerment theories were chosen as I realised that as stigma and discrimination are used a tool to achieve empowerment in the support group for women. The support group strives at empowering the women though different activities and meetings but I saw it doubtful whether the women truly were empowered. In this chapter empowerment are discussed from different ankles. Now I will reveal the theories in more detail.

5.1. Medical anthropology

Medical anthropology draws upon social, cultural and biological anthropology for a better understanding of the factors influencing health and well being (Medantro A). Medical anthropology gives us an understanding of cultural contexts and norms of health and diseases and the social construction of knowledge by using different theoretical approaches (Helman 2001: 1-11).

During the last years the importance of going beyond epidemiology has been acknowledged in order to understand issues surrounding HIV/AIDS. The study of culture and behavioural aspects in relation to a specific cultural context is an important approach to prevent the spread of HIV/AIDS and understanding the negative aspects surrounding this disease (Helman 2001: 12).

There has recently been a lot of criticism towards the global and westernised AIDS prevention model. Many international organizations have realized that there is no "one-size fit all" model when dealing with this disease. This means that Nicaragua has a different cultural context from the neighbouring countries and that HIV/AIDS must be analyzed within this specific context. When approaching other countries with different epidemiological models it is important to be aware of their specific cultural settings and understandings and take their different cultural baggage into consideration when approaching it in an anthropological manner.

With this in mind I will analyze HIV/AIDS in a Nicaraguan context. Beside my field work data, my main source of inspiration in this area is the book *Health, Culture and Illness* by the medical anthropologist Cecil Helman who states that "*you cannot understand how people react to illness without understanding the type of culture they have grown up in and the "lens" through which they perceive the world."* (Helman 2001: 268). I have dedicated a chapter for the analysis of the cultural circumstances the women have grown up in.

Paul Farmers is a physician and medical anthropologist and his book from 1999 *Infections and Inequalities: the Modern Plagues* has a big impact on the cultural understanding of HIV/AIDS and his work has mainly focused on Haiti where stigmatization and discrimination has a big impact on people with HIV/AIDS. His work has been used to compare the problems the women faces in Nicaragua with the problems Farmer reveals in his research.

5.2. Stigma, discrimination and deviance

In ancient Greece criminals and traitors were sliced and burned to be marked forever. Such branding was called "stigma" and the bearer of a stigma was avoided and discredited (Goffman 1963: 1). Today, stigma is used in a broader context. In the dictionary stigma is described as a mark or disgrace or a way of stereotyping and rejecting others using a social distance scale (Dictionary A, Dictionary B). Stigma is a way for people to create categories and to link them to stereotyped beliefs.

The sociologist Erving Goffman is seen as the founder of the stigma concept in social science theory. In his book *Stigma: Notes on the Management of Spoiled Identity* from 1963 he defined a stigmatized person as a *"person with a spoiled identity who deviates from society."* A stigma can be visible or invisible to the public. However, it can first be a stigma when individuals themselves become aware of their spoiled identity.

Other notions of stigma are its relation to power which Goffman left out. Patricia A. Adler and Peter Adler (2003), who are professors in sociology, use deviance in close relation to stigmatization and discrimination in their book *Construction of Deviance: Social Power, Context, and Interaction* where they define deviance and stigmatization as related to power and control. A stigmatized person deviates from the norm constructed by "moral entrepreneurs" in a given society. Their book examines the construction of deviance in terms of differential social power and processes in society that creates deviance. The book will be used as my inspiration to analyse how women with HIV/AIDS in Nicaragua are labelled as deviant and how society labels stigmatized behaviour and especially how the women feel discriminated against.

Social psychologists are maybe the most frequent analysers of the stigma concept. They define stigmatization as symbolic acts towards people who are seen as a threat to the normal and accepted behaviour and values. Deviant people will be stigmatized when seen as a threat to safety. To study why stigmatization of women with HIV/AIDS occur in Nicaragua it is important to understand where stigma comes from focusing on this disease within the cultural context. I have used the book *The Social Psychology of Stigma* by Heatherton et al (2000) for inspiration.

Stigma has a main focus as it is the women themselves who first brought up this concept. According to the women they truly feel stigmatized by different groups of people in the Nicaraguan society due to their HIV/AIDS status. The stigma theories have been chosen to try to understand mechanisms of stigma by the society and why the women feel stigmatized and discriminated.

Through the thesis stigma, discrimination and deviance will be interlinked. In my analysis stigma ought to be understood both as a construction from society and as an attribute of individuals. Stigma is contextually bound into the meaning that in one situation persons might feel stigmatized while another does not. What is understood as a deviant person also varies from culture to culture.

5.3. Empowerment

Empowerment theories have become a new tool and buzzword especially within development policies and in this way the concept has its base in the Western culture. Empowerment is believed to challenge and transform unequal power relations to help poor and marginalized people gain greater control over sources of power (Parpart 2002). Especially the United Nations [UN] organizations have since the 1990s focused on empowering women as they are categorized as a vulnerable group and empowerment strategies are seen to be a fundamental element in reducing the vulnerability of women and girls to HIV/AIDS and to achieve social transformation (MDGs 2007). Empowerment is used in more and more ways and in this way it tends to lose its original meaning.

In general empowerment is a tool to strengthen women to take control over their own lives. It is an action-oriented concept that aims at transforming power relations between communities, institutions and government (ONUSIDA 2002). Empowerment is seen to require action within the local context as international organizations have recognized that HIV/AIDS cannot be looked upon as an entirely medical problem. Empowerment should be seen both as a process and an outcome where the term "power to" concentrates on the ability to influence change (Rowland 1998).

It has been discussed how we are to understand and interpret the concept as it is often used very abstract. The word is difficult to translate adequate into any language. Dr. Jo Rowland who is an expert in development issues has defined empowerment as *"a tool to bring people who are outside the decision-making process, into it.*" She further categorizes empowerment in four terms such as "power over", "power to", "power with" and "power from within" – each with its own meanings. She criticises the power over view in the way that power can be given by one person to another. Further, this means that women can risk losing that power granted to them (Rowland 1998). Empowerment has been criticized for not being neutral laden but a highly power laden process (Cornish 2006).

Positively empowerment should be seen as a tool to gain power over ones own life and to participate in decision making processes. It should work as to bring the women from the periphery to the very centre. However it is not evident how we really measure levels of participation. Power can be economical, political, psychological and educative level. Empowerment occurs at the micro-level (development of self-esteem and increased control over one's life) and at the macro-level (development of social collective action and increased political power). Individual empowerment can lead to increased group consciousness and group empowerment can enhance the functioning of its individual members. In this paper I will analyze if the women really are empowered in the association and how. I will first and foremost look at group empowerment in form of support groups for women with HIV/AIDS (Parpart 2002).

However, it is crucial to use the empowerment dichotomy with care as all forms of power are people created. The main question surrounding the women with HIV/AIDS will be *in what way* the women are empowered or disempowered?

Now the different theories have been outlined and in the next chapter I will go in detail with analyzing and understanding how and why HIV/AIDS occur in Nicaragua and how it is coped with by different agents in society.

6. Cultural factors contributing to HIV/AIDS in Nicaragua

In the following chapter I will focus on two main cultural factors for the rising HIV/AIDS prevalence among women. By "cultural factor" I refer to a phenomenon such as the behaviour of the church. The first factor I will look at is religious morality and the second is a risky youth culture leading to the spread of HIV/AIDS and the stigmatization of women with HIV/AIDS. I realize that there might be various other reasons as well. However, I believe that the above mentioned issues are contributing in marginalizing women more since these social forces are mechanisms of gender equalities and poverty. A cultural analysis is important as scientists in epidemiology recently has realized that prevention efforts must take an understanding of cultural factors into consideration and the realities in which sexual behavior are shaped (Matute et al 2008: 108).

6.1. The Catholic Church, morality and AB

In Nicaragua, the Catholic Church - closely connected to the Vatican in Rome - has always played a great role in the society and often intervenes in political matters. Many of the catholic priests have been high ranked on ministerial posts (Kirk 1992).

Focusing on HIV/AIDS preventive work the Catholic Church works differently from international organizations and donors by still preaching abstinence and loyalty as the best prevention against HIV/AIDS, however, leaving out the C from the campaigns to Abstinence, Be faithful and use Condoms. It is not unusual to hear priests openly condemn the use of condoms from the pulpit. Neither is it unusual to hear priests comment on condoms as dangerous. They use myths to keep order and to frighten people by saying that condoms have microscopic holes where the HIV virus can get through. Meanwhile international and local health organizations are striving to promote safer sex practices in Nicaragua with the use of condoms. However, the Catholic Church fights back with the aim at preventing these condom promoting campaigns (Moustgaard 2004).

Nicaragua has no state-religion but especially the Roman Catholic Church has a strong impact on the population and the government. The church portrays people affected with AIDS as having moral problems and understands AIDS as a moral disease caused by bad behavior such as promiscuity. The church believes that there is a meaning for everything and that people with HIV/AIDS deserve the disease (Moustgaard 2004).

As mentioned, believers of the Catholic Church in Nicaragua think that people catch HIV/AIDS because they break a moral rule in society. However it is the Catholic Church that decides what moral rules and norms to follow when working as what Adler and Adler categorizes as a “moral entrepreneur” (Adler and Adler 2003: 35). Adler and Adler (2003) write that moral entrepreneurs draw on elements in society such as drama, politics and deep mythic scenes to gain the visibility they need. Interviews with the Catholic Church show this tendency.

An interview with Father Carlos Salinas on HIV/AIDS prevention, published in the local Nicaraguan newspaper El Nuevo Diario, shows the use of dramatic symbols in the clerically moral battle against HIV/AIDS. *"When you teach young people to use condom they will think that they can do whatever they feel like. This will only lead to more HIV/AIDS cases…The use of condoms will only lead to promiscuity and condoms are not safe at all. They say that condoms are safe, but that is not the truth…It is like telling young people - here you have 5 bottles of Coca Cola where one of them is poisonous. Choose one. You don't know which one is poisonous. On the other side you have 5 bottles representing chastity and abstinence and none of them are poisonous. Which one do you chose? Do you choose a risk?"* (El Nuevo Diario 02.12.05).

Church representative Monsenor Eyleen Castro (Vicario Episcopal de Educación) says to the local News paper: *"As a church we want to participate in the HIV/AIDS preventive campaign with a new vision. We want to participate in HIV/AIDS prevention at schools, but our vision is not to use condoms but more from a moral point of view."*(El Nuevo Diario 02.12.05).

Father Salinas further explains how sexual education at schools should be abandoned and moral education promoted. He thinks it is money issues that promote the use of condoms and that the Catholic Church cannot make campaigns in the same way as the many condom promoting campaigns due to lack of money in the Catholic Church. He further states: *"It is a hard and difficult battle. Sometimes we feel like we are fighting a monster. Our fight is against a deadly culture and not against sexual education…"* (El Nuevo Diario 02.12.05).

Adler and Adler describe how "moral entrepreneurs" work to successfully create a moral panic in society (Adler and Adler 2003: 135). Moral entrepreneurs in this way portray condoms as a threat to society using strong symbols and myths associated with

HIV/AIDS. The Catholic Church sees safe sex campaigns and the promotion of condoms as “evil forces” because it promotes loose morals.

Many of the women believe that AIDS is a punishment from God for having done something immorally wrong. One of the respondents refused to receive ARV treatment because she believes that it is up to God to decide whether she shall live or die: *“God has given me this disease, if it is the meaning that I will be cured then he will take care of it.”* Many of the clerical moral mottos functions as a way of controlling the women and the population as a whole.

This battle between the church with abstinence and the NGOs with condoms clearly divides the Nicaraguan society into two moral poles in HIV/AIDS campaigns. On the one side, the Catholic Church and its followers strive to control the population using moral symbols and on the other side the HIV/AIDS preventive organisations argue in favour of safe sex practices. The Catholic Church sees the women as criminals while international organizations see them as victims. The women find it difficult to be both followers of the Catholic Church and involved in condom promoting campaigns made by international organisations at the same time. This is especially the case with women already infected and active members of support groups and networks as will be discussed in detail later.

The spokes woman for ASONVIHSIDA explains the difficult relationship to the Catholic Church “*The AIDS epidemic is not only a question about the use of condoms. It reaches further than that. We are sometimes afraid of ruining our relationship to the church and try to cooperate with it even though we sometimes do not share the same points of view. We believe in many of the Church’s family values but we also believe that it is up to oneself to choose protection against HIV/AIDS. One year ago we were very happy about the initiative the Church showed regarding HIV/AIDS. Today we are sad…”*

The spokes woman refers to the initiative about sexual education at schools. In 2004, the Ministry of Education, MECD, with help from international organisations had a national plan ready for implementing sexual education at schools. The Catholic Church then started protesting and the plan never came through (Envio B). Most of the media in Nicaragua are close connected to the church and write about how the ministry was about to promote a culture based on foreign anti-values (Moustgaard 2004).

Information about sexual transmitted diseases is non-existent at schools because the Cardinal is involved in politics and especially in the area of education. He will attend all important governmental meetings in this area and condemn any promotion of sexual education (Meeting at the Danish Embassy 02.04.06).

Some of the women consider the moral messages from the Church as harmful in the fight against HIV/AIDS, while other women have become even more religious after contracting the disease. Some of them have changed from the Catholic to the Evangelic church due to discrimination after revealing their HIV/AIDS status. The top down influence of Nicaraguan religious leaders on the social construction of HIV/AIDS appears to remain significant on large scale in Nicaragua (Takahashi 1997: 197).

> Maria, 27 years old: - *The priests say that if you do not have sex before marriage, congratulation! There might be some who can, but I think they are outnumbered by those who have sex before marriage. I think condoms are the only way to fight HIV/AIDS. This way you get more freedom and stay protected against infections. Now I don't know how to listen to the church.*

Sex is not to talk freely about and it is the Catholic Church that educates society about morality instead of sexual education. Nicaragua is a conservative society in the way that sex is not debatable. However this does not mean that sexual intercourse outside marriage do not occur. Parents do not inform their children about the risk of having sexual intercourse without protection and children do not receive any sexual education at school. The only information available comes from the church that promotes the AB – but not the ABC or D (de-stigmatization). Nevertheless even though people follow the church very strictly they still practice unsafe sex. The messages of abstinence and fidelity from the Church do not kill risky behaviour in Nicaragua.

> 25 year old Ruth explains: - *I was 23 years old when I got to know that I am HIV positive. It was my special birthday gift (with irony in her voice). Earlier it was more difficult to talk about sex in Church. It was out of the question. The Church still says that as husband and wife you are not allowed to be together with others, and the Church does not promote the use of condoms. I do not see any problems using condoms. As I say, meat is weak. And we see it everywhere…Condoms is a way to protect oneself.*

The women have strong religious beliefs and they are placed in a difficult position. On one side they have to follow the message of the Church and on the other side they listen to the information from the many organisations fighting to prevent the spread of HIV/AIDS. The women need to be a part of their community where the Church council is the leaders but they also need the help and backup from the support group at ASONVIHSIDA, which does not condemn the church. Nevertheless, messages from these different instances are often very contradictive.

As seen in this section the Catholic Church may play the critical role in determining how women with HIV/AIDS are perceived by different groups in Nicaragua. The Catholic Church works against international campaigns and women thinking otherwise have to walk a narrow line between preaching of religious morality and preaching from international HIV/AIDS preventive campaigns.

6.2. "Show me the test of love" – a symbol of a deadly culture

According to UN organizations in Nicaragua (meeting with UNFPA 23.05.06) the proverb "show me the test of love, if you really love me" (Darme la prueba de amor si te me amas) is outspread among youth. The proverb is the subject of a new UNICEF supported campaign in Nicaragua first and foremost to inform young males about the risk of contracting HIV/AIDS. The campaign illustrates the girl or woman as a helpless victim who by force are pressured into sexual intercourse.

The proverb UNICEF uses is supposed to symbolize the youth culture in Nicaragua where young Nicaraguans tend to change partner often and especially young boys are believed to pressure young girls into sexual intercourse in their early teens. According to the NGOs – international as well as national - the problem with HIV/AIDS is due to a strong machismo culture where young males are encouraged by older males to have their sexual debut at an early age to assert their manhood (Meeting with UNICEF in Managua 16.05.06). Girls are encouraged to demonstrate their love to the boy through sexual intercourse and are even believed to be taken by force and physically threatened (Envio A).

On the other hand women are expected to stay pure and virginal until marriage and to have little sexual knowledge. Girls are believed to be brought up to accept the husbands sexual meandering while staying faithful herself (Helman 2001: 239). *"The emphasis on machismo encourages males to have multiple uncommitted sexual contacts which start in adolescence as a sign of manliness."* (Helman 2001: 239). The dominant picture of gender differences in Nicaragua is supposed to be as here mentioned and that is why international organisations stress the importance of changing the machismo culture and risky behaviour to prevent HIV/AIDS. The women tell that they have had sexual intercourse before marriage, but they do not recognize UNICEF's slogan in the way of being pressured into sexual intercourse by males. Nevertheless, they all say that they have stayed faithful when married.

> Cecilia 31: - *Of course I have had boyfriends before marriage…yes about 5. I have never been unfaithful to my husband. He would kill me. You hear about these things. They are very jealous. There is this difference you know...and we know the rules.*

Although information about HIV/AIDS is getting around in Nicaragua it does not automatically stop or change behavioural patterns due to power differences between the sexes. Jonathan Mann an expert in health and human rights states that in cultures where women's primary task is to produce children it is difficult to insist on the use of condoms (Mann 1999: 207). This is also close to the Nicaraguan context. The women are often fully aware that their husbands have sex with other women but have little bargaining power when it comes to taking measures to protect themselves from possible infections.

> Arlene, 32 tells: - *I once asked my husband if we should use a condom. He got very upset and asked why I asked him this silly question and if I didn't trust him. A woman has no right to ask her husband about such things because he will then believe that she has been unfaithful to him or that she doesn't trust him.*

A request that a condom should be used may result in verbal and physical abuse with accusations that she has been sleeping with other men or that she is lacking trust in her partner and according to UNICEF about every second woman are victims of domestic violence (UNICEF 2000). This mechanism also works in reverse, as sometimes men having sex outside of their marriage or relationship don't use protection with their partner for fear of arousing suspicion (Helman 2001: 240).

"In Nicaragua women have little autonomy over her body and her own sexuality. It is the man who dictates when, how, and how frequent sexual relations will take place.
This same sexual inequality allows men to maintain many sexual partners while within a marriage (Mann 1999: 203)."

The interviews with the women give voice to similar stories either about ignorance of how to protect against HIV/AIDS or the lack of understanding and interest from their partner. None of the 20 respondents were able to use condoms with their partners. And all of the women blamed their partner for not wanting to use a condom.

> Maria, 27 years old: - *It was first after I got my third child that I heard about protection at the hospital. As men do not like to use condoms I chose to take pills in secret. I did not know about HIV/AIDS at that time. I just didn't want to get pregnant again. The only guys who use condoms are men who have sex with men. That is what you hear. We will be asked a lot of questions attached with prejudice if we ask our man to use a condom.*

The Nicaraguan machismo culture expresses itself in the way that men according to unwritten rules have the right to be with several women. The machismo culture expects the male to live up the male ideal which includes taking personal risks and endangering the lives of others (Mann 1999: 206) These socio-cultural factors such as the machismo culture together with the lack of use of condoms contribute in making HIV/AIDS more outspread among young housewives. Homosexuals are such a stigmatized group that they will act bisexually with a "normal" family life with a wife and kids beside their male lovers (Meeting with Cepresi 15.05.06).

"The most frequently encountered and easily circulated theories about women and AIDS are far more likely to include punitive images of women as purveyors of infection – prostitutes, for example, or mothers who "contaminate" their innocent offspring… Dominant readings are likely to suggest that women with AIDS have had a large number of sexual partners…" (Farmer 1999: 88).

The women all tell parallel stories about how they were perceived by society when they discovered their HIV-status. According to the women the Nicaraguan society will always believe that the woman was unfaithful to her husband and that she first contracted HIV/AIDS. This may be due to the many myths attached to HIV/AIDS where the most dominant is that AIDS is a disease of promiscuity and especially associated with prostitution. Most of the women have lost their husbands due to HIV/AIDS which indicates that the husbands contracted HIV/AIDS and were the first to be infected. However their stories of being innocent when contracting HIV/AIDS may have another meaning as well as revealed later on.

Helman states that in cultures where a woman has little or no formal education and children to feed she has but few opportunities for self-employment. Therefore she is left with little choice but to accept her partner's behavior. Nicaragua is still such a country where women both socio-economically and culturally are valued less than men. From childhood women are told that they are inferior to men and that their role is to serve the man and satisfy his needs (Helman 2001: 111).

All Nicaraguan women are at risk of contracting HIV/AIDS because being born a woman means that you have to live up to certain societal roles. Power imbalances between gender roles facilitate the spread of infectious diseases and inequality between women and men fuels the spread of HIV/AIDS. The women are seen to be vulnerable to AIDS because of social processes that are political, economical and cultural.

This chapter has focused on the Catholic Church and its way of dealing with HIV/AIDS which is in contradiction to international and national organizations focusing on HIV/AIDS preventive campaigns. It has discussed how the Catholic Church works as a guardian of public morality labeling moral and immoral behavior in Nicaragua and also spreading fear about the disease through strong metaphorical pictures in order to control the public. While the church sees the women as criminal the international organizations label the women as victims. It has further explained the machismo culture in Nicaragua leading to a rise in prevalence of the disease. The machismo culture legitimizes why men have the right to several sexual partners, but it does not legitimizes other women's willingness to have sex with these men.

7. Voices

"To listen to a person's life story is a great gift. Such personal gifts should be given voluntarily and be handled with the greatest respect", (Johansen 2003: 19).

Voices and narratives are used to a greater extent in development policies as it is seen as an empowering tool to give voice to the poor and marginalized. Voices and narratives are social products produced by people within a certain context in order to represent themselves and others and their relation to the social world (Lawler 2002). They can also be referred to as individual stories where feelings and thoughts are clearly brought forward.

In this chapter I will more or less give the word to the diseased women and study how they experience their world. However, narrative inquiry takes as a given that people may exclude details of events or exaggerate aspects of stories (Riley and Hawe 2004). Thus what becomes interesting is how and why these exclusions or exaggerations exist. I do not take for granted that what the women tell me is actually the exact picture of the context they are living in. I understand that their might be a reason for them to cover up sides of the story.

7.1. Knowledge about HIV/AIDS and protection – an observation

"Who have heard of sexual transmitted diseases?" The two women who now work with HIV/AIDS assistance for the Nicaraguan NGO Inhijambia have the same background as the 15 girls gathered. They have also lived in the streets most of their lives, taking drugs and survived as commercial sex workers. The course has just started and it is already about 30 degrees in the shadow. The 15 young women are still in an ecstasy from the glue they sniffed before attending the course. The two assistances gather small jars with glue promising the girls to return them at the end of the course. *"I am thirsty",* says a 16-year old girl sitting restless on her chair. She gets up and hurries to the assistants now cutting pieces of cake to the girls. It might be a long time since they have eaten last and they need fuel to keep focused for many hours. *"Sit down Maria",* yells another girl in a ragged t-shirt. *"Shut up",* Maria yells back. One of the girls with a one week old baby at her breast *"I know that there exist sexual transmitted diseases you have to protect yourself against",* she says. "*Very good",* one of the assistants responds. Another girl now raises her head from her hands when the young mother is credited. It is difficult to guess her age while her skinny childlike body does not fit to her serious facial expression. *"Syphilis",* she yells, *"and then there is this disease which gives you red spots." "Do you mean herpes?"* the assistant asks. *"Yes herpes"* the girl answers. "*Good",* the assistant says. The girl lights up in a big smile. *"Who has heard about HIV/AIDS?"* the assistant asks the girls. *"You will die of AIDS",* replies a girl with a head bandana on. She has a big tattoo on her arm with almost indistinct and invisible signs. *"Yes, if you get AIDS you will never be cured",* another girl from the group replies. *"I do not have AIDS",* Maria yells. She has now got a big piece of cake from the assistant and is again sitting calm on her chair. The mother with the child answers: *"You need to use protection and then you will not catch AIDS."* The assistant asks the group: *"How many of you use protection?"* The mother raises her hand followed by the rest of the girls (Observation made 02.06.06).

The observation from Inhijambia's HIV/AIDS preventive campaign representing the prostitutes shows that most of the girls already know about sexually transmitted diseases. They also know that with protection they can prevent getting infected. But one thing is what they say they are doing, another thing is how reality really is. The girls have received information from different HIV/AIDS preventive campaigns targeting vulnerable groups such as commercial sex workers, drug addicts and homeless. The young women from the observation represent the mentioned categories.

Mariam Sanches, director of Inhijambia tells:

> *- The girls represent one of the most stigmatized groups of the Nicaraguan society. They live in the streets, take drugs and many of the girls are forced into prostitution to survive. They all have about the same background. They have grown up in a home with violence, incest and alcoholism. Something has forced the girls into the streets. Some of them have told us that they prefer the life in the streets than a life with their families.*

Inhijambia has followed some of the girls for more than 10 years now. They know that they ought to use protection but Maria Sanches do not think that even one of them does it because their costumers do not allow it. Maria Sanchez says that most of their costumers are low- and middleclass men all with families. In this way it is very likely that these men bring the infection back home to their wives.

The girls residing in Managua have been target for many local campaigns on HIV/AIDS. However, these campaigns do not reach families in more marginalized areas of Nicaragua. This is why the women in the group as housewives did not know about the disease when first contracting it because they have not been targeted by HIV/AIDS preventive campaigns.

Nevertheless, a study conducted by ASONVIHSIDA shows that 52% of the women coming to the centre know about condoms while just 1% are using them. So either the women do know about condoms before transmitted or they have learned about condoms at health centres after their husband pass away. As discussed in previous chapters the reason for not using condoms emanates from the country's culture and especially from the deep-rooted differences between male and female behaviour and societal roles.

The observation shows that so-called vulnerable groups have the knowledge about HIV/AIDS and its ways of transmission. However, even though they have this knowledge it does not mean that they will change risky behaviour and use protection in order to not get infected. This section also reveals that their customers are men with families from the middle and lower classes.

The next sections will focus on the women categorized as "housewives" and their voices of lack of knowledge about HIV/AIDS and fear surrounding the disease.

7.2. Voices of ignorance

The women interviewed at ICW all appeared to lack knowledge about HIV/AIDS when transmitted. They can be categorized as housewives which gives them limited access to information related to the girls living in the streets due to several reasons. One is that, as mentioned earlier, housewives have not been a target group for HIV/AIDS preventive campaigns in Nicaragua such as sex workers have. Housewives are a difficult group to reach because of the machismo culture where men might not allow them to receive information about HIV/AIDS prevention but also due to their strong involvement with the church that condemn information about safe sex practice. The women all express feelings of being victims of this deadly disease in a variety of ways.

> Maria, 30 years old: - *First my son died in my arms after long time with fever and headache. Short after my husband died. In the beginning he was very sick. He could not walk and only stayed in bed. The doctors did not know what to do. Some weeks after his death a nurse came by. She asked me if this was the house were a boy died. I actually thought that they killed him at the hospital so I was very upset by her visit. I answered that both my husband and son have passed away. She asked me if I had received the result. I said no because I was not afraid. I did not understand what she talked about when she said that both died of AIDS...It was my husband who had AIDS and not me. I was fine. The*

> *nurse said that I should come to the hospital the next morning. She said that I probably also had AIDS. At that time I didn't know anything about this disease...*

The women who come from all parts of Nicaragua all share the same stories of ignorance. None of them knew about HIV/AIDS when contracting it. The women first received information about the disease when their husbands turned ill or died from AIDS or when their own sero-status got revealed. Their common voices show how difficult it is to target this group of women with information about the deadly disease.

> Miriam, 27 years old: - *I found out that my husband had AIDS two months after his death when I got the test myself. I thought that he died from pneumonia. When I talked with his brothers later they told me that he died of AIDS. They did not want to see me again. They said that they would kill me if they saw me. Then I thought that if he had it then I had it too. I have heard about HIV earlier but I actually thought that it was a person.*

The interviews show the myths attached to the disease. Because of dominant understandings about ways of transmission and what HIV/AIDS really is the women felt immune to the disease. Many of them told that they thought AIDS was a disease only to be found among homosexuals and sex workers. Further the women did not know about the opportunistic diseases caused by HIV/AIDS. They believed that to have HIV were immediately to write their own death certificate and that a person with AIDS would have a visible mark.

> Lopez, 32 year old: - *When my husband first got the test we thought it was meningitis. We once watched in the television that a famous actor got AIDS at the dentist. So my husband must have got it at his dentist too.*

The interviews show that the women feel it more acceptable to have contracted the disease by external and uncontrollable factors than through sexual intercourse which could have been prevented by abstinence (Peters et al 1994: 326). The women will tell that either they contracted the disease from their husbands, which of course is from sexual intercourse as well, or if not they have no clue about how. But with these stories the women become victims of AIDS.

One of the interviewed women could not understand that she was infected with the virus. She considered people with HIV/AIDS to be skinny and bald-headed. That is what she once saw in a movie. Another woman believed that her two children died of AIDS due to her giving birth by Caesarean section.

Women are the main caretakers at home in the sense of cooking, cleaning and caring for children and sick. This keeps them away from education and knowledge about AIDS and also places them at a higher risk of contracting HIV from infected family members. The women are often not allowed by their husbands to receive information about safe sex practices and HIV/AIDS preventive campaigns in Nicaragua has so far merely focused on high risk groups such as commercial sex workers. The women discover their sero-status late because of lack of knowledge about the symptoms. However, the women express that the hardest thing for them was not that they discovered their status but more how to deal with it emotionally.

7.3. Voices of fear

Fear is often described as a function of people's inability to deal with uncertainty (Chliaoutakis and Trakas 1996: 359-372). The women give voice to the fear they have experienced when first realising their incurable illness. Their anxiety mostly consists of different negative feelings about how people will react when knowing about their condition.

The women are afraid of revealing their status even to close family members due to apprehension about how they will react. Further the women are giving voice to feelings of guilt and blame caused by the clerical morality: "*you deserve what you get.*" They know that the society will respond negatively because of this motto.

21-year old Teresa tells that she knew about her boyfriend being unfaithful to her but could not do anything about it. When he revealed having AIDS at a severe stage she became aware of her own status. Due to ignorance she was afraid to touch other people not to infect them. She tells that she first received "real" knowledge about HIV/AIDS when being in contact with ASONVIHSIDA because she did not receive any information about the disease from the hospital where was tested HIV-positive. The women are all giving voice of fear caused by lack of information.

> Auxiladora, 32 years old: - *I found out that I had HIV/AIDS when I was 17-years old. I stayed inside my room for three months because I was so frightened and ashamed. I could only think: why me? My family did not know what to do either. They were afraid of touching me and my clothes. I got a room in the back of the house where I was isolated and washed my clothes separately….*

Many of the women have experienced what ignorance can do to people and they recognize Auxiliadora's history of fear and rejection when having told her family of her condition. However, when the women give the families information to kill the myths attached to the disease their families will react more calm and positive. Studies conducted on the stigma of HIV/AIDS reveal stories about separating household items, clothing and personal belongings and isolating the women. This might be the immediate reaction from ignorant relatives but the interviews with the women show that the negative reaction changed to a positive when the family learned about the disease and how it transmits.

The fear does not only come from the infected women but also from the society both due to lack of knowledge about how the infection spreads and because HIV/AIDS is a shameful disease in Nicaragua. Many studies focus on how diseased people are rejected from the society (Varas-Días, Serrano-García, Toro Alfonso 2005). Most of the women tell that they did not reveal their status to friends and family members due to fear of social death. Rather they stayed in silence and isolation or changed their social networks.

Fearing negative reactions some of the women have moved to the capital where there are fewer informal controls such as gossip, rumor and stigma from neighbors (Chliaoutakis and Trakas 1996: 363). Women who remain single are rare in Nicaragua. Being married is an attribute as housewives and will make the women safe and “normal” judged by the public and no one will question their status. But when their husbands die of AIDS the women will instantly become stigmatized as deviant and people immediately start to suspect that something is wrong.

The women refer to themselves as victims of AIDS. They did not know about the disease and say that as women they were unable to protect themselves. It was “out of their control”. They tell stories about fear and victimization in different spheres of society such as the home sphere with their families and the surrounding society such as hospitals, workplace and the church. Some have been denied access to health care while others have been thrown out of the church and even rejected by their own families.

7.4. Fear of going public

The response to HIV/AIDS is increasingly conceptualized as a continuum between prevention and care, and the effects of stigma and discrimination can also be framed within this model (Frasca 2005). Ideally, people seek counseling and testing to identify their HIV status without fear of repercussions. Their communities can support people living with HIV/AIDS, and their integration into society personalizes the risk to others aiding prevention efforts. However, a stigmatizing social environment poses barriers at all stages of this cycle. When people fear discrimination and stigmatization they refrain from being tested. Identified as HIV/AIDS positive people may refuse to disclose their status to partners or refrain from social networks to avoid negative reactions. Neither they seek care and support, nor do they contribute to reducing further transmission.

Lieber et al (2006) has revealed that studies conducted in China also recognize the problem when people choose not to get an AIDS test due to fear of social death. They state that people choose rather to live unknowingly of their status and avoid health care professional in addition to get stigmatized by different actors for the rest of their lives (Lieber et al 2006: 466).

As stated, feeling of shame and blame and the fear of stigma and discrimination can make people stay in the dark un-identified and they might continue to transmit the virus. As mentioned in the previous section, studies have shown that persons who reveal their status to friends and family actually most often get positive response. (Visser, Makin, Lehobye 2006: 54)

Other problems are the unacceptable late answers from the results in Nicaragua. The women tell about how they waited several months for answers from their AIDS test. Doctor Carlos Quant, who is the leading HIV/AIDS specialist in the country, points to some of the problems: "*sometimes it will take 3 months to get the result from a test in which earlier was sent to labs in Panama or Guatemala but today Nicaragua has the necessary equipment at just one hospital in Managua."* However, the poor provinces still have to send the tests to Managua and the problem is here and unsolved lack of proper boxes to transport the tests at a temperature below 4 Celsius. In a climate with 35 degrees the tests often have to be retaken. *"It is a very slow process and it can sometimes take up to a year before people get diagnosed and meanwhile some of them die due to opportunistic diseases,"* Doctor Carlos Quant says. (Interview with Doctor Carlos Quant, Managua, Avert C).

The test is free of charge at many of the larger clinics but in the small provinces it can cost about US$ 8 which is a big expense for a poor women living below the poverty line at 1 dollar a day. The women tell that this is the reason why many chose not to take the HIV/AIDS test.

In an interview, Director Arely Cano from ASONVIHSIDA points out:

> *"The problem is that people will not get tested because they have heard that there is no confidentiality. At once they step inside the clinic they will be met with: - so you are here to be tested for AIDS? After such a treatment people will run away from the clinic. No one can deal with such discrimination."*

The doctor and the spokeswoman from ASONVIHSIDA point out two different problems. The women further points to different problems. They tell that they were forced to be tested by the health clinics when their husbands died of AIDS at the health clinics. Both women and men fear revealing their HIV status due to stigmatization and while men may fear that it will be assumed that they are homosexual, women fear being labeled and stigmatized as "promiscuous" or sex workers. Hence we can see that the first problem of dealing with HIV/AIDS is itself bound up with cultural assumptions about the behavior of those with HIV/AIDS symptoms.

7.5. Fear of getting treated – and fear of treating

Near all of the 20 women have experienced what they call "stigmatization and discrimination" from especially health staff such as nurses and doctors at health clinics and hospitals. They tell stories about humiliation and in some cases how they were denied access to proper treatment due to their infection. In fact, the women accuse these places of spreading more fear into the society towards people with HIV/AIDS. According to the women, the health staff does not want to treat a person with HIV/AIDS (UNGASS 2005).

Studies conducted among nurses and medical students in New York also reveal that HIV/AIDS is a highly discriminated disease and that AIDS patients are considered "*social deviants who are responsible for having this disease…* and that *those who are infected will knowingly infect others."* (Helman 2001: 238). With this attitude it is not hard to understand how the women must feel at the health clinics. However the Nicaraguan factor of stigmatization is linked with perceptions of the disease by the clericals.

Let's now hear what some of the women have to say.

> Maria, 18-years old: - *I was pregnant when I got to know my HIV-status as 16-years old. The nurse asked me with disgusts how I could get pregnant when I had this disease. Last*

> *time I went to the clinic a nurse unknowing of my status said to me that I should not let my child run around because she might catch AIDS.*
>
> Beatriz 25-years old: - *My worst experience at the clinic was when the doctor revealed to all that I had AIDS. He yelled so everyone could hear it. I was so ashamed. Even the nurses still think that they can catch AIDS by a handshake and they look at you as if you are some kind of strange animal. At the hospital the staff will treat you as if you had leprosy… They send the ball around because no one likes to treat a person with AIDS. Can you believe that I had to tell the doctor that AIDS does not transmit through a handshake? They should know better!*

The most unbearable thing for the interviewed women is the lack of confidentiality. From their stories it appears that health staff is making them scapegoats and functions as the church's right hand in relation of branding the women as moral deviants. In this sense HIV/AIDS is truly a social disease. The women do not only bear the pain of having a deadly disease, they are also in pain due to people's awareness about their sero-status. HIV/AIDS are one of the diseases with the most painful lists with its association with bad or immoral behaviour.

> Carlota, 68-years old: - *The doctor treated me nice – thank God for that. It was the nurse who was the problem. To be treated well you need to have a good social background with good education. That is what I think. The nurses are so uncivilized…They believe that God gave us this punishment… But when I went to another doctor because of pain in my bones she asked me why I came when I had AIDS. That was very depressing.*
>
> Miriam 30-years: - *I needed a caesarean at the hospital but the doctors did not want to do it because I had HIV. It took long time before I got it and due to that my child was born with hernia in the navel. He needs and operation when he is 3 years old. Further, the doctor did not want to change my bandages so I had to do that myself. I had to take a bath by myself and they did not want to change my beddings either. I was left in a room all by myself. My sister had to bring me food because I got no food either…I felt terrible and just wanted to go home. I was lying there crying when I woman came by and talked with me. She then yelled at a nurse and I received help.*

Even though the women are giving voice to stigmatization due to their disease not many of them actually believe that this is the real cause behind the stigmatizing act. They have different views on why people stigmatize. Some of them think it is because they are women in a machismo society while other think it is because they are poor. While most if the women see AIDS as a punishment from God. However, the women also think that people stigmatize them because they are afraid of catching AIDS themselves. When asked why they think that health staff stigmatize the women seem to express a combination of the above mentioned circumstances.

People being afraid of the HIV-positive are not a new phenomenon and such things have happened at all times around the world with other diseased such as leprosy, tuberculosis, plaque and SARS. This chapter has revealed the women's fear of being stigmatized because of their infection and with stories showing how and where it happens.

The next chapter will analyze the stigma discourse further to reveal why the women feel stigmatized and more how and for what they use their experiences of stigma.

8. Stigmatization, deviance and victimization

The previous chapter has described the feelings of fear that the women experiences when tested HIV positive while their experience of negative feelings and psychological impact are mainly produced by fear of getting stigmatized and rejected by society.

Stigma and discrimination in relation to HIV/AIDS has often been referred to as the "third epidemic" and as a plague laden with negative multidimensional social and metaphorical meanings. In general, a stigma is a discrediting mark which elicits shame and it can be visible or invisible to the public, but nevertheless, a stigma is a defect which legitimizes its host to be treated in a dehumanized way (Chliaoutakis and Trakas 1996: 359-372).

Erving Goffman (1963) describes stigma in reference to a negatively perceived defining characteristic. In this way it is an attribute used to set the affected persons or groups apart from "normalized" social order and it is a characteristic that make people different and less desirable. In regard to HIV/AIDS the stigma may be the actual infection since to be sexually healthy in Nicaragua is to be morally pure. More dominant stigma is based on behaviors believed to lead to the infection. Goffman further defines a person with a spoiled identity (a deviant person) as one with a damaged reputation. When people are labeled with deviant characteristics it spoils their identity and reputation.

AIDS related stigma is found as prejudice, discrediting and discrimination directed to people with HIV/AIDS and its associated attributes. Stigmatization is not only an expression of individual attitudes it also involves social processes based on social, economic and political power (Visser, Makin, Lehobye 2006: 44).

"There are cultural differences in the degree of interaction with and prejudice against the higher risk groups based on fear of the disease" (Helman 2001: 238). Women with HIV/AIDS in Nicaragua might feel more stigmatized than women with HIV/AIDS from other countries.

Stigmatization of people with HIV/AIDS is often combined with auxiliary traits. Sometimes the combination of different traits creates double stigmas. Adler and Adler (2003) give the deviant or stigmatized a "master status" by reason of the direct stigma such as having HIV/AIDS where the auxiliary traits are courses leading to the disease. One can both be discriminated against because of the master status or due to the auxiliary traits such as being a drug addict, homosexual or commercial sex worker. The women are stigmatized because they have the disease associated with "imagined communities" (Takahashi 1997: 188). This perception is created as a result of the "fear" of single women and also by the clerical morality that reinforces the exclusion of women with HIV/AIDS. Stigma is a highly affective way to suppress certain groups.

Stigma has attached cultural meaning as showed in previous chapters. The cultural meaning can vary from different countries and therefore the cultural meaning of AIDS in Nicaragua can very well differ from neighboring countries. Stigmatization of women with HIV/AIDS in Nicaragua occurs because the believed actions leading to the disease where women are given a negative attribute. After having described the mechanisms of stigmatization and discrimination I will analyze in more detail how and where it occurs and how the women cope with it.

8.1. Stigma and discrimination in different societal arenas

The different metaphors linked to HIV/AIDS have also contributed to the awareness of it as a disease that affects "others", especially those who are already stigmatized because of their sexual behavior, gender, race or socioeconomic status. Therefore the HIV/AIDS related stigma and discrimination is seen as a result of an interaction between different sources of stigma and discrimination and fear of contagion and disease. The women fear being stigmatized and people automatically stigmatize infected women because they are seen as promiscuous and being responsible for getting infected.

Table 1 illustrates in detail where women are stigmatized as well as the stigmatized act by social groups.

Table 1: Perspective of discrimination and stigma in relation to HIV/AIDS in Nicaragua

Societal arenas	*Actions of stigmatization and discrimination*
Family/Friends/Immediate community (village)	• Isolation of both infected and affected due to fear of casual contact • Restrictions on participation in local community events • Lack of support for affected family members • Rejection or isolation by friends
Workplace	• Mandatory testing before hiring/refusal to employ • Involuntary periodic testing/dismissal on grounds of HIV/AIDS status • Violations of confidentiality

	• Refusal to work with infected colleagues out of contagion
Health services	• Refusal to treat • Violations of confidentiality • Behavior with clients that clearly identify their HIV status, instead of using universal precautions • Advice given or pressure applying HIV positive women to undergo treatment that would not be emphasized for others (sterilization)
Religion	• Restriction of participating in religious activities • Violations of confidentiality
Media	• Depiction HIV/AIDS as death, perpetuating fear and anxiety rather than normalization • Exhibit people with HIV/AIDS and their families in newspapers and on national TV

As seen above, discrimination is composed of the actions of treatments based on stigma and directed towards the stigmatized. The women find themselves disliked and rejected and some have experienced harassment, scapegoating or even violence based on the infection or association with HIV/AIDS. Discrimination in Nicaragua towards the women evolves from social disapproval of the infection and its implied behaviors (Bennett 1987). There are various degrees of stigma and discrimination towards the women and sometimes to their family members or immediate communities too. It is individual how the women grade a degree of stigma. Most of the women find it most difficult to be stigmatized by family and close friends and rank stigmatization at health clinics to come next. However I find it too narrow to generalize from 20 women's stigma grading as it might depend on space and time as well as who have influenced the women.

As mentioned, HIV/AIDS in Nicaragua is a strongly stigmatized disease due to its relation to behavior and the diseased women are seen as deviant because of the different myths and attributes associated with the disease Paul Farmer believes that attacking

AIDS related stigma will require an attack on the scapegoating of sex workers, gays and other groups (Farmer 1999: 90) but to reach further than Paul Farmer it is also an attack on the norms and values set by the Catholic Church.

8.2. Felt stigma and enacted stigma

In earlier chapters the *felt stigma* experience of the women has been described as their fear of being discriminated and stigmatized. To explain further e*nacted stigma* refers to actual discrimination and unacceptability by society as seen in the table 1 (Scrambler 1998). When analyzing the interviews it seems that the women first generate an acute sense of felt stigma before actually being exposed to enacted stigma. This is due to fear of peoples' reaction towards them. They create an experience of felt stigma before they experience the enacted stigma and in some instances the women only experience the felt stigma because they will avoid the enacted stigma before actually experiencing it. This is especially the case with family and friends. Enacted stigma has been shown in the examples of stigmatization at health clinics.

Stigma can be personal as experienced by the women and as a "community" or enacted stigma explained in the former section (Visser, Makin, Lehobye 2006: 45). Community stigma is a social construction that develops over many years in the respective cultural context by actors in society such as media, governments, religious leaders, doctors, health staff and the public. Felt stigma is the women's phenomenological feelings of fear, stigmatization and discrimination. Some of the women who have revealed their status to family and friends have felt that the families withdraw from them in silence or verbally or physically discriminates them. Some of the women tell stories about how their husband's families blame them for the husband's death.

> Patricia, 33 years old: - *I have always had a good contact with my husband's family. They helped me take care of the kids. However, when my husband died and I tried to seek help from them, they told me to stay away from their house. They called me all kinds of bad things…like whore…I have no contact with them anymore.*

A lot of the women tell how their dead husband's brother and uncles even have threatened to kill them. One of the women tells that she was forced to take an AIDS test by her employer because of rumors after being sick a lot. When she was tested HIV-positive she was fired from the job. Two of the interviewed women have been exposed by the media as being the first to go public with the disease in Nicaragua. However, after revealing their status to the media they experienced how neighbors discriminated them and spread bad rumors about them.

On the other hand, a few of the women tell stories about helpful neighbors not being afraid of their disease when revealed to them. Studies show that many people are more understanding when they are exposed to people with HIV/AIDS (Visser, Makin, Lehobye 2006: 54). As shown in the former chapter, the women expressed most distress about the treatment at the hospitals and health clinics where they experienced lack of confidentiality and refusal of treatment as well as direct stigmatizing and discriminating acts. Stigmatization at hospitals has in earlier studies conducted in different countries been explained as an asymmetrical relationship of power between people in different spheres of society (Wong and Wong 2006). The women tell that stigmatization at the hospitals have been the hardest for them to deal with since they had expected a really understanding and caring atmosphere in this field. Health staff stigmatizes because they personally don't know the women and maybe according to the women because they deserve it.

The next section looks at how the women with HIV/AIDS are labeled and how this affects them.

8.3. Labeling stigmatized behavior in Nicaragua – innocence and guilt

The reason for stigmatization can be due to the fact that when the global pandemic first received international recognition it was considered to be found among men having sex with men plus injection drug users and sex workers and these already socially marginalized groups began to face further stigmatization. Conversely, the women living with HIV/AIDS are getting implicitly associated to stigmatized behaviors such as promiscuity regardless of how they became infected and they are still threatened by these stereotypes (Miller and Major 2000: 244).

Stereotyping is a controlling mechanism influencing how people think, feel and react to others (Heatherton 2000: 96). When analyzing the women's stories in contextualization with the Nicaraguan culture and society it is the strong myths and opinion associated with HIV/AIDS that makes the women targets of stigmatization. The Catholic Church's more or less unwritten guidelines are coded into every sphere of the Nicaraguan society.

Moral and deviant behavior is culturally bound and can vary from one society to another. However, in social psychology stigmatization is believed to have two universal traits. Stigmatization of people occurs either because they are believed to be dangerous or because they are seen as personally responsible for the deviance (Heatherton et al 2000: 76). Hence the women are seen as responsible for their own fate and they have earned its consequences in the eyes of God (Crandall 2000: 129). When the women are described as responsible for their fate they are met with responses of anger and little willingness to help as seen at hospitals and health clinics.

Table 2: The most stigmatized and deviant dichotomies in Nicaragua.

Norm	**Deviance**	**Examples of labeling**
Carefulness	Indiscretion	Prostitution, homosexual behavior, incest, gambling, infidelity, substance abuse
Responsibility	Irresponsibility	Unsafe sex practices, promiscuous. Not being abstinence or faithful.
Participation	Alienation	Non-participatory lifestyles, anti-social, suicidal.
Honesty	Deceitfulness	Lying
Matrimony	Single hood	Promiscuous, paganism.

As seen in the table 2 a category of attribution justifications makes the women responsible for their own stigma and to be dangerous is to be in lack of individual control. (Crandall 2000: 129) The table is made after many hours of conversation with women in Nicaragua and after 3 months field work and observations and closely studying the Nicaraguan society both as a participant observer and through reading news papers, books and articles on the country. The table shows how religious and cultural norms dictate the exclusion of unacceptable behavior in Nicaragua such as infidelity, homosexuality and prostitution (Takahashi 1997: 193). Nevertheless it is universal to attribute moral goodness and value similarity to people to whom we are similar to. People with HIV/AIDS are looked upon as breaking moral societal rules and valued as anti-social beings (Chliaoutakis and Trakas 1996: 359-372). They are a moral threat.

In this sense stigmatization in Nicaragua towards people with HIV/AIDS is symbolic in the way it becomes a threat to ones moral and religious worldview (Heatherton et al 2000: 78). Stigmatization comes from violations of "purity" values and religious beliefs (Visser, Mankin, Lehobye 2006: 44).

Adler and Adler state that the deviant is one whom the label has applied and that deviant behavior are actions which only people can label (Adler and Adler 2003: 53). In this way it is the society who decides what is normal or deviant and in Nicaragua it is the church.

The Nicaraguan women are aware that the dominant opinion on HIV/AIDS is set by the Catholic Church with the lesson that women will not attract the disease if they stay faithful to their husbands. Analyzing the interviews uncover a clear grade of guilt and innocence and felt stigma which has formed the discourse surrounding the disease where women are seen as most guilty.

However, the behavior towards marked persons can be mitigated by negotiating the labels of innocence and guilt (Chliaoutakis and Trakas 1996). "Innocent" people with HIV/AIDS are being less stigmatized and discriminated against than "guilty" people with this incurable virus. As mentioned earlier, stigma can be internal and controllable and external and uncontrollable. The latter appears to be less stigmatizing because people in this category were victims of the infection such as children inheriting the disease or people getting it through blood transfusions (Helman 2001: 239).

The women strive to get an innocent label when creating feelings and stories of victimization such as: *"My husband gave me this disease. It was out of my control."* Sympathy towards people with severe illnesses is believed to be stronger if the illness isn't associated with behavior (Peters et al 1994: 325). According to Sontag diseases of various kinds have aroused negative feelings during different eras (Sontag 1990)**.** Tuberculosis and leprosy have been highly stigmatized diseases in different cultures. However, tuberculosis is a disease where the carrier is uncontrollable of the actual contraction while HIV/AIDS is a disease connected to negative behavior where the carrier has the control to prevent the contagion.

Dichotomies of what is considered moral and immoral in Nicaragua places the women into a dangerous category when afflicted by HIV/AIDS which seems to be almost impossible to escape. In the next chapter I will show what mechanism the women use to avoid stigmatization.

8.4. Feelings of victimization and cover-up stories to avoid stigma

The women appreciate being perceived as normal but acknowledge that normalcy is lost for them after being stigmatized.

The women attempt to cover up their illness either by lying or creating images of victimization However, this was before they joined ASONVIHSIDA and embraced their HIV/AIDS label so they no longer have to lie about their sero-status because they learn that openness can help exclusion and rejection from their social circles of friendship and family. However, the women tell about how they escaped getting stigmatized.

> Arlene, 35 years old: - *I have a small grocery stall at Mercado Oriental. One day my colleague and friend through many years came to my stall and started shouting that I have AIDS. She was trying to make people frightened. Then I had to do something to defend*

> *myself. I started reputations that she was crazy. Everyone knows that she can be crazy…some of my colleagues was about to believe her and came to me for answers. I told them that I did not know what was going on with her, and that she acted out of jealousy. I think they believed me. Now I don't work there anymore and I do not talk to either of them.*

Most of the women chose not to reveal their status but to try to "pass" as "normal" and healthy. Looking at how they at first deal with the disease they all have the same story of blame and shame and victimization. Social psychologists note that traits of victimisation become visible when stigmatized persons interpret all their interactions through their lens of their stigma and are especially vigilant to signs of discrimination and prejudice in others (Miller and Major 2000: 248).

The women use different accounts to normalize the deviant behaviour and to distance themselves from blame. As described, the women's narratives depict them as victims of a machismo culture - a culture where they were forced into sexual intercourse at a young age for later being victims of their husband's unfaithfulness and victims of cultural norms and values. During the interviews the women would avoid questions directed to them as being promiscuous. Smart and Wegner (2000) believe that this form of concealment is expected in order to hide a stigma and especially to avoid being blamed for it. The women do not explain themselves as direct victims of AIDS but rather point out the social circumstances surrounding the disease because it is difficult to blame a disease. However the women clearly deny any responsibility of contracting the disease and create identities as innocent victims.

The women all showed difficulties telling other people about their disease because they were afraid of stigmatizing consequences. Some of the women fooled their friends and family into thinking that they did not have the disease in order to avoid the deviant stigma and they either remain in non-acceptance or hold someone responsible such as their diseased husbands. All of the 20 women believe that they have contracted the disease from their husbands who have been fooling around. Adler and Adler state that fear of exclusion might make the women try to transfer the stigma and blame to others to deflect the stigma away from them (Adler and Adler 2003: 281).

> Lopez, 33 years old: - *When my husband died at the hospital there was another young guy who just died of AIDS in his room. The talking started immediately. I did not want to ask his family what he died from because I could see they were in such a pain. I have always told people that my husband died of meningitis. I am always very careful that only my children know about the true cause of his death. None of us wants to get discriminated against, you understand. Just imagine if people knew what he really died of. How horrible!*

To hide the disease also eliminates the need for confrontation and conflict concerning the understanding of HIV/AIDS as a disease of immoral persons. However, when the women lie they break another moral rule and feel guiltier - the Catholic Church sees lying as a highly immoral act. The women strive to change reality to reject blame from society and lying and denial becomes a coping strategy for social survival and a tool to make other believe that they are normal but also to convince themselves that everything is "normal" (Takahashi 1997: 196). However, the women can only be in denial for a certain period of time because eventually the disease will develop to a severe stage.

8.5. Changing social networks

When the women discover their disease they have to adapt to a new identity. As mentioned earlier shifting from a normal behaviour to a deviant will make them try to balance the two sides without anyone knowing it. The women will for a certain time believe in their cover up stories. However, when the image cracks the women will rather loose the old social networks than risk being exposed to stigmatization.

When the women change social networks into groups of people with the same stigma they do not need to feel different (Smart and Wegner 2000: 220).

Nearly all the women had changed their social network before actually experiencing any discrimination or stigmatization. Social psychologists acknowledge that stigmatized people will avoid non-stigmatized people whom they fear will discriminate them (Miller and Major 2000: 255).

Helman states that people diagnosed as having AIDS often become the victims of not only discrimination and prejudice but also of violence. In extreme cases, this social rejection may lead to the social death (Helman 2001: 238).

As mentioned, even though the women do experience negative reactions from the society at many places they choose not to reveal their status to close associates. They tell that they feel more secure and accepted “among equals” at ASONVIHSIDA. Adler and Adler (2003) explain that changing circles of associates to people with the same deviance will help them to not experience feeling stigmatized. The women do not need to hide their disease which will minimize their feeling of guilt.

“Regardless of which general pattern the moral career of the stigmatized individual illustrates, that phase of experience during which he learns that he possesses a stigma will be especially interesting, for at this time he is likely to be thrown into a new relationship to others who possess the stigma too” (Goffman 1963: 63).

Most studies on stigma focus on how people with HIV/AIDS will change networks when being excluded from non-deviant circles. However, from the interviews it appears that the women change networks before they actually experience stigma from non-deviant friends. There were few examples of women who revealed their status to friends and actually were rejected. In most cases it was their husband’s families who rejected them. The families may in the beginning take special precautions against the women such as separating things due to fear of contagion. However, the women tell that this fear changes when the family receives proper knowledge about the disease and its ways of transmission.

8.6. Embracing the stigma label

Adler and Adler have defined 3 stages of deviance. First: denial of the deviant identity. Second: embracing the stigma label - when the women accept their new identity. Third: goes past accepting their deviance and to see the moralising actors behind and raise an awareness of justice. This means that the women realize that they are stigmatized and understand the societal mechanisms. However, the interviewed women do not come to this awareness by themselves. When being in the last stage they will reject the dominant view and engage in politics to fight it. Adler and Adler describe that they may organize, lobby, protest, educate or conduct individual or collective activities to fight the deviant label and stigma (Adler and Adler 2003: 209).

The observations made at ASONVIHSIDA and Inhijambia gave an understanding of the three stages from denial to embracing the deviant identity and to organize. The young women from the workshop at Inhijambia showed no knowledge about what stigmatization and discrimination meant as well as the meaning behind its actions. The women first became aware of being stigmatized and discriminated on the many workshops at ASONVIHSIDA where they learned that discrimination against people with HIV/AIDS is illegal and that they have to stand up for their rights. They were encouraged to give voice to their experiences of stigmatization and discrimination in a circle of equals and little by little they accepted the label as women with HIV/AIDS. In this way they also had to embrace the stigma attached to it and their consciousness about how the society perceived them changed while being in contact with ASONVIHSIDA.

This chapter has discussed how stigmatization and discrimination towards women with HIV/AIDS thrives in Nicaragua. The women's stories reveal that they are so afraid of being stigmatized that they will try their best to hide their disease. Most of the women move away or otherwise "exit" from their social networks in order to avoid the risk of being stigmatized and discriminated against.

The next chapter will focus on the way the women go from being victims to active agents of change. It will in more detail explain how the women use their spoiled identity and feelings of stigma and discrimination to achieve recognition, empowerment and financial support.

9. Power or empowerment?

UNAIDS writes: - *Together, stigma and discrimination constitute one of the greatest barriers to dealing effectively with the epidemic. This discourse governments from acknowledging or taking timely action against AIDS. They deter individuals from finding out about their HIV status…experience teaches that a strong movement of people living with HIV that affords mutual support and a voice at local and national levels is particularly effective in tackling stigma* (UNAIDS C).

Empowerment activities for vulnerable groups exist as development approaches in many LIC all over the world. It is believed that empowerment is an important approach to give women power and control of their lives. Empowering women with HIV/AIDS is understood to be reached in different ways described in the theory chapter. Empowerment is a process and the women are understood to be active in changing their own lives.

Self-empowerment is created through support group meetings and other collective activities where women share a common identity and thereby feel stronger and by this are empowered from within. Activities are usually also actions that raise the women's quality of life. Such activities can be psychological counseling to alleviate grief and to raise the women's self esteem, economic support such as paid work as well as providing them with knowledge and education.

But what the women actually do when participating as well as how they become empowered and who empowers or "overpowers" them are questions which will be discussed in the following sections.

9.1. Support group for women with HIV/AIDS – a new family

UNAIDS writes: *"organizations of people living with HIV are a key driving force in the AIDS response, and with appropriate support individuals living with HIV can take a central role in their own country, region, or locality in the direction and delivery of AIDS programmes. Their participation gives a personal power and immediacy to AIDS efforts that drives and inspires others into action."* (UNAIDS D).

All the women are active members of ICW and ASONVIHSIDA and the ones residing near Managua attend activities such as psychological counselling and empowering group meetings. These activities are supported by international donors. Some of the women will come to the centre several times a week to participate in different activities.

Inside the organisation the women have found a new social network. ICW is a network for women with HIV/AIDS and the women feel secure and accepted as among equals. They think that the time together in this forum is an important contribution in continuing with their lives.

> Lopez, 32 years old*: - ICW is a network for suffering women. Here we share experiences and talk about difficult things. I feel at home here. We are like one big family.*

Goffman states that persons falling into a certain stigma category can be applied a membership in terms of a group and this group will often use the label *we* or *our* people (Goffman 1963: 23).

> Arlene, 35 years old: *- ICW teach us that AIDS does not close doors but open doors. We learn to look at things in a new way. Every minute we evaluate on things that we did not know about before…Earlier it was only crying. Now I only cry once in a while. I feel more outgoing. The solidarity at ICW has taught me to live again. Here we are equals. Here we understand each other… We must stick together.*

The women feel strong when together as a group and within the group they feel safe and normal. Studies reveal that stigmatized people may gather in groups to create their own culture (Miller and Major 2000: 256). The stigma the women share becomes associated with a group identity.

9.2. Participation and transformation

The many activities at the centre teach the women about the importance of giving voice to their stories. The centre directors tell that their common voice might be able to reach a political level and change the conditions of women with HIV/AIDS in Nicaragua (Interview with centre director Arely Caño 04.05.06). However, the importance of catching possible donors becomes visible too. This is of course crucial for the organization to survive and the women are not able to dedicate much time at the centre when not receiving salaries.

The activities focus on ways to transform from an "I" to a "we" identity because people who possess stigmas are believed to be more collective likely to identify with a group. When a strong group identity is created people with stigmas may be more expected to attribute outcomes to prejudice (Miller and Major 2000: 260). The voices of a group are stronger than voices of solitary women's despair. However, the effects of a HIV status and the workshops at ICW seem to transform the women from marginal positions into a highly specific discriminated-against group (Berger 2004). Social psychologists believe that stigmatized groups are more likely than non-stigmatized groups to report that they personally as well as members of their group have more frequently been victims of discrimination (Miller and Major 2000: 248).

The educational workshops on discrimination and human rights make the women change to a sense of "believing in a just world" which the girls living in the street do not share (Heatherton et al 2000: 78). Stigmatization and discrimination of women with HIV/AIDS is the threat the women will strive to change. With the voices and feelings of victims they want to show the injustice in Nicaragua and also that they are morally pure. The stories and feelings of stigmatization and discrimination create a new social identity (Heatherton et al 2000: 89).

At the workshops the women receive a T-shirt with the name of the organization and with words showing their HIV/AIDS status. The T-shirt makes the women look alike and they express feeling proud of wearing the T-shirts. The women are now members of an important group and they have a new goal and mission with their lives.

"*What one does find is that the members of a particular stigma category come together in small groups whose members all derive from the category, these groups themselves being subject to overarching organization to varying degrees…"*(Goffman 1963: 23).

As mentioned in the last chapter the women suffer from remarkable unawareness of what stigmatization and discrimination mean before they join the meetings with themes such as *"stigmatization and discrimination"* and *"human rights."* After attending the different workshops on discrimination it appears that the women feel more like victims than before.

It is noteworthy how stigma shifts during the women's life course. When entering ASONVIHSIDA the women were depressed and had difficulties accepting their status (from my interviews with new members). Interestingly, the stories of newly recruited members focus more on fear and cover up stories as mentioned in earlier chapters while older members give voice to strong feelings of discrimination and stigmatization in different public spheres.

9.3. Recruitment of women with HIV/AIDS

All the women have been contacted by the centre director after they received the answers from a positive AIDS test. The centre leader Arely Caño explains how she asks the different health clinics to collect the phone numbers of the women when tested HIV positive so that she can call them and persuade them to come to the centre. One of the diseased women tells about her first meeting.

> Alicia, 30 years old: - *When Arely called me I didn't want to go to the centre. I just wanted to continue my normal life the best I could. I wanted to be alone. She convinced me to come to the centre. Finally I agreed. When I came to the centre and attended a workshop for women I realized that I was not alone…They are like my sisters.*

The women who have joined the centre for a longer period take good care of the new members of the group and encourage them to share their feelings and experiences with the older members or/and the centre psychologist who is in charge of some of the workshops on stigma and discrimination. Knowing from their own experience what it is like to have this particular stigma, they can provide the new members with instruction on the "tricks of the trade" and provide a circle of lament where they can withdraw for moral support and for the comfort of feeling at home, at ease and accepted as a person like any other normal person (Goffman 1963: 20).

"In the case of the individual who has recently become physically handicapped, fellow-sufferers more advanced than himself in dealing with the failing are likely to make him a special series of visits to welcome him to the club and to instruct him in how to manage himself physically and psychically" (Goffman 1963: 36).

It is important to have as many members as possible as in any other club in order for the association to survive, even though the association is created to help the women. Membership of ICW in Nicaragua is free of charge. However, everything has its price. The women have to reveal their stories of despair in the Friday circles or they might get rejected by the other members or maybe even from the circle. Their stories are like an invisible threat binding the women's lives together. Their voices of despair and victimization are their membership fee and ticket into the new club – their new society and new family.

9.4. Power or empowerment?

ASONVIHSIDA uses different empowerment approaches to strengthen the women's position. Every Friday the women attend a psychological workshop where they reveal their problems which make them feel equal and autonomous. The centre hosts different workshops for the women. However, not all the women attend the same workshops.

The women experience a "rite of passage" where they finally accept their new identity from being "normal" to having a deviant character which makes them feel normal again within the group of equals where the women do not need to cover up their illness anymore, which is a big relief for them (Kottak 2002: 455).

Empowerment is thought to be achieved through participation (Kornberg & Datta 2002). The women tell that their self-esteem has increased due to the activities at the centre. Some of the women tell that they are more confident in claiming their rights such as to notify any discriminating person about law 238 and that they will sue him or her. The women tell that within the Nicaraguan society people are not aware of the existing law. When the women reveal the law to unknowing and discriminating persons (especially at health clinics) they will often receive apologies. Further the women learn about the patriarchal ideology. However it didn't seem as if the women are given any tools to transform these structures even though the tone inside the circles often is very male inhospitable. So in this way they have become very conscious about power relations.

Empowerment is to be seen as a way for people to participate and produce changes (Cornish 2006). However, it was not clear if all of the women were equally strengthened and how long this process would take them. It is only a few numbers of women – about 20 – who received economic help when receiving salaries working as peer educators. It is not receiving salaries which is empowering but their capability of being active and working for the course of the centre which is the empowering act (Rowland 1998). Working also leads to a higher self-esteem in the women. But it did not appear as if the women had the same level of motivation and participation at the centre. This was either due to stages of illness and where they lived in the country. The women residing near the capital were capable of participating to a wider extent than the women living in marginalized areas.

Some of the older members are asked to work as “educators.” This title give them salary and status. However, this also creates a hierarchy of power at the centre since the women not working as educators will strive to receive this title. Most of the women have never worked before and the salary working as an educator is a big income in the women’s lives. In this way the women are given power with a new title but this title can be taken away from them again.

As I see it there is a severe problem at the centre that if the women are not capable of attracting donor money then they will loose this type of empowerment or support. It seems like there exists a ladder of empowerment where the women who have been at the centre for a longer period and have experienced the rite of passage from “I” to “we” are being empowered (Cornish 2006). Though, the only way of measuring empowerment comes from the women’s phenomenological stories of feeling more confident and their capability of taking collective action. However, Flora Cornish states that empowerment should not be seen as a feeling of confidence or a sense of mastery but more as an ability to take action such as giving voice to their misery (Cornish 2006: 305). The women are certainly capable of this but it is uncertain if it will lead to any good for them. The group activities are mostly long term projects working to change the political system when raising awareness about the poor situation for the women. It is not many of the women who will experience these changes before the disease take over their lives.

The criteria for selecting the 20 women working as educators have not been quite clear. Were they chosen due to their physical or emotional well being? Or because of their level of motivation and dedication at the centre? Or did the choice fall on the women with the biggest voices? It appears to be the women who already posses power who are given more power at the centre and it becomes visible that this power will be taken from the women if excluded from the centre in any way. At the support group meetings the women are encouraged to give voice to their feeling of being victims of HIV/AIDS and as I see it they are actually being taught how to be a victim. This is important in order for the centre to survive and to attract the attention of donors. Even though I argue that the women are being empowered I do not se the process to be very critical. The women are more undertaking a course of misery on how to create identities as powerless victims.

Flora Cornish (2006) states that it is important to look at the kind of action the women are empowered to take. At ASONVIHSIDA they are taught how society perceives them and how they are disqualified according to moral standards. They learn about international human rights and how to use them when they are up against any discrimination. They experience how they have been passive victims in a male dominated society. They have been empowered through more knowledge and information. But what do they really need all this information for?

The women reveal that one problem is the promotion of condoms when working as educators. They give voice to fear when talking about the Catholic Church's reaction. Even though they recognize that condoms are important it seems less important than keeping a good relationship to the church.

> Carlota, 42 years old: - *Actually each brochure we hand out promotes the use of condoms. The church says that condoms are a way of giving freedom to young adults. I don't like to hand out those brochures in my neighbourhood. The problem is that people from the Church will get angry with us. The Church does not accept it because it means that a person is promiscuous.*

The women state that they do feel better after entering the support groups. However, it appears that the women are supposed to be able to "play the game" of attracting donors in order to actually be empowered.

9.5. Voices of stigma as a tool of empowerment

Social psychologists acknowledge that expressions of ones thoughts and feelings about a particular stressor are an important instrument in self-empowerment (Smart and Wegner 2000: 237). The women's stories are both used as a tool for the women to raise awareness about difficult issues disempowering the women and to improve their quality of life. Though, their stories of victimization are also used for what Goffman quotes as "secondary gains." *"Finally the person with a shameful differentness can break with what is called reality, and obstinately attempt to employ an unconventional interpretation of the character of his social identity. The stigmatized individual is likely to use his stigma for secondary gains…"*(Goffman 1963: 10).

Social psychologists see perceptions and behaviors as social phenomena. In this way they state that when individuals perceive that their likelihood are being threatened in terms of stigmatization and destruction of an individuals identity, then they will exaggerate their perceptions – such as blaming other people – and share the belief with others (Heatherton et al 2000: 75). This can be a process the person is aware of but most likely not. It is doubtful whether the women are aware of how they use their stories of victimization and for what gains.

Unknowingly the women become part of the "development game." They are pieces in a puzzle needed in order to attract donor money. The charismatic leader Arely Caño is a front figure all the women look up to. She started the organization as one of the first women to come forward as HIV/AIDS positive and has during the last years been in the spotlight as a strong spokeswoman – leader with followers who all wants to claim justice. During the self-identity process the women's feelings and experiences of stigma and discrimination grew stronger than before. Feeling more secure and accepted the women are able to take action to change their lives and the lives of other victims of HIV/AIDS. Nonetheless, it is not for sure if the women will keep this state of empowerment (Rowland 1998).

Stigmatization and discrimination manifest in a wide range of community contexts. This includes: family, work place, health services, religion and media. The women's participation in ICW reduce both felt and enacted stigma by "normalizing" and personalizing the experience of HIV/AIDS. Further, the support group meetings create a common identity of standing and fighting together for a common course – for equal rights. But as I see it the women are also to a wider extent being labeled as victims than before entering the support groups.

Being the only organization supporting women with HIV/AIDS in Nicaragua the centre leaders tell that it is still difficult for them to attract donor money. Their activities are only supported for a few years by one or two donors so they really need to find other donors to financially support their activities. Without money the organization cannot survive but most donors will not support non-preventive activities. If the organization cannot attract donors the women will lose their economic empowerment and maybe their newborn identity too.

10. Summary and conclusions

This thesis has strived to understand how and why Nicaraguan women with HIV/AIDS feel being stigmatized and discriminated and further in what way they use their single voices of despair in togetherness with equals to achieve empowerment and secondary gains.

In Nicaragua there is an alarming tendency of rising infections of HIV/AIDS especially among housewives and I have revealed this tendency to be 1: due to a machismo culture where women are unable to protect themselves and 2: but also to moral codes made by powerful public moralizers such as the Catholic Church.

I have described how the Catholic Church has a strong impact on the Nicaraguan society and intervenes in any HIV/AIDS preventive campaign seen as evil forces. The clerical assembly use strong symbolic pictures to keep social and moral order and moral education at schools are still emphasized over sexual education. Many of the diseased women believe that AIDS is a punishment from God they have deserved.

Through this thesis I have showed that stigmatization in Nicaragua is not only to bear a visible and physical stigma but also a moral one which automatically discriminate and label the women as promiscuous when afflicted with HIV/AIDS - no matter how they actually contracted it. The women express through their narratives that the contagion of the disease was out of their control and that they were given it unknowingly about what it was or how to protect against it. I believe that the women in this way try to avoid additional stigma by raising sympathy by presenting themselves as innocent victims and claiming moral standards. This is also a way for them to cope with the disease. However, they understand that when first receiving a stigma and a so-called spoiled identity label, this will most likely follow them through the rest of their lives.

The problem in Nicaragua is that discrimination and fear of stigmatization affect transmission patterns and contribute to determining the success or failure of prevention and care support efforts. Nicaragua has a wide web of NGOs and international organizations working to prevent the spread of HIV/AIDS but not a lot of organizations are supporting people already affected. As seen, fear of discrimination and stigmatization make people with HIV/AIDS stay in the dark. The women express fear of going public with the disease and fear of getting treated because they presume to experience high levels of discrimination and stigmatization at especially health care settings.

My study has not been to deny that women are stigmatized and discriminated but rather to understand how the women cope with felt and enacted stigma. As shown from my interviews with the women, fear of rejection by the dominant society make them lie about their status and change social networks to groups with the same deviant character – even before experiencing any discrimination from close associates. It is important to note that awareness about what stigma and discrimination means mostly occur after entering the support group. The women first become aware about prejudiced terms when learning about it at the centre. Here they receive information about the injustice in Nicaragua towards women with HIV/ AIDS and knowledge about the anti-discrimination law 238. And they actually learn how to be a victim of a social disease. Not to say that women were not stigmatized before, they did just not know what it actually meant.

Through my observations at the centre ASONVIHSIDA and ICW it became obvious that strong feelings inside the support groups create a collectivity of highly discriminated and stigmatized against women. The women feel even more stigmatized after attending the support group meetings and activities than they did before getting in contact with the centre. Their voices are a membership to the new club and in that way connecting the women but as I see it the women have to participate actively with stories of stigma and discrimination in order to stay inside the circle.

Another important conclusion of this study is that when the women experience a “rite of passage” through the many supporting meetings they create a new purpose in life with a new “justice in the world” view and a mission to combat any discrimination and stigmatization. Some of the perhaps most active and most motivated women will receive salaries to work as educators. However, I noticed how this creates a ladder of power and jealousy between the women.

From the interviews the women express that they feel more secure and accepted and that their self-esteem has improved when being at the centre and in this way they have become empowered from within. Even though the women are afraid of working against the Catholic Church by handing out HIV/AIDS preventive brochures about protection via use of condoms it is still believed that collective actions are the most effective ways to gain political awareness and change such situations in Nicaragua. However, it was not clear how the women really coped being in the middle of the morality of the Catholic Church and the international AIDS preventive campaigns.

What I find interesting is that the women will more or less knowingly use their voices as a tool to achieve secondary gains. The centre receives only donor money for a limited period of time and it is of greatest importance to find and attract new donors for the organization to survive. The women’s voices are used as a powerful tool to attract donor money and by this to be empowered economically. However, when empowerment is given economically by international donors it can easily be taken away from them again.

It is uncertain if the women will be able to free themselves from any feeling of being stigmatized no matter whether the organization and its activities are economically supported or not. Is the organization unable to attract money then the women will drop out one by one starting with the least strong. When not having somebody to lean on they are on their own again and this might lead to the very return of the vicious circle of stigma.

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