"THIS IS TOBAGO"
SOCIAL AND CULTURAL 'INFLUENCERS' OF HIV INFECTIONS IN TOBAGO

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INTRO: In Tobago, HIV rates continue to increase (prevalence rate ≈5%). Women and youth are increasingly being infected, and heterosexual transmission accounts for most HIV infections. If these trends continue, Tobago's economic and social structure will be in jeopardy. This study has public health significance because it identifies and makes recommendations for incorporating relevant social and cultural factors into HIV prevention programs in Tobago.

METHODS: Qualitative methods (participant observations, ethnographic and in-depth interviews) were utilized to unearth (a) pre- and post-HIV infection experiences of People Living With HIV/AIDS (PLWHAs), (b) relevant cultural and social "influencers" of HIV/AIDS rates, (c) how these factors influence community norms and individual behavior, and (d) appropriate methods/model for incorporating relevant factors into HIV/AIDS prevention programs. PLWHAs, health professionals, community members and leaders were interviewed.

RESULTS: 14 PLWHAs, ≈ 10 health professionals, ≈ 15 community leaders and ≈ 25 community members were interviewed. Participant observations occurred in homes, businesses, entertainment events, HIV-related organizations and health facilities.

206 PLWHAs are currently being treated in Tobago (HIV-related medications free to Trinidad and Tobago citizens). Infidelity, sex-in-exchange for resources, abuse and economic need increased PLWHAs' HIV risk. Lack of confidentiality is an issue, and stigma and discrimination are prevalent.

There is lack of information about the causes, prevention and treatment of HIV in the general population. Sex is not openly discussed, however youth sexual behavior is common. Serial monogamy coupled with multiple sexual partnering increases general community risk. Consistent and correct condom use is not common, and purchasing or requesting condom use is difficult for women, youth, and married individuals. HIV testing is not common, and pre- and post-test counseling is inadequate. Current HIV prevention programs focus on abstaining, being faithful and using condoms, which do not take into account the complexities surrounding sexual decision making. There is a need for comprehensive HIV prevention programs.

RECOMMENDATIONS: A client-centered, risk-reduction model of HIV prevention is recommended. Using the socio-cultural theory of learning, this study highlights the zone of proximal development, the knowledge-in-waiting, knowledge-in-use, agents of change, needed resources, and social environment needed to improve HIV prevention strategies in Tobago.

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PREFACE

This has been a process – life is a process. Part of the process includes touching, and being touched by various individuals. I take this opportunity to publicly thank those individuals who touched my life and contributed to my process. To each of you, I say *Asante Sana* (thank you very much).

To the teachers whose advice guided my success. Mrs. Broomes who told me to "hit them back", Mrs. Dick and Mrs. Melville who believed in my ability from an early age, Mrs. Carrington and Mrs. Prescott who made Roxborough Secondary School the best school in Tobago, Mr. Garth James who told me to "look at how he treats his mother and his sisters" and Mr. James Jack who knew that we could do it, and worked very hard to ensure that we were a success – Saturdays at your house made history worth knowing. Life is a process.

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In Loving Memory Of Mambu Kawa

Thanks for getting lost on the bus so that we could meet.

Thanks for allowing me to lie on your couch, eat, watch TV and sleep.

Though you may not have known it,

You've helped me through it.

Life is a process (and unfortunately so is death).

MAY YOUR SOUL REST IN PEACE

1.0 INTRODUCTION

1.1 MY INTRODUCTION TO "IT"

We knew he had "it", but no one knew exactly what "it" was. We knew that he was gay and that all of his boyfriends had died from "it", but no one really knew what "it" was. The term "healthy carrier" was floating around, but I didn't know what that meant. The 'he' in this story is a close family friend in Tobago. My first introduction to HIV was hearing my family members gossip about him and the dreaded disease that only gay men had. Then "it" got closer. A female friend of mine, had just moved to another country. To gain entry, she had to have an HIV test done. This was very traumatic because she had just found out that her last boyfriend, the first guy she was sexually active with, was sexually active with a girl who had "it". Luckily, she didn't have "it". Then "it" got even closer. A family member came to our house because she had "it". She was kicked out of her house because they didn't want "it" living with them. Still, no one knew what "it" really was, but suddenly "it" was living in my house. We didn't want "it" living with us either, so we sent her back to her house, 'where she belonged'. These three cases served as my introduction to HIV/AIDS in Tobago. This dissertation represents the deepening of my understanding of this disease. In this work, I finally begin to learn what "it" is, who "it" is, where "it" happens and most important, why "it" happens to the people of Tobago.

1.2 BACKGROUND/OVERVIEW

According to the Joint United Nations Programme of HIV/AIDS (UNAIDS), approximately 38.6 million people were living with HIV/AIDS in 2005, with approximately 4.1 million becoming newly infected in 2005 [1]. Second only to sub-Saharan Africa, the Caribbean has an adult prevalence rate of 1.6%, which represents approximately 330,000 People Living With HIV/AIDS (PLWHA) [1]. Women represent approximately 51% of these documented cases [1]. HIV/AIDS is the leading cause of death in the 15 - 44

age group in the Caribbean [2]. In the Caribbean Epidemiology Centre (CAREC) reporting countries[1] the incidence rates of HIV continue to grow, increasing from approximately 2 per 100,000 in 1982 to approximately 2662 per 100,000 AIDS cases in 2000 [3].

In the twin island state of Trinidad and Tobago (population 1,262,366 [4]), there were approximately 27,000 (estimated range of 15,000 – 42,000) PLWHAs by the end of 2005 [5], while according to the Ministry of Health, up to December 2005 approximately 3,380 people had died from AIDS-related illnesses [6]. The yearly national incidence has been steadily increasing from approximately 200 in 1988 to approximately 1600 in 2004 [7]. Forty-five percent of all new HIV cases occur in females, while 70% of new infections among 15 – 24 year olds occur in women in Trinidad and Tobago [6]. In addition, approximately 3,600 children were estimated to be orphaned by HIV/AIDS from the inception of the disease in the 1980s up to 2001 [8]. The prevalence rate in Trinidad and Tobago (approximately 2.25%) is significantly higher than the overall world rate of 1.0% [1] and the United States rate of 0.6% [1]. The prevalence rate in Tobago (population approximately 54,000 [9]) however, is estimated to be 100% higher than the reported rate of the country as a whole. Tobago's HIV rate is estimated to be over 5% [10].

1.3 STATEMENT OF THE RESEARCH PROBLEM

Twenty-five years after the discovery of HIV/AIDS, the scientific community agrees that being sexually abstinent, being sexually monogamous to one partner, using a condom correctly and consistently, and getting tested and treated for HIV are important arms in the fight against HIV. As the HIV infection rates decrease in many areas of the world, the rate of HIV infections in the Caribbean generally, and specifically in the small island of Tobago continue to increase. Tobago's population is approximately 54,000. If this upward trend continues, the social and economic structure of Tobago will be in jeopardy, and the degree of human suffering will significantly increase. As a result, effective prevention and treatment programs must be developed and implemented to halt and reverse the HIV infection and death rates in Tobago.

This study is a step in the development of effective HIV prevention programs by focusing on the people of Tobago, their culture, forms of social organization, and economic circumstances as they relate to

[1] There are currently 21 CAREC-reporting countries. Trinidad and Tobago is the host country, while Anguilla, Antigua & Barbuda, Aruba, Bahamas, Barbados, Belize, Bermuda, British Virgin Islands, Cayman Islands, Dominica, Grenada, Guyana, Jamaica, Montserrat, Netherlands Antilles, St. Kitts & Nevis, St. Lucia, St. Vincent & the Grenadines, Suriname and Turks & Caicos are the other member countries.

sexual health. It re-examines some of the social and cultural factors previously identified as influencers of sexual behavior, as well as identifies new aspects of socio-cultural influences on sexuality and HIV transmission in Tobago. In addition, this study examines current HIV prevention and care programs in Tobago, and makes recommendations for improving these services. In the end, by looking at both the micro and macro influencers of HIV in Tobago, this study identifies and provides a broader, more comprehensive understanding of HIV/AIDS and therefore HIV prevention in Tobago. The lessons learned from this study may also be extrapolated to other communities, where the rates of HIV continue to increase.

1.4 RESEARCH QUESTION

This study is based on the proposition that human sexual behavior is influenced by a complicated interconnection of social and cultural factors; therefore programs that try to alter individual human sexual behavior (i.e. increasing HIV preventative behaviors, thereby decreasing HIV infection risk) are most successful when these social and cultural factors are understood and incorporated into prevention programs.

1.4.1 General Objectives

- To examine some of the social, cultural, and economic factors that influence sexual behavior practices, and to determine how these factors influence HIV prevention behavior in Tobago.
- To make recommendations for prevention strategies that are comprehensive and tailored for the Tobago population, by ensuring that they address the identified socio-cultural factors.

1.4.2 Research Questions

- What are the pre- and post-HIV infection experiences (social and cultural) of people living with HIV/AIDS in Tobago?
- What are the major cultural and social factors that influence the high HIV/AIDS rates in Tobago?
- How do these factors influence (a) community norms and therefore (b) individual behavior patterns with respect to HIV prevention strategies in Tobago?
- What methods might be used to incorporate relevant social and cultural factors into HIV/AIDS prevention programs?

- What are the most appropriate models/methods for improving HIV prevention in Tobago, including but not limited to the type of information needed and the most appropriate methods of dissemination?

1.5 SIGNIFICANCE OF STUDY

Doing biomedical/social science research without the expressed purpose of improving human life (in the long or short term) is in my view, a waste of time, money, talent and other precious resources. In addition, it insults the individuals or communities for whom research is needed to improve or "develop" human life. As a result, I did this study because it has five distinct significances or contributions to HIV research and ultimately human development.

(1) The current literature highlights several social and cultural issues that influence HIV prevention strategies in several countries of the Caribbean. Very little has been written about Trinidad and Tobago, and as a result, this study is the first in-depth analysis of the culture of Tobago and its influence on HIV/AIDS. Though this study reaffirms previously identified issues, it also reveals new factors unique to the island of Tobago. Since these social and cultural factors heavily influence individual behavior, the results of this study will form the basis for prevention program development, implementation and evaluation.

(2) Secondly, this study is significant because it is the first to specifically look at the lives and experiences of people living with HIV/AIDS in Tobago. It gives a "face" to PLWHAs in Tobago by highlighting their current experiences and circumstances, in addition to the situations and circumstances that influenced their risk of infection. These issues are extremely important in the development and implementation of prevention and care programs. Unfortunately, PLWHAs represent the failures or lack of HIV prevention programs; therefore identifying and studying these individuals may be the key to successful prevention strategies in Tobago.

(3) This study explores the *emic* and *etic* perspectives of HIV/AIDS in Tobago [11]. The *emic* perspective refers to the views of the individuals whose lives we are trying to understand. This includes their knowledge, fears, gender identities, views about health, and religious beliefs for example. This is extremely important since these *emic* perspectives directly and indirectly determine whether someone uses a condom, or gets tested, or seeks treatment after getting a positive result. Another factor that is extremely important is the fact that the community members, versus the researcher identify these emic perspectives. The *etic* perspective includes other "external factors", which include economics, politics, and other macro-factors that heavily influence individual, community and island-wide HIV related

behaviors. These *etic* factors directly or indirectly influence HIV-related behaviors, therefore it is essential to incorporate these factors into HIV prevention programs.

(4) There are HIV prevention and care programs offered by the National AIDS Coordinating Committee (NACC), the Health Promotion Clinic, and other agencies on the island. This study develops an inventory of the HIV/AIDS programs currently being offered in Tobago. It also includes PLWHAs', as well as community members', views about these programs. This study provides an understanding for whom, how, when, where, and why these programs work (or don't work), which is important for future HIV prevention strategies.

(5) Finally, this study discusses new models and methods of examining HIV/AIDS in the Caribbean and other regions where conventional methods have been unsuccessful. The incorporation of (1) the expert knowledge of PLWHAs, (2) the *emic* and *etic* perspectives of the wider community, and (3) theories of behavior change not normally used in behavioral health will provide a basis for prevention strategies that are suited for the Tobago population.

1.6 RESEARCHER'S PERSPECTIVE

I am a Tobagonian[2]. For the first 18 years of my life I lived within the social and cultural milieu of Tobago, and this has influenced my worldview and therefore my sexual behavior. At first, when people spoke about HIV prevention, I quickly asked myself "why the hell don't these young boys/girls or men/women use condoms? Don't they know that having unprotected sex can kill them?" I am quickly jolted back to reality when I think about my own sexual history. In my opinion, I am a well-educated, very independent woman; however, on several occasions I have also "chosen" not to use condoms. Knowledge wasn't the issue, because I knew that consistent and correct condom use prevents HIV infections. As a result, I walked into this study with the first hand understanding that the traditional knowledge, attitudes, and beliefs models were not sufficient in HIV prevention. Since these traditional methods have failed in Tobago, my perspective is this: we need to think about sexual behaviors and therefore HIV risk reduction in alternative ways, which include incorporating the context of peoples' lives into prevention strategies.

[2] The term "Tobagonian" is used to identify individuals from the island of Tobago. Individuals from the island of Trinidad are called Trinidadians, and the collective term for the nationals is "Trinbagonian".

1.7 ORGANIZATION OF THE DISSERTATION

In this chapter, *chapter one*, I discuss my introduction to HIV/AIDS in Tobago, followed by a brief introduction of HIV/AIDS in the world, the Caribbean, Trinidad and Tobago and finally Tobago. I then identify the rationale for doing this research, the general objectives and finally the specific research questions of the study. The significance of the study is then highlighted, followed by my perspective and how it influenced this study.

In *chapter two* I discuss the literature about HIV/AIDS in the Caribbean. This includes the rates of HIV infection and the main methods of infection in the Caribbean. The concept of "structural violence" and its influence on HIV is also discussed. Other social, economic, and cultural factors are also discussed. Finally, this chapter examines gender and its influence on HIV/AIDS infections by presenting a definition of the term "gender", and examining the gender-related biases that increase females' risk for contracting HIV.

In *chapter three* I outline the methods used in this study. I discuss qualitative research and the paradigms surrounding qualitative methods. I argue that due to the goals of this study, it is best suited for a qualitative design. Finally I identify the specific research methods, which include the study population, the types of data collected, the data collection methodology, and the analysis techniques.

I present the results in the following chapters. Instead of the traditional "results" then "discussion" chapters, I present the results and discussion in "thematic chapters", where each chapter seeks to answer a specific research question. In *chapter four* I discuss the study population and settings. I create profiles for the PLWHAs interviewed, I discuss the types of community members ethnographically interviewed, and finally I discuss the settings where participant observations were conducted.

In *chapter five* I discuss the experiences of PLWHAs by identifying their sexual relationships, including the influence of economics and abuse. I discuss how they learned about their HIV infection and how that affected their ability to deal with their HIV diagnosis. I examine how they view themselves as PLWHAs, how they cope with the disease and how HIV/AIDS has influenced their lives. I delve into the levels of stigma and discrimination experienced in the PLWHA community, which includes the issue of confidentiality and disclosure in Tobago. It must be noted that I use quotes from the interviews, therefore I allow the PLWHAs and community members to tell their own stories. Finally, I discuss the treatment options in Trinidad and Tobago, and how PLWHAs view these services.

In *chapter six* I discuss the social and cultural factors that influence sexual behavior, which therefore influence HIV infections. I give a basic overview of Tobago including demographics, governance, and HIV-related statistics. I then discuss the views about HIV in Tobago, the types of sexual relationships common, condom use and views about condoms, abortions, pre- and post-test counseling,

and finally the protective services and their influence on HIV infections. I conclude the chapter by discussing how all of these factors influence HIV infections in Tobago.

In *chapter seven* I first discuss the literature about HIV prevention in other Caribbean countries, then I identify the prevention programs currently occurring in Tobago. In the end I discuss the pros and cons of these programs. In *chapter eight* I make recommendations for HIV prevention strategies in Tobago. I discuss the need to move towards a "client-centered, risk reduction model" for HIV prevention. Finally I use the Socio-Cultural Theory of Learning to guide my recommendations for HIV prevention strategies, these include highlighting possible zones of proximal development, the type of information needed in Tobago, the specific skills required, the possible agents of change, the available resources need for effective HIV prevention and finally the social environment that is conducive to healthy sexual behavior.

Chapter nine, the final chapter is a synopsis of the study. It includes a brief summary of the findings, highlighting the most important factors. I also discuss the why qualitative methods were ideal for this type of study, including limitations of the methods and the study. Finally I identify possible suggestions for future HIV prevention research in Tobago, followed by a review of the positive attributes of Tobago.

2.0 REVIEW OF LITERATURE

2.1 WHY IS THIS IMPORTANT?

An age-old cliché states that if one does not know his history, he is likely to repeat the mistakes of his fore-parents. This literature review is in essence a history of HIV/AIDS in the Caribbean. It highlights the rates of HIV and the main methods of infections in the Caribbean. In addition, it reviews some of the social and cultural factors previously identified as influencers of HIV in various Caribbean communities.

2.2 HIV/AIDS IN THE WORLD, THE CARIBBEAN, AND TRINIDAD AND TOBAGO

At the end of 2005, the Joint United Nations Programme on HIV/AIDS (UNAIDS), in conjunction with the World Health Organization (WHO) reported that approximately 40.4 million people were living with HIV/AIDS (PLWHA) in the world. Of those, 17.5 million were women and 2.3 million were children. Close to five million people were newly infected in 2005, while 3.1 million AIDS related deaths occurred in 2005. The largest proportion of those infected resided in sub-Saharan Africa, where 25.8 million people are currently living with the disease. The overall adult prevalence rate in sub-Saharan Africa is approximately 7.2 percent [12].

Second only to sub-Saharan Africa, the Caribbean has an adult HIV prevalence rate of 1.6% [12]. The first cases of HIV/AIDS were diagnosed in 1982 [13] in Jamaica [14]. There are approximately 300,000 PLWHAs in the Caribbean, of which 240,000 are living within the Caribbean Community and Common Market (CARICOM)[3] region. Voelker however, suggested that due to under-testing and underreporting,

[3] The Caribbean Community and Common Market (CARICOM) is an association within the Caribbean that was created to provide a continued economic linkage with countries within the Caribbean Sea. There are 15 full members (Antigua and Barbuda, Bahamas, Barbados, Belize, Dominica, Grenada, Guyana, Haiti, Jamaica, Montserrat, Saint Kitts and Nevis, Saint Lucia, Saint Vincent and the Grenadines, Suriname, and Trinidad and Tobago), five associate members and seven observers.

this number was closer to 500,000 [15], while the World Bank in 2000 estimated that underreporting of HIV and other STD rates varies between 30% and 75% in the Caribbean [16]. Thirty thousand new infections occurred in 2005, and 24,000 people died from AIDS related illnesses in 2005 [12]. There are about 140,000 documented cases of women living with HIV/AIDS in the Caribbean, and HIV/AIDS is the leading cause of death in the 15 - 44 age group [2]. Youth, aged 10-24 make up 30% of the total Caribbean population [17]. The national prevalence rate varies for individual countries. It is estimated to be over one percent in Barbados, Dominican Republic[4], Jamaica and Suriname, over two percent in the Bahamas, Guyana and Trinidad and Tobago, and over three percent in Haiti [12]. The incidence rate has grown in the Caribbean, increasing from approximately 2 per 100,000 in 1982 to approximately 2662 per 100,000 AIDS cases in 2000 [3].

As previously stated, in the twin island state of Trinidad and Tobago (population approximately 1.2 million [4]), there were approximately 27,000 PLWHAs by the end of 2005 [5], while according to the Ministry of Health, up to December 2005 approximately 3,380 people had died from AIDS-related illnesses [6]. Forty-five percent of all new HIV cases occur in females, while 70% of new infections among 15 – 24 year olds occur in women in Trinidad and Tobago [6]. In addition, approximately 3,600 children were estimated to be orphaned by HIV/AIDS from the inception of the disease in the 1980s up to 2001 [8]. The prevalence rate in Trinidad and Tobago (approximately 2.6%) is significantly higher than the overall world rate of 1.0% [1] and the United States rate of 0.6% [1]. The prevalence rate in Tobago (population approximately 54,000 [9]) is estimated to be 100% higher than the reported rate of the country as a whole. Tobago's HIV rate is estimated to be over 5% [10].

2.2.1 Modes Of HIV Transmission In The Caribbean

HIV is transmitted via the exchange of bodily fluids. There are three routes of HIV transmission: (1) sexual contact, (2) blood or blood products and (3) mother to child [18]. In the Caribbean, sexual intercourse has been listed for 75% or more of the reported cases. The majority of these identify heterosexual contact, while approximately 12% indicate homosexual contact [12 (p. 53)]. Injection drug use is not prevalent in the Caribbean, and therefore has not been associated with HIV infections (except in Bermuda and Puerto Rico). Crack-cocaine and marijuana use have been associated with HIV infection, however only as they are linked to sexual contact (sex in exchange for money or drugs and unprotected sex with multiple partners) [18, 19]. Screening of blood began in the Caribbean in 1985 and by 1989 all 19-CAREC-reporting countries had facilities for initial blood screening [16]. By 1994, 19 Caribbean countries had instituted HIV testing in blood banks, hospitals, public health facilities, or reference laboratories, as a

[4] Not to be confused with the island of Dominica, the Dominican Republic shares the island of Hispaniola with Haiti. Dominica on the other hand, lies within the Caribbean Sea, about one-half of the way between Puerto Rico and Trinidad and Tobago. See figure 1 below.

result, HIV infections due to blood transfusions is not significant in the Caribbean [13]. Mother-to-child transmission accounts for approximately 6% of the reported HIV cases in the Caribbean [20].

Figure 1: A Map of the Caribbean
The islands printed in red represent independent states, while those printed in black indicate a colonial relationship (with the colonial power listed in parentheses). The islands of Trinidad and Tobago are identified via a red circle [21].

2.3 FACTORS THAT INFLUENCE THE EPIDEMIC IN THE CARIBBEAN

Though the disease, HIV/AIDS, is transmitted via biological agents (the Human Immunodeficiency Virus), there is increasing evidence that other external factors directly or indirectly influence the rates of HIV transmission [22, 23]. Social, economic, and cultural factors influence behavior patterns, vulnerabilities, expectations and norms, which in turn influence people's actual risk for infection, their perception of their risk, and their ability to protect themselves. These complex interconnections can also be seen in the Caribbean, where unlike other places, the correlation between HIV rates and economic indicators is minimal. For example, the HIV rates are highest in Haiti where the income per capita is very low, however the rates are also very high in the Bahamas and Turks and Caicos, where the per capita income is very high [14]. Income therefore is not the only factor that influences HIV rates. As a result, several authors [24, 25, 26, 27], including Lewis *et al* (1997), while writing on behalf of the Pan American

Health Organization (PAHO), stated that interventions should "address the complex factors that [holistically] influence sexual behaviours" [13 (p. 279)]. Though these "complex factors" vary from island to island, there are several factors common to CARICOM and other Caribbean countries. These common factors are explored below; however *structural violence*, a model used to explain how these factors interact, is first discussed.

2.3.1 Structural Violence

Structural violence is a term frequently used to explain the causes and consequences of the disparity seen with respect to disease prevention, acquisition, and subsequent care [28, 29]. HIV/AIDS, due to its uneven infection rates (overwhelmingly high rates in underdeveloped or developing countries), has also been explained using this concept [30]. Structural violence is a term coined by Galung in the late 1960s [29], and further explained by Weigert in the late 1990s [28]. It refers to "preventable harm or damage … where there is no actor committing the violence, or where it is not meaningful to search for the actor(s); such violence emerges from the unequal distribution of power and resources or, in other words, is said to be built into the structure(s)" [28 (p. 431)].

Castro and Farmer, specifically used this concept to explain the uneven distribution of HIV/AIDS in Haiti [31, 32]. The uneven distribution of HIV/AIDS infections, is the "preventable harm or damage" in this setting. While the "uneven distribution of power and resources" refers to the existence of racism, sexism, political violence, poverty and other social inequalities experienced in the history, social structure and economic context of the community. As documented in the literature, these factors together correlate highly with the HIV/AIDS infection rates. According to Castro and Farmer, "together [these] social forces determine" [31 (p. 55)] HIV infection, along with the resulting stigma associated with the disease. These "social forces", as they relate to the Caribbean context are discussed below.

2.3.2 Economics

HIV/AIDS and impoverishment/poverty are highly correlated. In fact, impoverishment is the single most predictive criteria of high HIV/AIDS rates in the world. According to Krieger, to be impoverished is to "lack or be denied adequate resources to participate meaningfully in society" [33 (p. 695)]. There is a reciprocal relationship where the most impoverished individuals are most affected by HIV/AIDS [34], and individuals who are HIV positive tend to become poorer as a result of the infection [35, 36]. In addition to the financial effect of the disease on individuals, the financial resources needed to combat HIV results in these countries/regions becoming more impoverished [2, 37, 38]. In a report of the Pan American Health Organization (PAHO) published in 1997, mathematical modeling estimate that the total cost of the epidemic for the Caribbean region will be approximately $500 - $1,200 million USD, or two to five percent of the gross domestic product (GDP) [13].

As under-developed and developing countries become increasingly incorporated into the global market economy, money must be exchanged for food, clothes, health care, education, and technology, among many other necessary items. As a result, when money or other means of exchange are not available, choices must be made at the individual or higher levels that can have negative effects on HIV prevention and the subsequent care of infected individuals. Several of these "choices" are discussed below.

2.3.2.1 Economic Change and the Need for Migration

The economic structures of Caribbean countries vary due to several factors. According to Ramkissoon (2002), the factors that foster good economic development within the Caribbean include a higher degree of openness to trade; economic structures based on tourism, offshore finance sectors, natural resources and geography (beaches, forests, proximity to the United States); political stability; and cultural and societal cohesion [39]. While countries like the Bahamas, Antigua & Barbuda, St. Kitts & Nevis, and Trinidad & Tobago have experienced flourishing economies due to these favorable factors, the economies in countries like Jamaica and Haiti have not experienced that type of success. In fact, Haiti has been plagued with political unrest and natural disasters (droughts, hurricanes, land erosion) [40], while Jamaica has experienced extensive gang violence associated with drugs and politics.

This economic hardship has resulted in individuals needing to migrate for work [26]. Contrary to other regions of the world, in the Caribbean both men and women migrate for work (within and outside the Caribbean) [41, 42]. However since individuals migrate by themselves, they participate in behaviors that increase their risk of HIV infection. For example, studies have shown that migrant workers engage in casual sex with multiple partners, engage in sex with prostitutes, and have serial or concurrent sexual partners for economic gains [16, 26, 43, 44, 45]. This migration for work, and its influence on HIV infection is seen extensively in Haiti, which is the poorest of the countries within the Western Hemisphere [46, 47] and has the highest HIV prevalence rate in the Caribbean (over 3%) [18].

The migration of Haitians occur within the country (rural to urban) [31] and outside the country (to the Dominican Republic and the United States) [26, 44, 48]. Family members migrate for long periods without the accompaniment of their spouses. As a result, casual sex or sex with prostitutes is common. Brewer *et al* (1998) reported that in *bateyes*[5] in the Dominican Republic, the HIV prevalence for individuals who migrated with a partner was 4.2%, while the rate for those who migrated without a partner was 11.4% [26].

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[5] *Bateyes* are communities that are within or very close to sugar cane plantations in the Dominican Republic. The vast majority of workers on *bateyes* are poor, uneducated Haitian immigrants or Dominico-Haitians resulting from the unions between Haitians and poor Dominicans (the verb used to describe people from the Dominican Republic – but it is also used to describe people from Dominica).

In the Brewer study, the HIV rates in the *bateyes* (approximately 5.3%) were comparable to the rates in men who have sex with men (MSM), commercial sex workers (CSW) and prisoners in the Dominican Republic. In this study, the HIV prevalence rate for self-described prostitutes was approximately 23% [26]. Only 3.2% of the participants used a condom during their last sexual encounter, and the prevalence of other sexually transmitted diseases (STDs) were also relatively high (18.3% for syphilis and 35.1% for Chlamydia, gonorrhea or trichomonas) [26].

From these limited studies of the Caribbean migrant population, it is apparent that the population is at increased risk for contracting HIV and other STDs. As a result, understanding the issues that promote migration (without spouses or other family member) and the specific situations of migrant workers while they are away from their families is critical to the development of effective HIV prevention programs.

2.3.2.2 Sex Tourism

In 2002, over 19 million tourists visited the Caribbean from the United States, Canada and Europe. Five million of those visited CARICOM countries [49]. The economics of many Caribbean countries is fuelled by tourism. In the Dominican Republic for example, tourism accounts for one-fifth of the gross domestic product [50]. The economic situation of many Caribbean islands, coupled with the foreign currency exchange rates makes tourism lucrative for gaining much needed financial resources for Caribbean countries. For example, one United States dollar is equivalent to two Barbados dollars, six Trinidad and Tobago dollars, 33 Dominican Republic Pesos, 42 Haitian Gourdes or 65 Jamaican dollars [51]. These popular tourist destinations are known for the beautiful sand, sea, and sun. They have however, increasingly become known for an additional attraction – sex.

In Trinidad and Tobago, both local men and women engage in sex with tourists, either for cash or other goods. The women are known as prostitutes or escorts, while the men are known as "beach boys" [52]. In some circumstances sex tourism is facilitated by "travel agents", hotels, and guest houses (club prostitution, escort services and residential commercial sex workers [53]). The trade also occurs within informal settings [52]. Sex tourism is usually not accompanied by safe sexual practices. In 1995 a Swiss visitor named Simonetta was deported from Trinidad and Tobago after she announced on a national news program that she was HIV positive and had unprotected sex with several locals while in Tobago. This announcement was ignored and many of the men with whom she had sexual intercourse did not get tested. Even after the Simonetta scare, the sex trade continued in Trinidad and Tobago [54].

In a study done in the Dominican Republic, 39% of the tourists polled as they departed the country stated that they perceived themselves to be at increased risk for contracting HIV on vacation compared to when they were at home. This number was significantly higher for tourists traveling alone (53% traveling alone versus 38% traveling with company). In this same study, 17% of the hotel workers

surveyed indicated that they had sexual relations with tourists (29% male workers, and 5% of the female workers). The difference between the percentage of male and female workers who had sex with tourists was due to the high proportion of male musicians who indicated sexual relations with tourists (52% of the male musicians). The hotel workers reported very high condom use (95%) when having sex with tourists, however only 8% reported condom use with a regular partner [50].

A review of the literature, done by Rogstad (2004), reported that data collected at STD clinics in the United Kingdom showed that 21% of individuals with syphilis and nine percent of individuals with gonorrhea reported sexual contact "abroad" within the preceding months. Up to 66% of these individuals did not use condoms consistently [55]. In addition, 32% of medical students surveyed in another study indicated sexual encounters with a new partner while on vacation. There seemed to be equal proportions of men and women acknowledging a new sexual partner while on vacation [55]. These studies highlight the high incidence of casual, unprotected sex that occurs during vacations, resulting in STD transmissions.

Sex tourism has been identified for the increased HIV infections in Tobago and other Caribbean islands [54]. The freedoms associated with being on vacation on an "island paradise", in conjunction with the liberal use of alcohol and drugs, and the subsequent impaired judgment, perpetuates risky sexual behavior including casual sex with multiple partners and the use of commercial sex workers [52].

2.3.2.3 Social/Family Structure

Due to the changing economic structure, and the need to migrate for work, the structure of Caribbean households continues to change. Generally, in developing countries, women are increasingly taking the responsibility of managing the household, and maintaining a stable source of income for the family [27]. As a result, women increasingly participate in the workforce [56]. In many instances in the Caribbean, women have become the head of the household, and sole breadwinners [57] because they are single parents or because their spouses have migrated. In addition to accepting the role of head of household, and financial breadwinner, women generally are expected to continue with their traditional roles of being caregivers [57]. In developing countries, like developed countries, women are compensated at lower rates compared to men, consequently a woman's final net salary is usually not enough to meet the needs of the family. As a result, the female head of the household usually relies on other means of income, including sex for the exchange of goods [58].

In addition to the head of the household exchanging sex for resources, many younger girls get into relationships with older men because they can provide needed resources. In some cases the family encourages this type of relationship since they benefit from getting food, or because the families are no longer responsible for providing the girls' needs. Since these men are older, many have been previously infected from prior relationships and they therefore infect the younger girls [59].

This need for male financial support directly impacts the number and types of unions seen in the Caribbean. For example, in Jamaica there are extremely high levels of *common-law marriages* and *visiting* relationships. *Common-law marriage* is the name given to the union of unmarried couples who live together, have sexual relations, and care for children within the home [27]. The legal system does not sanction these unions, however, recent legal cases within Trinidad and Tobago have recognized *common-law marriages,* giving common-law wives rights similar to marriage wives. *Visiting relationships* on the other hand are sexual unions, not living together, also frequently resulting in children [27]. In one study of working women in Jamaica, 17% were in visiting relationships, 40% in common law marriages and 9% were legally married [27].

Very similar to *visiting relationships*, is the concept of *plasaj* used in Haitian cultures. *Plasaj*, which literally means "placed with", is defined by "long-term relationship not formalized by a religious or civil ceremony, often resulting in children and commonly not monogamous" [40 (p. 497)]. In one study, approximately 51.3% of the women (median age of 25 years) were in *plasaj* relationships [40]. Since these relationships are not monogamous, individuals involved in *plasaj* are at increased risk for HIV infection.

2.3.3 Cultural/Traditional Practices

In sub-Saharan Africa, where the rates of HIV infections are particularly high, certain cultural practices have been identified for the increasing rates of HIV transmission. Some of these traditional or cultural practices include wife inheritance, where the widow of a male who has died due to HIV/AIDS complications is inherited by the husband's brother or other male relative [60, 61], female genital mutilation using non-sterile equipment [62, 63], and male circumcision using non-sterile instruments [64, 65]. Though these are not common in the Caribbean, a couple traditional practices appear to increase the spread of HIV/AIDS. These include the belief in "obeah" or "voodoo", and the practice of "dry sex".

2.3.3.1 Belief in "Obeah" or "Voodoo"

A large proportion of the population in Trinidad and Tobago continues to embrace and participates in many traditional African belief systems. One such system is the belief in *obeah*[6] or voodoo. Many people believe that if someone is ill or has several bad things happen to them that "somebody work *obeah"* on them. This is also the case with HIV/AIDS, as a result, when individuals show signs or symptoms of HIV infection they would visit the "bush doctor" or spiritual healer and accept their prescriptions to get better

[6] *Obeah* is difficult to explain. It consists of the belief in the spiritual world, including the idea that spirits can protect or punish individuals. Spiritual leaders have the ability to summon these spirits, and they can be used to harm or heal individuals. Therefore, when the phrase "someone wuk *obeah* on mi" (someone worked *obeah* on me) is used, it conveys the belief that an evil spell was cast on that person.

[10]. These include drinking concoctions of herbs, herbal baths, *mourning*[7] in the church, praying in specific ways or other traditional remedies. Consequently, proper care is not taken to treat HIV/AIDS or prevent transmission to other individuals.

2.3.3.2 Dry sex

Though "dry sex" is a preference associated with Southern African men [66, 67, 68], Halperin (1999) reported on the practice in the Dominican Republic and Haiti [69]. Dry sex is a practice where drying agents are used to remove the moisture from the vagina before sexual intercourse. Natural substances like *Zwanamina* (plants used in a 'love potion') and *Mutundo wegudo* (baboon urine), in addition to modern substances like *alumbre* (an industrial salt used for dyeing, purchased at pharmacies in the Dominican Republic), boric acid, commercial bactericides, Vicks and cold water are used to cause this dryness [68].

Those who practice dry sex believe that the dry vagina feels more like a virgin and therefore is preferred. Others believe that the moisture is the cause of diseases and it is thus frowned upon. Women who are moist are ostracized and are blamed for not pleasing their mates. In fact, some Haitian men residing in the Dominican Republic describe the "wet" vagina as feeling like "soft dough", "corn meal mush" or "walking in mud"[69]. Dry sex facilitates the spread of HIV in several ways. First, when condoms are used without adequate lubrication they are more likely to break and are therefore ineffective. In addition, this lack of moisture increases tearing of the vaginal walls, which produces lesions on the woman's cervix. The presence of cuts, bruises and lesions increases the probability of transmitting HIV.

2.3.4 Lack of Information, Misinformation and Stigma

2.3.4.1 Myths and Misinformation about HIV/AIDS

Although Trinidad and Tobago has a high adult literacy rate[8] of approximately 98% [8], there are many misconceptions and myths about HIV/AIDS, its transmission and prevention methods. Like the initial response in the United States, the idea that only certain people (e.g. gay men, prostitutes, immoral women) are infected with HIV/AIDS continues to resonate among many citizens of Trinidad and Tobago [10]. The disease still carries intense stigmatization; therefore to be associated with a disease that only affects "high risk groups" means that you are also "high risk"/immoral. As a result, many people do not see themselves as being at risk for HIV infections. Precautions are therefore not taken to prevent infection, nor are individuals tested after possible infections.

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[7] A specific type of prayer and fasting ritual.

[8] The adult literacy rate is defined as the percentage of men and women aged 15 years and older who can both read and write with the understanding of a short simple statement on their everyday life.

This lack of information or misinformation about HIV within the Caribbean community was reported by Gadon *et al* (2001) after interviewing migrant farm workers from Haiti and Jamaica in the United States [44]. Some Haitian men believed that HIV infection was a result of disobedience, while several Haitian women believed that a jealous mistress could "send" HIV via the husband to "infect the wife". Similarly Jamaican men believed that "germs" and "dirty blood" caused HIV. Jamaican men also believed that if you didn't ejaculate during sexual intercourse then you were not at risk for contracting the disease. Compared to African Americans who worked on the farms, the Caribbean migrants seemed to have more instances of misinformation about the disease [44]. Another study comparing the knowledge, attitudes and risk-behaviors between African-American college women and Caribbean college women (in Jamaica) found similar knowledge discrepancies. This study showed that African-American women had more accurate information about HIV/AIDS [24].

Since information about how HIV is transmitted (i.e. information about the virus, and transmission modes) is frequently incorrect, then information about how to protect oneself was often also incorrect. Knowledge about your or your partner's HIV status is one such method of protection. The rate of consent for HIV testing within Caribbean populations is very low. In a United Kingdom study comparing African men and Caribbean men, only 35% of the Caribbean men consented to being tested for HIV, compared to 45% for the African men [70]. According to Allen (2002), this lack of consent may stem from the perceived (and sometimes very real) lack of confidentiality and privacy in Caribbean settings pertaining to HIV testing and results [71].

In addition to misinformation about the causes and methods of preventing HIV/AIDS, studies have shown that individuals are unaware of the treatment options available if one is tested positive for HIV/AIDS. According to one Jamaican migrant farm worker, he would "seek God because modern science wouldn't help" [44 (p. 793)]. This lack of knowledge about treatment has also influenced people's willingness to get tested. For example, in studies with community members in Haiti [31], and PLWHA from the Dominican Republic [72], it was reported that they were hesitant to get tested if medications were not available, since they believed that nothing could be done about the disease. Others reported not wanting to be tested for fear of being deported from the United States if a positive result occurred [72]. Due to these misconceptions and myths, individuals do not protect themselves, are not tested, are not treated if positive, and ultimately do not protect themselves or others from further infection.

Understanding the types of misinformation, lack of information or myths about HIV is important in the development of HIV prevention strategies, since these directly influence human sexual behavior. The incorporation of these factors increases the probability of HIV prevention programs being successful.

2.3.4.2 HIV Related Stigma – Religious and Moral Theories

Due to the populations that were initially infected with HIV/AIDS in Haiti, Jamaica and Trinidad and Tobago (homosexuals) [14], and the subsequent infections of other "high risk" populations in the Bahamas and Trinidad and Tobago (drugs users and prostitutes) [19, 73], there have been two main theories pertaining to the acquisition of the disease that has resulted in HIV being associated with immense stigma and discrimination [2] - the religious theory of disease, and the secular/moral theory of disease. The religious theory states that individuals who have sinned against God are punished by disease or death [74]. This stems from several instances in the bible where God warns about the punishment for sin, particularly sexual sin (Leviticus 18:22, Leviticus 20:13 and Romans 1:24-32 for example) [75]. As a result, renowned clergy like Charles Stanley and Jerry Falwell, who are popular religious figures in the Caribbean, professed that HIV was God's way of showing his displeasure with the sinful nature of homosexuals and drug addicts.

The second theory, the moral or secular theory, states that disease occurs as a result of irresponsible behavior [74]. Using this theory, individuals infected with HIV are seen as being responsible for their HIV infection status because they were homosexuals, had unprotected sex, or used drugs. When it was recognized that other members of the population were at risk for HIV infection, the idea of the "innocent" victim (the wife who was infected by her injection drug using husband) began to surface. In this case, the wife is innocent, implying that while the wife is not "blameworthy", but the husband is [74].

Due to these associations, individuals who are HIV infected have endured immense stigma and discrimination. This stigma, which is the "result of an undesirable label that causes ignominy and discredits the bearer" [48 (p. 163)] is still very common in the Caribbean. In Haiti, there have been several reports of individuals losing their jobs, losing customers at their businesses, being threatened with violence, been violently attacked, and been shunned by the community, among a host of other actions due to their HIV status [31, 32, 40, 48, 76, 77]. A study of physicians in Barbados indicated that many were uncomfortable treating HIV positive patients, and had refused them service [78]. Some HIV positive immigrants in New York did not seek services because they feared being classified as homosexuals [72], which is highly stigmatized in the Caribbean, while some HIV-infected Dominican Republic immigrants in New York, migrated to escape the stigma associated with HIV in the Dominican Republic [72].

This fear of being associated with HIV/AIDS was also reported in studies that examined sex tourism [50, 54]. When asked about highlighting HIV prevention information within the tourism sector, some hotel managers in the Dominican Republic thought that having signs and other information in hotels would result in stigmatization of the entire tourism industry. Tourists interviewed, however, did not agree, but thought that seeing information about HIV prevention would let them know that the hotel or the government was doing something about HIV/AIDS [50].

In addition to experiencing stigma because of an HIV infection, Haitian immigrants within the United States have also experienced discrimination due to the belief that Haitians are "AIDS-carriers" [48]. In the Chicago area, Haitian-American women reported that this stigma and the resulting discrimination affected their intimate relationships. They believed that men assumed that they were HIV positive, thus the men rejected them. Additionally, the women reported having self-doubt and lower self-esteem. Finally, they felt rejected by the dominant culture (Americans), and by other Haitians. To distance them from the stigma associated with HIV and Haitians, many Haitian women choose to socialize with non-Haitians, thus "self-rejection" is experienced [48].

This fear of stigmatization and discrimination may influence a PLWHA's willingness to disclose an HIV positive status. They may also be afraid to suggest condom use for fear of indirectly disclosing their HIV status. Non-disclosure, coupled with inconsistent condom use increases the risk of HIV transmission.

2.3.5 Caribbean Sexuality

2.3.5.1 Conservatism and Sexual Permissiveness

Religious and moral norms are very strong within the Caribbean context. As a result, behavior, particularly sexual behavior, is seen as either right or wrong within certain settings. Christianity (Catholicism and Protestantism) stresses sexual abstinence outside of marriage, however, there is a big discrepancy between what the church and other organizations within society recommend (abstinence before marriage) and what actually occurs in the Caribbean [13]. Due to this discrepancy, and the shame that is associated with disobeying the teachings of the religious orders, sex is something that is done, but it is never spoken about [54]. This guilt and shame "dissuade younger adolescents from acknowledging that they are sexually active," [79 (p. 38)] which prevents them from talking about sex, buying condoms, getting tested for STDs and getting treatments when infected [13, 79]. According to Allen (2002), reporting on a study conducted in Tobago, "sex is not something you talk about; it just happens" [71 (p. 198)].

Contrary to religious and moral influence, however, there are unwritten gendered rules that promote early and frequent sexuality. For example, it is stated that Jamaicans are socialized to have "guilt free, pleasure-oriented attitudes towards sex" [80 (p. 125)], where individuals, particularly males, are encouraged to experiment with early sexual activity and multiple partners [81]. This socialization is seen in the music (reggae, zouk and soca), and it is not censored in the print or video media [10]. As a result, studies in the Bahamas have identified "core" groups of very sexually active individuals – high school girls who have sex with older men for money, sex workers, Bahamian men who spend weekends at "hang-outs" called "fish-fry" where they meet women for casual sex, and construction workers who spend their weekends "wining and dining" women then having sex with them [57].

This sexual permissiveness can be seen when looking at the total number of sexual partners reported in the Caribbean. In a study in the United Kingdom, 77% of Caribbean men had more than five lifetime sexual partners. In addition, a higher percentage of the Caribbean men (35.7%) reported vaginal sex more than three times a week compared to African men (19.5%) [70]. Another Caribbean study showed that 34.1% of participants (aged 10-18) had already engaged in sexual intercourse, with 13.2% of females and 39.5% of males having had five or more lifetime sexual partners [17]. Specifically, a Haitian study showed that 43% of youths aged 15-19 had three or more lifetime partners [79], while of the women (mean age 36.3) in *bateyes* in the Dominican Republic, 23.5% had more than three lifetime sexual partners [26]. In one study of the sexual behavior of youth in Tobago, it was reported that about 20% of sexually active 10-14 years olds had more than five lifetime partners, while 25% of those aged 15-19 had more than five lifetime partners [71]

In addition to the total number of lifetime partners, having concurrent sexual partners is also prevalent. One report of sexual activity in the French Caribbean showed that concurrent relationships is very common [82]. In Martinique, Guadeloupe and French Guyana, 13%, 14% and 13% respectively of participants had concurrent relationships at the time of the study, 17%, 20% and 18% had at least two concurrent relationships within the last 12 months before the interview, and 23% 29% and 20% had an overlap between the last two partnerships respectively [82]. A report of Jamaican males showed that 33.4% had more than one partner within the last three months. Those with more than three partners in the last three months were three times as likely to have STD symptoms within the previous year [81].

As expected, having more cumulative sexual partners increases an individual's risk of contracting HIV. Therefore having knowledge about what are average numbers of sexual partners, and incorporating the factors that influence increasing or decreasing that number is important for HIV prevention strategies.

2.3.5.2 Age At First Sexual Experience

Since sexuality is very permissive in the Caribbean, a large proportion of the population is engaged in sexual activities at a very early age. Again, due to the shame and guilt associated with sexual activity outside of marriage, individuals who engage in sexual activity at an early age usually do not adequately protect themselves, resulting in high rates of HIV and other STDs. In addition, the total number of sexual partners is larger for individuals who engage in sex at early ages, again, increasing their risk for HIV infection. Approximately 50% of all new infections are in young people between the ages of 15 – 24, and 70% of all the reports HIV/AIDS cases fall within the 15 – 44 age group in Trinidad and Tobago [2].

In one Caribbean study, of the individuals who had engaged in sexual intercourse (one-third of the study participants), half of the sexually active boys and a quarter of the sexually active girls had their first sexual encounter by age ten or younger [17]. In the United Kingdom, the mean age of first sex for

Caribbean men was 15.5 in one study comparing STD rates in Caribbean and African men [70]. In Jamaica the mean age of first sex was 14, however, for some boys sexual activity started before ten years [81]. In a Haitian study looking at HIV prevention-related sexual behavior in 15-19 year olds, the mean age of first sexual encounter was 13, with 39.3% having sex before the age of 13 years [79]. Another Haitian study reported the median age of first sexual activity at 18 [40], while the women in the Dominican Republic *bateyes* reported a mean age of first sex was 16.4 years for women [26].

In Tobago, one study reported that the average age of first sexual experience for males was 13 years, while the corresponding age for females was 15 years. In this study, 6.5% of the participants had sex by age ten, while 25% has sex by age 12 [71]. In addition to the young age of first sexual contact, in Tobago the age of the sexual partner is different between males and females. For example, in 2000, of the female participants interviewed, their sexual partners were on average four years older, compared to males (one year age difference). In this study, a girl aged 19 was more likely to be in a relationship with a male with 6 years sexual experience. The sexual partners of males aged 19 however had little or no sexual experience, which may explain the high rates of HIV in teen age girls, but not in teenage boy in Tobago [59].

Obviously, early first sexual encounters results in increased cumulative numbers of sexual partners, which increases an individual's risk for contracting HIV and other STDs. Finally, it is believed that greater trauma occurs within the cervix during sexual intercourse in younger females, which facilitates HIV transmission [83].

2.3.5.3 Forced Sex

Forced sex, which includes rape, sexual assault, incest and statutory rape accounts for a large percentage of early sexual encounters in the Caribbean. According to Halcon's (2003) Caribbean study of adolescent (aged 10-18) sexual activity, 10.5% of the females and 9.1% of the males reported a history of sexual abuse, while 15.1%of females and 10.0% of males worried about being sexually abused [17]. Of those adolescents sexually active, almost half reported that their first sexual encounter was forced [17]. Smith Fawzi *et al* (2005) reported that in Haiti 53.3% of the women interviewed at a women's health clinic experienced forced sex, with 68% of those being under the age of 30 years at the time of the interview [84]. In Tobago, 12% of young male and 14% of the young female participants reported that their first sexual experience was forced [59]. Crack cocaine users in Trinidad and Tobago also reported very high levels of physical and sexual abuse as children [19]. Forced sex usually does not include the use of a condom; as a result, HIV infections have occurred directly as a result of forced sex [85]. Indirectly, forced sex, particularly at earlier ages is often followed by sexual promiscuity, which is directly related to HIV infection [86].

2.3.5.4 Homosexual and Lesbian Issues

Homosexuality within the Caribbean context is laden with stigma, discrimination and violence. This is due partly to certain Christian ideals that homosexuality is a sin, punishable by disease and death; or the gendered expectations that have strict "male" and "female" behaviors, with deviations interpreted very negatively. Though homosexuality is not openly discussed in the Caribbean, members of the younger generations are beginning to speak about it more openly [17]. Homosexuals tend to have very private relationships, particularly since sodomy is still illegal in the majority of the Caribbean islands, and is still strongly associated with HIV. Initial reports about HIV infections indicated that the strongest risk factor for being HIV positive was homosexual sex with a partner from the United States [87]. This linkage has also fuelled the stigma and discrimination against homosexuals in the Caribbean.

One comprehensive Caribbean study of youth, however, reported that 10% of the males and females reported having a same sex sexual experience and/or attraction [17]. In some Caribbean countries up to 17% of men have sex with other men, however many of them do not consider themselves homosexual [15]. This concept of men who sleep with other men (MSM), who state that they are not homosexual, is very common. For example, in Trinidad and Tobago, the need to acquire crack-cocaine [19] and alcohol use [88] have been the reported reasons for MSM. Throughout the Caribbean, sex tourism is also noted as being responsible for MSM due to economic need, as opposed to sexual orientation [17].

The documented HIV infection rates related to MSM in the Caribbean is approximately 12% of all reported HIV cases [18]. Due to the stigma and discrimination associated with homosexuality, however, this figure may be grossly underestimated [17]. In addition, since homosexuality is stigmatized, and illegal in many cases, there are very few prevention programs targeting that population in the Caribbean. This lack of prevention programs may be responsible for the incidences of HIV associated with MSM not decreasing in the Caribbean as it has done in the United States. For example, by 1999 the Dominican Republic reported that the HIV prevalence rate among MSM was about 8-12% [88], while in a study in England, Wales and Northern Ireland, 32.3% of the new HIV cases in Caribbean men were due to sex between men [89].

2.3.6 Condom use

According to the official prevention policy paper of UNAIDS (2005), second only to sexual abstinence, consistent and correct condom use is the best protective mechanism against HIV infection [90]. Although studies have shown that the correct use of condoms can reduce your risk of HIV infection by over 90% [91], consistent condom use is not common in the Caribbean, particularly with regular sexual partners. It is widely believed that using condoms decreases the intimacy within the relationship [79]; as a result, requesting condom use carries very high social costs [79]. To confirm this understanding of the social costs

associated with condom use, focus groups in Tobago with young males and females reported that girls who described themselves as being "in love" were easily persuaded to have sex without condoms [59].

In marriages or long-term relationships, the request for condom use implies sexual relationships outside of the primary relationship [13], which could result in suspicions of infidelity, violence, and sometimes dissolution of the relationship. Additionally, when there are suspicions of male infidelity, many women believe that if their partners use condoms with the "other" women (without using them in the primary relationship), the primary relationship remains "safe" [92]. In a study of Hispanic women in the United States, 59.3% of the Dominican Republic women reported asking their partners to use condoms with their "other" partners [92].

Evans *et al* (1999) reported that in a study of Caribbean men in the United Kingdom, 46.9% of those interviewed had never used a condom with their regular partner, while 12.3% always used condoms [70]. A Jamaican study of youths showed that 12.2% never used a condom, 37.7% always use a condom with their steady partner, while 65.3% always use condoms with non-steady partners [81]. In a Hispanic study with women aged 18-40, 67% of the Dominicans reported never using condoms in their current sexual relationship [92]. In Tobago, where reported consistent condom use with steady partners was very low, the females believed that it was the male's responsibility to buy condoms and put them on during sex [59].

With respect to overall condom use, only 53.3% of Caribbean youths polled used condoms during their last sexual encounter [17]. Among Haitian youths (15-19) only 17.5% "sometimes" or "always" used condoms while having sex, while 27% reported using condoms during their last sexual encounter [79]. In the *bateyes,* 3.2% of women acknowledged condom use during last sexual intercourse. These results also include the women who stated that they had more than one sexual partner within the last month [26].

Commercial sex workers (CSW) generally report higher rates of condom use. In the Dominican Republic, 60.1% of the established CSW used a condom with their most recent regular paying partner. This use was altered by their degree of intimacy with the clients however. Specifically, their intimacy rate inversely correlated with condom use (76.7% condom use with low perceived intimacy, compared to 41.3% condom use with high perceived intimacy) [25]. Perceived intimacy, and therefore condom use, was also associated with the length of the "relationship" between the sex worker and the client. For example, the sex workers reported 50% condom use in relationships over 6 months, compared to 70.6% condom use in relationships less than 6 months [25].

2.4 GENDER AND HIV/AIDS

2.4.1 Why Look At Gender and HIV/AIDS?

Jewkes *et al* (2003) reviewed several research studies and identified the fact that "sex and gender create circumstances of greater HIV risk" [93]. These "circumstances" include violence against women, women giving priority to their partners' sexual needs, the significance of fertility, the economic status and thus the dependent status of women, among many others. Due to these reasons, it is impractical to curb the HIV epidemic by focusing only on women. In fact, several researchers [94, 95, 96] have recommended focusing, or increasing the male responsibility factor, to reduce HIV/AIDS infections and improve the sexual health of both men and women. Some of the issues specifically relating to HIV/AIDS and gender in the Caribbean are discussed below, however gender is first defined.

2.4.2 Definition Of Gender

There has been growing interest in the role of gender-related power issues, particularly with respect to its influence on sexual health. In Gupta's address to the XIIIth International AIDS Conference in 2000 [97], she highlighted the difference between gender and sexuality. She conceptualizes gender as "shared expectations and norms within a society about appropriate male and female behavior" [97 (p. 1)]. In other words, gender is "relational because expectations, scripts, and behaviors defining what is feminine and masculine are manifest in the context of social relations and transaction, rather than being determined by biological or intrapsychic factors" [56]. Sexuality on the other hand is "defined by whom one has sex with, in what ways, why, under what circumstances, and with what outcome" [97 (p. 1)].

These distinctions are very important, since they influence individuals' sexual health seeking behaviors and subsequently influence intervention development. Gupta believes that women and men are "vulnerable" to HIV because of some of these expectations and norms. For example, women tend to be judged by their sexual "morality" which inhibits them from seeking information about sexual health, while men tend to be judged by their "masculinity". This includes having multiple sexual partners and producing many children, both of which increase HIV risk [97].

2.4.3 The Changing HIV Epidemic

Similar to the situation in the United States, the population in the Caribbean initially infected with HIV was homosexual men in Jamaica, Haiti and Trinidad and Tobago [14], followed by drug users (crack-cocaine) and sex workers in the Bahamas and Trinidad and Tobago [19, 73]. This has since changed and heterosexual sex is the main transmission mode in the Caribbean. Forty seven percent of the Caribbean HIV cases are women (approximately 140,000) [18]. In the late 1990s, in the Bahamas, there was a 23%

increase in infections in women, compared to an increase of 6% in men [57]. As a result, young girls and women (aged 15-45) represent the fastest growing sector of the population infected by HIV [12]. As a matter of fact, in Trinidad and Tobago, by 2001, 82% of all reported HIV infected women were within the 15-45 years age group [98].

In Haiti there seems to be a positive change, where the rates in pregnant women decreased from 9% in 1993 to 3.7% in 2003-2004 [18]. This shift has not occurred in Trinidad and Tobago, however, where women giving birth in Tobago currently have an HIV positive rate of 2.6%. The rate for women under 25 years is 3.8% in this population [18]. The percentage of HIV infections that are represented by women in Trinidad and Tobago has increased from 0% in 1983, to 33% in 1990, to 45% in 1999 [2]. The overall infection rate in females aged 15-19 is six times the rate of males in that same age group [18]. For example, in 2004 in one region of Trinidad in the 20-24 age group, there were 49 new HIV cases (33 females and 14 males) and in the 25-29 age group, 45 new cases of HIV (33 female and 12 males) [98].

2.4.4 Types Of Sexual Relationships

2.4.4.1 Sexual Roles of Males and Females

The gender divide within Caribbean cultures is very distinct. Men and women are expected to behave in very distinct ways. Though the terms used to identify the characteristics may vary from island to island, the basic concept about what is "acceptable" and what is "expected" is very similar. The terminology used in the Spanish speaking Caribbean (*machismo* and *marianismo)* will be used, since they are the most written about, and the terms are more recognizable. *Machismo,* used to identify the 'manly' characteristics, stresses "virility, independence, physical strength, and sexual prowess" [56]. According to one woman interviewed in Trinidad and Tobago, "... in my culture, a man is not a man unless he has five women" [15], while in a Haitian study it was estimated that 32% of the fathers had a sexual partner outside of the primary relationship [40].

Women, on the other hand, are expected to follow feminine characteristics that are outlined in the bible and locally interpreted to emulate the characteristics of the Virgin Mary, or fit the definition of a "virtuous woman", as outlined in Proverbs 31:10-31 [75]. The *marianismo* characteristics as traditionally interpreted include "chastity, abnegation, and sacredness", with an emphasis on obedience and virginity [56]. As a result, men are expected to have several sexual partners, while females are expected to remain virgins until married [27, 79]. After marriage women are expected to be innocent and submissive in their sexual relationships [92].

In Trinidad and Tobago the number of children that a man fathers, in addition to having several sexual partners, defines his "machoness"[9]. According to one author, men in the Caribbean are expected to father "as many children with as many women as possible" to show their *machoness*, since that improves their image with their friends [57]. Obviously, since children are being produced both "inside" and "outside" the primary union, males are not wearing condoms, therefore increasing the risk of HIV infection. This concept is also widely accepted in the Jamaican culture [81].

2.4.4.2 Relationship and Children "Define" Women

Very similar to the ideas of *machismo* and *marianismo*, the concept *familismo* explains expected relationship within the family structure. This concept describes the immensely strong relationship seen in Caribbean families (both nuclear and extended) [56]. There is intense identification with the family in addition to dependence on the family. This concept of needing a "family" has several implications for HIV prevention behavior. For example, young girls are afraid to "go against the family", or "bring shame to the family" by admitting that they are sexually active (a behavior that is not compliant with the *marianismo* ideology). Consequently, they do not purchase condoms, or obtain medical help when STD infections occur.

Likewise, after a certain age, girls/women very often seek intimacy with men, because they are defined by having a man [57]. The cohesion of this new union is very important, since it also measures a woman's ability to "keep her man". She is expected to do everything in her power to maintain the union. Having children is the main mechanism used to maintain the relationship. Since a woman's self-worth is defined by her family and her children (the number of children), the use of condoms is counterproductive for several reasons. First, condoms usually imply lack of intimacy, suspicion of infidelity on the part of the male or infidelity on the part of the female, which may all result in the relationship being dissolved. Secondly, using a condom prevents conception, which reduces the number of children that the woman bears [57].

One study in Barbados looking at the demographics of HIV positive childbearing mother indicated that 39 (21.4%) of them had a pregnancy after learning that they were HIV positive. Of those women with repeat pregnancies after their HIV diagnosis, 6 got pregnant at least three times, while 2 got pregnant at least 5 times. Compared to the HIV negative women used as controls in this study, the HIV positive women where more likely to be unemployed, unmarried, have five or more lifetime partners, had

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[9] "Macho" is another commonly used term that is roughly equivalent to *machismo*. A man's "manliness" is very important in this community. His prestige and worth is determined by this manliness in addition to other factors including wealth, etc. This term is used by the locals to measure manliness. You are "macho" if you have many partners, produce many children and in some cases abuse your partners.

first sexual experience before age 15, and have their partners be more than five years older than them [99]. A study in Bahamas also reported that HIV positive women in the Bahamas have been coerced into having sex without a condom, and have been pressured into bearing children [57]. In addition to the effect of being an HIV infected female in the Caribbean, the need to maintain the family is detrimental if the male is HIV positive. Studies have shown that increased length of time in relationship with an HIV positive person increases infections rates, possibly due to increased exposure (increased cumulative episodes of sexual intercourse) [100].

2.4.4.3 Economic Relationships

Like the need for migration, the economic situation in many Caribbean countries has made "economic (sexual) relationships" a necessity for increasing numbers of Caribbean women. Though most women are not sex workers, it has been shown that in Haiti, for example, the changing economic situation has resulted in changing sexual patterns [40]. Poor women, particularly single women with children, now need to rely on men to provide food and shelter. The majority of these women are faithful to their partners, however, the men usually have several other sexual partners [40]. Again, due to the social taboo that is associated with condom use, women are not able to protect themselves from contracting HIV or other STDs. This indirect link between economic need and HIV infection was seen in a case controlled study in Haiti, where the women who were HIV positive were more likely to have sexual relationships with truck drivers and soldiers (stable, financially secure jobs), compared to the women who were HIV negative (they have relationships with peasants) [32]. In addition, as previously stated, these truckers and solders are also more likely to have multiple sexual partners due to the migratory nature of their jobs.

As explained above, one mechanism used to maintain these relationships is the bearing of children. As a result, when a relationship ends, the single mother enters into another relationship due to financial needs. In every new relationship, the new man usually requires that the woman become pregnant, since it is a sign of weakness to "take care of another man's child." After a while, this new relationship dissolves, leaving the woman to restart the process, now with "plus one or two" children [27]. As a result, it is very common to have a mother with multiple children from multiple fathers. For example, in the Haitian study of women in *plasaj* relationships, 37% of the women were not living with the father of their children, and 38% had been pregnant with more than one man. Thirty percent of the women in *plasaj* relationships admitted that they entered relationships due to financial necessity [40].

When it is believed that having one sexual relationship will not satisfy the financial needs of the family, women may enter into multiple relationships. For example, in a Jamaican study, one woman describes the course of action needed when the male in the primary relationship did not provide financially:

> "I know that him have it [money] and don't want to give it to me, … [there are] other people out there … I [am] going to where I can get it" [27].

This feeling of needing to get money from other men also influences women's decision to become sexually involved with a male who is already married or is in a long-term relationship. One participant in Jamaica discussed the positive attributes associated with being with a married man:

> "this girl from the ghetto … [is] now with a married man … she have washing machine … has traveled 2 times … she can drive now … has a baby for the man … she drives in the front of the car … she has it made now" [27].

Though many women readily admit that sex is used in exchange for money or goods, either with one or multiple partners, this is not seen as prostitution since their main source of income isn't the sexual relationship. It is seen as a common survival mechanism particularly for single women [26]. The *bateye* presents an interesting "closed" system that highlights the complex incorporations of the external factors that influence women's behavior. The individuals living within these communities are extremely poor; as a result unsafe actions must be taken. 7.4% of women living in *bateyes* reported having more than one sexual partner within the last month. The women born in the *bateyes* were more likely to describe themselves as prostitutes, possibly resulting from being raised in an environment where sex in exchange for money or goods was common. This concept is known as being the "daughter of the *bateye*" [26]. These women (the "prostitutes) have a median number of lifetime partners totaling 48, with about nine partners within the year prior to the study. The women who describe themselves as "prostitutes", are also more likely to be the head of the households [26].

2.4.4.4 Negotiating Safe Sex

Economic hardship, coupled with the cultural expectations of women, men and families decreases women's ability to effectively negotiate safe sex. In the Caribbean, safe sex negotiation is seen as questioning the trust and intimacy within the relationship [92]. In addition, women are trained to believe that it is their duty to please their husbands, regardless of their feelings [56]. Finally, the word "condom" carries sexual stigma. As a result, a woman buying condoms or requesting that her partner use them implies that she is promiscuous [57], and/or is insinuating that her spouse has other partners. In the Caribbean setting, it is not wise on the part of the woman to discuss any of these issues, since this discussion usually results in violence or the relationship being dissolved [27]. For example, this gendered power difference pertaining to condom use was reported about in the Dominican Republic, where a 100% condom-use policy was implemented for sex workers. It was reported that sex workers possessed the skills to demand condom use by their clients, however they lacked the skills needed to introduce condoms in their "home" relationships [101]. For example one key informant stated:

> "With the client she [the sex worker] is tough, difficult, a frank negotiator, ready to fight or pull out a knife, but when she returned to her husband, she [sex worker] looses this role" [101].

This knowledge, that discussing safe sex would only result in negative reactions, has prevented many women from raising the issue within their relationships. In a study of Hispanic (Puerto Ricans, Mexicans and Dominicans) women in the United States, the Dominican women were most likely to expect a negative reaction from their partner if condom use was mentioned [92]. In other studies, this "negative reaction" was not just anticipated, but was real to several women who tried discussing the use of condoms. In Jamaica, one woman revisited the physical violence that occurs when women try to negotiate for safer sex:

> "... big violence, fight, lick down, chop up, and all them things go on ... stab up too ... if him have him gun on him, you going get butt up too ...] [27].

Given the structural violence that encompasses women in the Caribbean, thus influencing their need to enter into economic relationships that include sex, and their lack of ability to negotiate safe sex, it is easily understood that programs "stressing behavior modification may have little impact on a desperate mother to ensure the survival of her children through a series of sexual relationship" [40 (p. 499)]. Obviously increasing a woman's income is one mechanism that improves her ability to negotiate safe sex. Ironically, established commercial sex workers in the Dominican Republic who made more money (more than $233USD) had a 66.1% consistent condom use, compared to a 50% consistent condom use in those who made less than $233USD [25]. Other suggested mechanisms include using pregnancy prevention [56], or stressing the idea that women need to protect themselves so that they'll be available to protect their families [56]. These recommendations however may be met with other cultural barriers, therefore a full understanding of the economic, social and cultural factors is extremely important.

2.4.4.5 Denied HIV Risk

There seems to be a lack of awareness about the link between infidelity within a relationship and risk for HIV infections. Dominican women who knew or suspected that their partners have other sexual relationships, did not associate that with their own risk of HIV infection [92]. As a result, these women were less likely to communicate about HIV or try to encourage behavior change.

2.4.4.6 Nonvolitional Sex

Catharine MacKinnon describes rape and the difficulties in truly determining when a woman was raped because "it [rape] transpires somewhere between what the woman actually wanted, what she was able to express about what she wanted, and what the man comprehended she wanted" [102]. This ambiguity about a woman's true ability to state her sexual preference is very important in the Caribbean context. Since Caribbean women are raised to take care of their husbands' (men's) needs, many women do not, or do not

believe that they have the right to refuse sexual advances. In the literature, this concept is known as nonvolitional sex.

Specifically, Kalmuss (2004) states that nonvolitional sex occurs when an individual "engages in sexual behavior that he/she did not freely choose because of constraints emanating from individuals (partners, peers, family, and strangers); norms regarding sex, gender, and families; or societal institutions (religious, legal, and economic systems)" [103 (p. 199)]. Given the social, economic and cultural factors surrounding sex in the Caribbean, it is safe to say that women there experience varied levels of nonvolitional sex, ranging from being raped, to being "coerced" into sex with their husbands, to being economically constrained and therefore enter or maintain sexual relationships. This unequal relationship between men and women ensures that true sexual communication does not occur, since it is strongly linked to gender-based power [24].

In the studies looking at forced sex, it is difficult to determine what degree of forced sex has occurred (rape versus assault). None-the-less, forced sex seemed to be more common with women who were poorer or who stayed in relationships longer. The majority of those who experience forced sex, state that this occurred with men with good jobs (for example construction jobs), again indicating an economic connection within the relationship (if the forced sex occurred within a sexual relationship) [84]. In instances where the forced sex occurred outside of an established relationship, the women were usually very poor. For example, in Haiti, the women experiencing forced sex were usually uneducated servants, and the perpetrators were usually their employers or other men close by (who are aware of their financial situation) [32]. As expected, forced sex has been associated with increased occurrences of STDs, unplanned pregnancies [84], and HIV/AIDS infections [32].

2.4.5 Women's Health

In situations where there are very specific gender expectations, women tend to neglect their health, while working towards improving the health of their families. Particularly with respect to HIV, women do not seek medical help when symptoms of HIV are present [57]. In the Bahamas and other Caribbean countries, women have indicated that the stigma associated with HIV, in addition to the fear that they will be blamed for having multiple sexual partners, have prevented them from seeking medical care for HIV symptoms [57]. In addition, women with children refuse to be tested for fear of being labeled as unfit, and having their children taken away if the HIV result is positive [57]. Conversely, women tend to encourage their male partners to seek medical help if they are ill, as a result males are more likely to get tested if they have a family [72].

In the end, the interconnections between gender, power, economics, and other issues that affect women in the Caribbean seem to directly and indirectly HIV rates. As a result, these factors must be understood and incorporated if HIV prevention programs are expected to be successful in the Caribbean.

2.5 SUMMATION

The literature about HIV/AIDS in the Caribbean is focused mainly on a few countries, namely Haiti, Dominican Republic, Dominica, Jamaica, and to a lesser degree Trinidad and Tobago. Only one study specifically examines sexual health in Tobago. Though the cultures of Caribbean countries are similar, there are significant differences that warrant specific examination of the different communities. In addition, due to my knowledge about Tobago, there are specific factors in Tobago that have not been discussed, or have only been peripherally examined in the literature. These factors must be understood and incorporated into sexual health/HIV prevention strategies. For example, there is little or no information about the influence of music on sexuality; incest is only peripherally discussed; the acceptance of infidelity and its influence on HIV is recently coming to light; and the interconnection between the protective services and HIV infection has not been discussed as it relates to the Caribbean. Finally, the literature does not provide an insight into the lives of PLWHAs in the Caribbean. This is essential because HIV prevention involves uninfected individuals remaining uninfected and infected individuals protecting themselves from secondary infection and preventing HIV transmission to others. How PLWHAs experience life before and after infection directly affect their ability to protect themselves and others. In the end, there is still need for additional information about what influences HIV infections in Tobago, and this study is a step in that direction.

3.0 METHODOLOGY

3.1 QUALITATIVE RESEARCH

3.1.1 What Is Qualitative Research?

Qualitative research is the use of different data gathering methods and methods of analysis to answer research questions using either the interpretivist and/or the critical approach. Qualitative research is also said to follow a naturalist approach, since research of human behavior is done in the most natural settings possible. It is very rigorous and requires intense training and skills. Qualitative research is both a science and an art. This study, due to its exploratory purpose, focus on sensitive issues and populations (people living with HIV/AIDS) and expected outcomes that take into consideration the lived context of the people of Tobago, utilizes qualitative research methodologies.

3.1.2 Research Theoretical Paradigms

Research has been traditionally looked at from two broad theoretical paradigms – positivist and interpretivist. In this document I discuss the interpretivist paradigm. The interpretivist paradigm views the world as "constructed, interpreted, and experienced by people in their interactions with each other and with the wider systems"[104 (p. 18)]. In other words, an individual is influenced by and influences the animate and inanimate items within his or her environment. As a result, in addition to the objective facts about a community, the understanding of people's "subjective meanings" is also considered important. The interpretivist paradigm utilizes and incorporates findings from three main components to understand human behavior. These include (a) subjective perceptions and understandings (gained from experience of the people being studied), (b) their objective actions and behaviors and (c) the context. For example, it is well known in the Western medical arena that consistent, correct condom use prevents HIV transmission, and ideally, if individuals used condoms the rate of HIV infection would halt and begin to reverse. However, understanding the subjective perceptions and context of condom use in the Caribbean may explain why consistent condom use is minimal, even with adequate information. Specifically these "subjective meanings", "perceptions" and "context" include the fact that condoms prevent pregnancies and in Caribbean cultures producing children defines the family. In addition, as discussed earlier, condom use implies lack of intimacy and infidelity, which jeopardizes the family structure. The

understanding of these factors explains the lower than expected condom use in Caribbean cultures. As a result, interpretivist paradigms address the issues of "why, how and under what circumstance" do people undertake or fail to undertake certain health-related behaviors.

Some researchers propose a third methodological paradigm often referred to as the critical approach. One particular expression of this is the feminist paradigm. The feminist paradigm is very similar to the interpretivist one, however it emphasizes the influence of power relationships (particularly between genders) on health. In other words, it looks at these subjective, contextual factors from the perspective of women's health, in addition to looking at power and how long lasting power differentials (and access to power) negatively affect the health of populations [104 (p. 21)].

3.2 WHY THIS STUDY IS SUITED TO A QUALITATIVE DESIGN

The incidence of HIV/AIDS in Trinidad and Tobago and many other parts of the world continue to rise regardless of the available information and the available materials like condoms, which have been proven to prevent HIV transmission [105, 106]. As a result, it is obvious that to help prevent HIV infections, information about why the incidence rates continue to rise regardless of these advances must be gathered. In many instances, these factors are very subtle AND complex. Consequently, specific questions about "why" this occurs can't be directed to the most affected/influenced community members because they have not conceptualized or cannot verbalize how these factors influence them. This type of in-depth understanding can be obtained via qualitative research though, since via qualitative research methodologies (a) the subjective perceptions and understandings of the people being affected can be studied, (b) their objective actions and behaviors can be observed and (c) the context within which this occurs can be understood.

These three benefits of doing qualitative research are very important in improving HIV prevention, because as stated in the previous chapter, sexual activity is influenced by a host of internal and external factors (moral values, economics, location, etc). These "internal' and "external" factors are further explained and dealt with in qualitative research using the concepts of "emic" and "etic" perspectives [11, 107]. The *emic* perspective refers to the insider's perspective (i.e., the perspective of Tobagonians who participate in the study). Frequently, *emic* perspectives do not conform to *a priori* assumptions of how systems work, which usually explains why interventions do not work, or recommendations are ignored. As a result, understanding the multiple *emic* perspectives of individuals, and incorporating those realities into interventions, increases the possibility of success. The *etic* perspective refers to the "external, social scientific" perspective, which includes the realities outside (but not separate) from the individuals under investigation. These factors include the economic status of the

community, the social and cultural norms that influence human behavior, and the political or religious factors that influence policies, etc [11 (p. 20-22)]. Since qualitative research methodologies allow for the understanding of both the *emic* and *etic* perspectives, and the interaction of these two perspectives is extremely important in HIV/AIDS prevention, this study is most suited for qualitative research.

Another way to think about how complicated the issues surrounding sexual health can be is by looking at "culture" and how culture influences individual behaviors. Culture refers to shared ideas, beliefs, norms, and values that guide how individuals view the world, and their reactions to what is experienced. Culture therefore is not just traditional ceremonies and practices, but is also the emotional, psychological and intellectual interpretations and reactions to one's surroundings. As a result, a person's culture will influence how they define illness and ultimately how they prevent or seek cures for their illnesses [108, 109, 110, 111, 112]. As Goodenough states, culture consists of "standards for deciding what is, standards for deciding what can be, standards for deciding how one feels about it, standards for deciding what to do about it and standards for deciding how to go about doing it" [113]. It is also important to understand that "culture is not static". It changes with time, as the group acquires new knowledge, or new understanding of knowledge; in addition, it changes when the physical and other environmental circumstances surrounding the group change. Culture can therefore be looked at as a vehicle through which one understands why individuals behave the way they do. Qualitative methods allow for the holistic analysis of the culture of Tobago and how this culture influences HIV infections on the island.

3.3 RESTATEMENT OF THE RESEARCH PURPOSE

- To examine some of the social, cultural, and economic factors that influence sexual behavior practices, and to determine how these factors influence HIV prevention behavior in Tobago.
- To make recommendations for prevention strategies that are comprehensive and tailored for the Tobago population, by ensuring that they address the identified socio-cultural factors.

3.4 RESTATEMENT OF THE RESEARCH QUESTIONS

- What are the pre- and post-HIV infection experiences (social and cultural) of people living with HIV/AIDS in Tobago?
- What are the major cultural and social factors that influence the high HIV/AIDS rates in Tobago?
- How do these factors influence (a) community norms and therefore (b) individual behavior patterns with respect to HIV prevention strategies in Tobago?
- What methods might be used to incorporate relevant social and cultural factors into HIV/AIDS prevention programs?
- What are the most appropriate models/methods for improving HIV prevention in Tobago, including but not limited to the type of information needed and the most appropriate methods of dissemination?

3.5 THE SPECIFIC METHODOLOGY EMPLOYED

3.5.1 The Specific Qualitative Design

This study follows the philosophy and design of "Applied Ethnography". The term "ethnography" is very difficult to define, and ranges from "a way of collecting data (a set of research methods); the principles that guide the production, analysis and interpretation of data (a methodology); and/or a product (the written account of a particular ethnographic project)" [114 (p. 384)]. In this instance, I am focusing on ethnography as a methodology, or a way of conceptualizing the problem, which directly influences the method of data collection and analysis of that data. The function of "basic" or "traditional" ethnography has been to increase knowledge or understanding about a particular culture or subculture. Usually, the ethnographer enters the field attempting to limit his or her preconceptions, with the idea of learning about the culture or subculture, solely from being immersed within that culture or subculture for an extended period. In addition, the goal of traditional ethnography has not been to inform policy [114, 115, 116].

In applied ethnography however, in addition to understanding a culture or subculture, the goal or a goal is to directly inform policy [115, 116]. As stated by Noblit (1984) the applied ethnographer does not "wait for someone to find the results convincing", but sets out at the beginning of the study to "guide" administrators, politicians and other policy makers [116 (p. 96)]. As a result, applied ethnographers enter the field with a topic or concept focus, and the questions and observations are focused on that topic or focus.

Also, applied ethnographers tend to spend less time in the field (months versus years) compared to traditional ethnographers [115].

3.5.2 Modifications to the Generally Recognized Methodology

Traditionally, ethnographies have been used in explorations of cultures or subcultures and not as evaluative tools [107, 117]. Though this study does not include traditional program evaluation techniques (process or outcome evaluations), there are evaluative components incorporated within the explorative process. One aspect of this study is to examine some of the HIV/AIDS prevention and care programs already implemented in Tobago. This is important for several reasons. First it establishes an inventory of HIV/AIDS prevention and care programs in Tobago, by identifying what types of programs available, and how they are received and perceived by different sectors within the society. Secondly, the examination of these programs explores the *emic* perspectives of the PLWHAs and general community members. This gives PLWHAs and general community members an opportunity to discuss their views of the current prevention and care programs. Moreover, it gives them the opportunity to make recommendations for improving these programs.

3.5.3 Role of the Researcher

In qualitative research, the roles of the researcher are varied. These roles include being an observer, analyzing the information observed, and situating the observations within the larger context [118 (p. 38)]. Observations occur in varied settings and include (1) listening in interviews and other conversations, (2) looking at behaviors, actions and environments, and (3) asking appropriate direct questions or steering conversations when necessary. Finally, the researcher is expected to document these "observations" via written notes, audio or video recordings, or drawings.

In this study I was the main data collection agent. I conducted the in-depth and ethnographic interviews in addition to taking part in the participant observations (techniques described below). I believe that my educational background, in conjunction with my life experiences renders me competent to conduct this type of research. I was born and raised on the island of Tobago. As a result, I am familiar with the social and cultural nuances of the island. Although English is the official language of Trinidad and Tobago, the majority of the inhabitants speak various dialects of English, and I am fluent in these dialects.

3.5.4 Design Specifics

3.5.4.1 Unit Of Analysis

This study is situated on the island of Tobago. Trinidad and Tobago is a twin-island state in the Caribbean, approximately 7 miles from the coast of Venezuela. The population is approximately 1.3 million, with approximately 54,000 people residing on the island of Tobago. According to the Joint United Nations Programme of HIV/AIDS (UNAIDS), there were 27,000 (range 15,000 to 42,000) people living with HIV/AIDS in Trinidad and Tobago in 2005 [5]. There are no officially published records of the number of PLWHAs in Tobago, however the prevalence rate is estimated at 5%.

3.5.4.2 Sample Population

(a) Description of "Information-Rich Cases"

Since a socio-cultural and community approach to intervention development is used, this study included data collection from varied sectors of the Tobago population. The information-rich cases can be divided into two main categories: (1) community non-PLWHAs, and (2) PLWHAs. The community non-PLWHAs are Tobagonians over the age of 18 years, and are further subdivided into (a) community leaders/elders, (b) healthcare professionals, and (c) members of the general population (identified as community members).

Figure 2: A map of Trinidad and Tobago
Tobago is circled in red. This map highlights the relational distance and size between the two islands. It also highlights the proximity of Trinidad to Venezuela.

Community leaders/elders were ethnographically interviewed (described in following section) to determine the norms and expectations of this community, in addition to identifying what this community deems as appropriate methods and models of HIV prevention. This group was also included to increase the community trust, ownership and acceptance of the resulting recommendations. Health professionals were ethnographically interviewed to determine what role they played in the counseling and testing of clients (both PLWHAs and non-PLWHAs). In addition, information about the stages (HIV negative or positive, AIDS, end stage AIDS, etc) of the disease frequently seen was gathered. Finally information about what treatment, counseling, social services, support systems, educational information is currently available to the general population, in addition to recommendations for prevention programs, was gathered from this sector of the population. Male and female community members were ethnographically interviewed to determine several factors. These include their views about HIV/AIDS in Tobago; their views about the current prevention programs in Tobago, their views about how they have or have not protected themselves and why/why not; in addition to recommendations for prevention programs.

Individuals already infected with HIV/AIDS are a great source of information in this study, and therefore in-depth interviews (described in following section) were conducted with members of this population over the age of 18 years. PLWHAs are "information rich" [119] since they represent a group where prevention programs/strategies have failed, and therefore their experiences and perspectives will highlight situations/circumstances/factors that must be incorporated if prevention and care programs are to be successful. PLWHAs can highlight the social and cultural circumstances surrounding their infections, in addition to what they believe could have prevented their infections. Additionally, PLWHAs can relate their experiences as people living with HIV/AIDS in Tobago (highlighting the presence of stigma, or lack of adequate treatment and care, for example), which may also be important factors in the development and implementation of HIV prevention and care programs in Tobago.

(b) Sampling Strategy

Purposive sampling methods were used in this study. Purposive sampling refers to selecting participants because they are "information-rich cases from which you can learn about issues that are important to the study" [119]. Due to the exploratory nature of my research questions, and the relatively short period in the field, I believe that purposive sampling is the most effective and efficient method. Two purposive sampling methods: snowball sampling (current participants identify other individuals who are "information-rich") and opportunistic sampling (new participants are recruited due to information gathered in the field, while taking advantage of unexpected opportunities) were used in this study [120]. These methods were used because of the sensitivity of the subject. For example, many PLWHAs have not disclosed their status to uninfected individuals; therefore the only way to identify them is to have previously interviewed PLWHAs encourage them to contact me. This method was also important for identifying the health professionals, community leaders and community members because credibility and social networking is very important in Tobago. The fact that I speak with one community leader, who

suggested that I speak to another community leader, gave me credibility, and it increases the probability that the second community leader would speak with me. Other sampling methods would not afford me these benefits.

(c) Recruitment Procedures

Initially, participant observation was the primary data collection method. From these observations and conversations with the leaders and members of the community, individuals were identified for ethnographic interviews. In addition, churches, community centers, youth groups, health centers, etc were approached to identify and obtain leaders and other community members for ethnographic interviewing.

Relationships were developed with the Tobago AIDS Society (TAS) and the Tobago OASIS Foundation (OASIS), the two organizations that serve people infected with and affected by HIV/AIDS in Tobago. Representatives from these organizations were asked to inform members that this study was being conducted, giving them the opportunity to contact the researcher if interested. In addition, during the course of participant observation, if an individual disclosed his/her HIV positive status, he/she was asked if he/she was interested in participating. As the snowball sampling technique describes, after PLWHAs were interviewed, they were asked to tell other PLWHAs about the study, giving them the opportunity to contact me if interested in being interviewed.

3.5.4.3 Data Collection Methods

To do effective qualitative research, several qualitative methods have been developed. Three data collection methods were used in this study: (1) Participant Observations, (2) Ethnographic Interviews, and (3) In-depth Interviews. These are described below.

(d) Participant Observation

Participant observation was one of the methods used in this study. Observational methods are used to study peoples' lived realities, since sexual health decisions occur within the "lived realities" of community members. As a result, an in-depth understanding of these "lived realities", and the incorporation of these "lived realities" into prevention strategies would greatly increase the probability of individuals reducing their risk for HIV infection. This method relies on the use of the researcher's senses (primarily sight and hearing, but also touch, taste and smell), instead of relying on self-reports of the subjects [121 (p. 3)]. *Participant observation* occurs when the researcher participates in the lives of the people being studied, while maintaining a certain "professional distance" that allows systematic observation and data recording. This process allows the observation of everyday practices, patterns of behavior and rituals, which may be important in understanding the research issue. Ideally, this involves living within the community for at least six months.

(e) Ethnographic Interviews

Ethnographic interviews were a second method used in this study, where the health professionals, community leaders and community members were the "information-rich" cases. Ethnographic interviews involve engaging participants in conversations about the issues identified in the research objectives. These "interviews" are not rigidly structured (specific questions outlined on paper, specific ordering of the questions, structured responses, with the same questions repeated to several participants). Rather they are in the form of directed casual conversations with participants. The direction of the conversation is based on the specialty of the individual being interviewed, and may include questions about issues raised in the in-depth interviews or from participant observations. For example, a health professional may be asked about the facilities/services available to PLWHAs, or they may be asked about whether community members regularly request HIV testing. A young community member may be asked about the sexual health practices at parties and other social venues where alcohol is served, or whether the have interacted with someone who is HIV positive, or what would be their reaction to a positive HIV diagnosis. While an older community member may be asked about how HIV is viewed in that community, whether this view has changed within the last 25 years, and what they would recommend to decrease the infection rates. This method is used to illicit individual perceptions about issues and compares those to the perceptions of other individuals within the same community.

(f) In-depth Interviews

The final method used in this study was in-depth interviews of PLWHAs. In-depth interviews are conversations between one interviewer and one participant, which are goal-directed. Usually, an interview guide, with informally structured (open-ended) questions is used, however the conversation is very flexible, and is guided by the participant as well as the researcher. The goal of in-depth interviews is to illicit personal information, experiences, and even suggestions for change from individuals within the community being studied. These interviews reinforce a sense of confidentiality, and therefore participants may divulge information that is private, embarrassing or "deviant", which would not normally be discussed in focus groups or other public settings [11 (p. 37), 122 (p. 81-82)]. The interview guide used in this study is included as Appendix A.

3.5.4.4 Post-Activity Data Management

Since qualitative research produces large volumes of data via interviews and observations, different methods of managing this data are important in maintaining the integrity of qualitative research. These methods include writing extensive fieldnotes, audio recording interviews and other events, transcribing these interviews and taking digital photographs when appropriate.

(a) Fieldnotes

Fieldnotes have been the traditional method of recording data in ethnographic research, and simply put, they are the written accounts of the qualitative researcher's observations. These include observations in the field, observations of participants during interviews, conversations, and any other information that may be related to understanding the research topic. In addition, in a manner that is obviously distinct (using the margins, different color ink, or a separate "analytic section"), fieldnotes should include the initial interpretation of those observations. Fieldnotes are written because they provide "raw data that can lead to more focused follow-up interviewing or additional observation" and analysis. These notes should include "thick descriptions" including physical space, the actors, interactions between actors, general behaviors, and the expression of feelings and emotions. In other words, fieldnotes record the description of 'social processes and their context'. Finally, they should be recorded as soon as possible to prevent lost of information due to memory lapses [121 (p. 12), 123 (p. 57), 124 (p. 175)]. In this study a password protected Microsoft word document was used to record fieldnotes.

(b) Audio and Visual Recorders

In this study the in-depth and ethnographic interviews were audio recorded, while digital photographs were taken when appropriate. Audio and visual recording devices are important in qualitative research because they allow the researcher to be completely involved in the interviews, for example, without being distracted by manual recording. In addition, they record the words and actions of participants precisely, which is very useful in later analysis [11]. The audiotapes of my in-depth interviews were transcribed verbatim, while the audiotapes of the ethnographic interviews were summarized.

(c) Theoretical Memos

Very early in the analysis process, as interviews were completed and observations were made, theoretical memos were written to record the new insights about the study. These initial memos were usually written on a "series of discrete phenomena, topics, or categories". As the analysis continued, and the researcher becomes clearer about the emerging themes or ideas, more focused memos were written. These "integrative memos" link and clarify the ideas, themes and categories unearthed throughout the analysis [125 (p. 143)]

3.5.4.5 Data Analysis

Qualitative data analysis is a continuous and iterative process. It begins in the early stages of the study where analysis of newly acquired information influences future data acquisition methodology, and/or participant selection, as well as the refinement of research questions. Traditionally individuals use the techniques like "coding" [123 (p. 76-77)] and "comparative analysis" [126 (p. 339)]. I however decided to use another, more thematic/iterative based approach. This thematic approach to qualitative analysis is very

cyclical and incorporates writing fieldnotes, and reading and re-reading the fieldnotes, and interview transcripts, while using the data analysis theories described below. The process continues with the writing of theoretical memos (described in the previous section), as fieldnotes and interview transcripts continue to be reread, and the audio of the interviews listened to. The analysis continues with the writing of the dissertation. According to Ely *et al* (1997), "writing can be alive" because our "understanding is informed through writing" and rewriting [127]. As each section is written a better understanding of the data emerges. In addition, as new sections are written, older sections are rewritten for clarity and deeper understanding. This then informs the writing of new sections of the dissertation. In the end qualitative analysis identifies the major themes, constructs and relationships that influence human behavior [128]. In this study two theories are used to guide the analysis of the data, and a third theory is used to inform the development of prevention programs. These theories and how they are utilized are discussed below.

(a) Data Analysis Theories

PEN – 3 Model

The PEN-3 model was developed to be used in the planning, development and implementation of culturally appropriate health education programs in Nigeria [129]. It emphasizes the use of the concept of "cultural empowerment" which focuses on both the micro (individual, family, and community) and the macro (national and international) development, instead of just "self empowerment" which focuses on individual development [129]. PEN-3 consists of three dimensions of health belief and behavior, which are interrelated and interdependent – "health education, educational diagnosis of health behavior and cultural appropriateness of health behavior"[129 (p. 29)]. Within each of these dimensions, there are sets of categories that are represented in the PEN acronym.

The *health education* dimension refers to the specific issues that health education should focus on. The categories include ***P***erson, ***E***xtended family, and ***N***eighborhoods. *Educational diagnosis of health behavior*, the second dimension of the model, is used to identify or determine the "factors that influence individual, family, and/or community health actions". At the core of this dimension is the central role of culture, and its influence of "health actions". The categories include ***P***erception, ***E***nablers, and ***N***urturers. The third dimension of the PEN-3 model refers to the *cultural appropriateness of the health behavior*. The categories include ***P***ositive behaviors, ***E***xistential behaviors, and ***N***egative behaviors. The inclusion of this dimension ensures that the intervention developed is culturally appropriate by reinforcing the positive behaviors, creating programs that address the negative behaviors, while leaving the existential behaviors alone since they neither help nor harm the health of the participants. In this study the third construct of PEN-3, the *cultural appropriateness of health behaviors* was used to identify the social and cultural aspects of health behaviors in Tobago that were either **P**ositive, **E**xistential, or **N**egative as they relate to HIV infections risks. The **N**egative behaviors were highlighted for behavior change intervention.

Theory of Gender and Power

In 1987, Connell developed the theory of gender and power (TGP), after a review of the literature and existing theories connecting gender, power imbalances and sexual inequality. This theory identifies three constructs that influence the relationship between men and women. These constructs include the *sexual division of labor* (specific jobs for men and women), the *sexual division of power* (gendered power given to men by society and taken away from women) and the *structure of cathexis* ("social norms that govern appropriate sexual behavior for women and encompasses the emotional attachments involved in social relationships" [130 (p. 33)]). According to Connell, the interconnection of these constructs "explain the cultural bound gender roles assumed by men and women" [131 (p. 540)]. These constructs exist at two levels, the larger *societal level* (social norms that govern appropriate sexual behavior for women and encompass the emotional attachments involved in social relationships), and the lower *institutional level*. In this study, the factors that perpetuate gender imbalances, and therefore follow the Theory of Gender and Power were also identified.

(b) Triangulation

In this study, triangulation is the method used for substantiating the data. Triangulation is the process of looking at a problem using "as many different methodological perspectives as possible". This process crosschecks the information gathered, and identifies and then allows further investigation to explain gaps and discrepancies. In addition to triangulating using different methods (participant observation, ethnographic interviews and in-depth interviews), a researcher can triangulate using different data sources. For example, using both method and source triangulation, if interviews with physicians in the Caribbean identify their belief that adequate information about HIV/AIDS is present in the community, however participant observations involving young girls indicate that they lack basic information about HIV transmission, the combination or triangulation of the data gathered from these two methods and sources might lead to the understanding that more group-specific information is needed in the community. In addition, using the different methods allows the same question to be answered from different angles, thereby enriching the response. It must be noted however, that in qualitative research, information gathered from one method is neither correct nor incorrect. This information highlights the *emic* perspective of the participants being interviewed and therefore the utilization of several methods insures that valued information isn't neglected [11, 132].

(c) Program Development and Implementation Theory

The Socio-Cultural Theory of Learning (SCTL)

Lev Semyonovich Vygotsky developed the SCTL in the field of education. It is part of a larger socio-ecologic model that does not view the individual as an isolated entity but as part of a larger context, and is therefore heavily influenced by the characteristics of that larger context. The SCTL specifically identifies this "larger context" as the Zone of Proximal Development (ZPD), which is where the individual lives and therefore where learning occurs. Learning is defined as a two-step process where individuals (1) acquire knowledge (knowledge-in-waiting) and then (2) apply that knowledge (knowledge-in-use). The agents of change or "instructors" are individuals with greater cultural capital and memberships, who pass information and skills to other individuals within the zone. Information flows in both directions, therefore, there is "cultural reciprocity" [133] which ensures that all participants are attuned to the context within which the other resonates. Finally, in the SCTL, learning is most influenced by the available resources (accuracy and availability of information for example) and the social environment (which includes social relations, cultural ideas, economics resources, etc) [134].

(d) Use of SCTL In Program Development and Implementation

The SCTL identifies at least six (6) factors that must be considered in learning. In this study, these six factors are identified and recommendations for their application in the Tobago setting are discussed:

(1) Zone of Proximal Development (ZPD) – places where learning can take place

(2) Knowledge-in-waiting – what information is needed

(3) Knowledge-in-use – what skills are needed

(4) Instructors - who are the most appropriate people to impart this knowledge, teach skills, and provide examples

(5) Available resources – what is already available, and what needs to be added to increase the likelihood of behavior change

(6) Social environment – what social and cultural factors (including policies) influence the behavior change and methods of altering these factors.

4.0 STUDY POPULATION AND SETTING

4.1 INTRODUCTION

This section presents basic demographic information about the study population and settings. This includes demographics about participants interviewed (in-depth and ethnographic), in addition to information about the settings for the participant observations.

4.2 IN-DEPTH INTERVIEWS

In-depth interviews were conducted with 14 People Living With HIV/AIDS (PLWHA). I personally interviewed 11 PLWHAs, and a friend who is also a PLWHA interviewed the other three participants[10]. The participants are within the 22 to 52 age range. Six of them are males, and eight are females. All of the participants are of Afro-Caribbean decent. The interviews averaged one and a half hours. The following table outlines the number of participants in each age group, sub-divided by sex.

Table 1: Distribution of People Living With HIV/AIDS Interviewed.

Age group	Male	Female	Total
18 – 24	0	1	1
25 – 34	2	2	4
35 – 44	3	3	6
45 – 54	1	2	3
Total	6	8	**14**

[10] These three individuals were not attached to any HIV related organization, had not disclosed their status to many individuals, and therefore did not feel comfortable being interviewed by me.

4.2.1 Giving My Friends Names

I had the pleasure of spending a great deal of time with the study participants before I interviewed them. As a result, I developed a relationship with each of them. I therefore feel the need to give each a name, a pseudonym that somewhat describes their personalities. I used names that are very common in Tobago, and in many of the cases, I used the names of other friends and family. A brief description of each is included below:

Sharon is an Afro-Caribbean female in the 35 - 44 age group. She is heterosexual, single and currently lives in her own home. She has three children. Sharon completed secondary school[11], is currently not working outside the home, and lives on monthly social welfare stipends (income approximately $700TTD[12] per month). Her status is HIV positive and she has known about her status for approximately 10 years. Sharon is currently on antiretroviral medication.

Robert is an Afro-Caribbean male in the 45 - 54 age group. He is heterosexual, single and currently living in the house of his deceased common-law wife. He has two children. Robert has some secondary education, and is working outside the home (income approximately $3000TTD per month). His status is HIV positive and he has known about his status for approximately 5 years. Robert has never taken HIV related medications because he doesn't believe that he needs them yet.

Eric is an Afro-Caribbean male in the 35 – 44 age group. He is heterosexual, in a visiting relationship (partner also HIV positive), and is currently living in work related housing. He has one child. Eric has some university education, and is currently working outside the home (income approximately $9000TTD per month). His status is HIV positive and he has known about his status for approximately 8 years. Eric is currently on antiretroviral medication.

Natalie is an Afro-Caribbean female in the 25 – 34 age group. She is heterosexual, single and currently living in her own home. She has two children, one of whom is HIV positive. Natalie has some primary education, and is working outside the home (income approximately $1400TTD per month). Her

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[11] The educational system in Trinidad and Tobago is based on the British system. All young people are expected to attend some form of formal education up to age 12 years. Each child is expected to attend pre-school from age three to five. Primary school follows from age five to approximately age 12 (1st year, 2nd year, standard one through standard five). In standard five each student is expected to sit the "Secondary Education Assessment (SEA)" examination, which determines which secondary school the student attends. Secondary school goes from approximately age 12 through 17 (form one through form five). In form five, the student is expected to take the Caribbean Examinations Council (CXC) Ordinary Level (O'Levels) exams. If the student wishes, he/she can then continue onto form six (two years), after which he/she will take the Caribbean Examinations Council (CXC) Advanced Level (A'Levels) exams.

[12] The Trinidad and Tobago currency is known as the Trinidad and Tobago dollar (TTD). The exchange rate is approximately $6.25 TTD = $1.00 United States Dollar (USD)

status is HIV positive and she has known about her status for approximately 5 years. Natalie has never taken HIV related medication because her CD4 count[13][135] is relatively high.

Janice is an Afro-Caribbean female in the 35 – 44 age group. She is heterosexual, single and currently living in her own home. She has three children. Janice completed secondary school, and is working outside the home (income approximately $3000TTD per month). Her status is currently unknown because she was clinically diagnosed as having AIDS approximately 1 year ago. However because she was treated for the infections, and she continues to take the antiretroviral medication, her viral load is now undetectable. Janice has known about her HIV positive status for approximately 15 years.

Rebecca is an Afro-Caribbean female in the 45 – 54 age group. She is heterosexual, in a common-law relationship (partner also HIV positive), and currently lives in her own home. She has three grown children. Rebecca completed secondary school, and is working outside the home (income approximately $700TTD per month). Her status is HIV positive and she has known for over 10 years. Rebecca is currently on antiretroviral medication.

Alison is an Afro-Caribbean female in the 45 – 54 age group. She is heterosexual, married (no longer living with husband), and currently lives in her own home. She has three children. Alison completed primary school, is currently not working outside the home, and lives on monthly social welfare stipends (income approximately $550TTD per month). Her status is HIV positive and she has known about her status for approximately 4 years. Alison is currently on antiretroviral medication.

Melissa is an Afro-Caribbean female in the 25 – 34 age group. She is heterosexual, in a visiting relationship (partner also HIV positive), and currently lives in her own home. She has one child. Melissa has some Advanced level education, and is working outside the home (income approximately $2000TTD per month). She has AIDS because her CD4 count is very low. Melissa has known about her status for approximately 5 years, and is currently not on antiretroviral medication, due to adverse side effects.

Richard is an Afro-Caribbean male in the 25 – 34 age group. He is homosexual, single, and currently renting an apartment. He does not have any children. Richard completed secondary school, and has had additional skills training. He is currently working outside the home (income approximately

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[13] "CD4" refers to Cluster of Differentiation 4, which is a glycoprotein that is expressed on the surface of T helper cells, regulatory T cells, monocytes, macrophages, and dendritic cells. HIV attaches to the CD4 and causes a reduction in these cells. The "CD4 count" represents the number of CD4 cells per cubic millimeter of blood. The CD4 count in a normal adult averages 600 to 1200 cells/mm^3 of blood. According to the World Health Organization's classification for HIV/AIDS, AIDS in adults is defined as "first-ever documented CD4 count less than 200 per mm^3", among other definitions.

$3000TTD per month). His status is HIV positive and he has known for approximately 10 years. Richard is currently on antiretroviral medication.

Camille is an Afro-Caribbean female in the 18 - 24 age group. She is bi-sexual, single, and currently renting an apartment. She does not have any children. Camille has some secondary education, and is working outside the home (income approximately $2000TTD per month). Her status is HIV positive and she has known about her status for approximately 3 years. Camille has never taken HIV related medication because her CD4 count is relatively high.

Donna is an Afro-Caribbean female in the 35 – 44 age group. She is heterosexual, married (no longer living with husband), and currently lives with relatives. She has six children and is currently pregnant. Donna completed secondary school, and is working outside the home (income approximately $3000TTD per month). Her status is HIV positive and she has known about her status for approximately six years. Donna has never taken HIV related medication because her CD4 count is relatively high.

Dave is an Afro-Caribbean male in the 25 – 34 age group. He is homosexual, in a visiting relationship (HIV status of partner unknown), and currently is renting an apartment. He does not have any children. Dave completed some secondary education, and is working outside the home (income approximately $2000TTD per month). His status is HIV positive and he has known about this status for approximately four years. Dave is currently on antiretroviral medication.

Andy is an Afro-Caribbean male in the 35 – 44 age group. He is homosexual, single and is currently renting an apartment. He does not have any children. Andy completed secondary school, and has had additional skills training. He is currently working outside the home (income approximately $4000TTD per month). His status is HIV positive and he has known for approximately 12 years. Andy is currently on antiretroviral medication.

Frank is an Afro-Caribbean male in the 35 – 44 age group. He is homosexual, single and is currently renting an apartment. He does not have any children. Frank completed secondary school, and has had additional skills training. He owns his own business (income approximately $6000TTD per month). His status is HIV positive and he has known for approximately 2 years. Frank has never taken HIV related medication because his CD4 count is relatively high.

4.3 ETHNOGRAPHIC INTERVIEWS

The ethnographic interviews were conducted at various settings, depending on what was convenient to the participants. These ranged from being in their offices, to sitting in their cars, to being in their business places helping them stock shelves. The ethnographic interview participants were divided into three broad

categories: (1) health professionals, (2) community leaders, and (3) community members. Approximately 10 health professionals and approximately 15 community leaders were ethnographically interviewed. The health professionals included physicians, nurses, social workers, counselors, endocrinologists, and health administrators. The community leaders included teachers, clergymen and clergywomen, politicians, NGO leaders and organizers, and HIV activists.

The total number of community members ethnographically interviewed is difficult to identify, however an approximate number of 25 will be used. The community members included all other members of the community that engaged in conversations with me. These conversations ranged from mini interviews at the beginning of the research period used as pilots for the in-depth interviews, to informal discussions about HIV in Tobago. Community members included family members, neighbors, my former schoolmates, church members, school students, administrators, researchers, etc.

It was very easy finding individuals who wanted to discuss HIV/AIDS with me. In many instances, because the community members/leaders communicated frequently with each other, I was approached with issues and ideas for HIV prevention. In other instances, when I introduced myself community leaders would spend a great deal of time trying to trace my lineage, or they would have already known about my research. There were a few community leaders and health professionals that I would have liked to talk to, but because of their schedules, etc. those meeting were not possible.

4.4 PARTICIPANT OBSERVATIONS

Participant observations occurred in various settings. These included homes of PLWHAs and other community members, businesses (drug stores, bakeries, grocery stores, etc), weddings, entertainment events (harvest festivals[14], fisherman fetes[15], house parties, other fetes[16]), health clinics, hospitals, HIV related organizations, professional offices, planning meetings, workshops, HIV support group meetings,

[14] Harvest festivals originated as celebrations of the agricultural harvest. There are 29 harvest festivals in specific villages every Sunday, or every other Sunday, depending on the time of the year. These have evolved from the agricultural base, to one where villagers cook extensive amounts of food, and buy extensive amounts of liquor. Members of other villages then visit their friends and families in the host village.

[15] In the historically fishing villages, a tradition of "fisherman fetes" has evolved. These consist of members of the host village cooking and providing free alcohol to other community members who visit them. Several fishing competitions, in addition to other games and competitions occur throughout the day. The festivities start with J'ouvert (a street party that starts normally at 2am and goes into day break), and culminate with a large beach party.

[16] Based on the French word (fête) that means festivals or holidays, in Trinidad and Tobago a fete is a party, usually associated with loud music, alcohol, and sometimes food.

and HIV testing labs. In addition, very close attention was paid to the current state of television and radio programming, and finally, the general environment was closely observed.

I became very involved in the daily running of one of the HIV related organizations in Tobago. For about four months, I spent up to six hours per day, at least four days per week at the office answering the phones; making social services and other types of arrangements for the PLWHAs; representing the organization at meetings, workshops, conferences and other events; organizing and attending support and other meetings of the organization; planning World AIDS Day and other major HIV related festivities; and simply "hanging out" at the office. After a while, the PLWHAs expected me to be at the office, and I became more like a friend than a researcher. If I missed a meeting, or did not show up, they would call me, or meet me in other settings and ask why I was not there.

Due to the nature of the other HIV organizations, I did not have an opportunity to spend extensive amounts of times with the PLWHAs that they served[17], however I did have an opportunity to interview other non-PLWHA members of those organizations, and spend time with them at other meetings. I attended four (4) meetings organized by the Tobago HIV/AIDS Secretariat aimed at planning World AIDS Day activities, which incidentally did not happen as planned. In addition I attended a strategic planning meeting aimed at laying out the plan for HIV in Tobago for the upcoming fiscal year. Voluntary HIV testing and counseling has recently been instituted in Trinidad and Tobago. In an effort to evaluate this process a questionnaire was developed by health professionals on the island. I aided in the development and administration of this instrument, and spent about three hours per day at least three times a week for approximately two months at the antenatal clinics and maternity wards administering these interviews[18].

Tobago is a hub of entertainment activity, where anyone, young or old can easily find a different party or lime[19] every Friday, Saturday or Sunday evening/night (or any other day or the week if you were really interested). As a result, it was very easy doing participant observations in entertainment settings. My friends and I attended concerts, fisherman fetes, harvest festivals, many other social gatherings. I was also welcomed into the homes of PLWHAs and community members alike. These ranged from having dinners, to just hanging out and watching television.

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[17] This issue is discussed in chapter five (5).

[18] I do not believe, according to research ethics, that this is an appropriate format to discuss in details the results of those interviews. As a result, only very limited information as they relate to my research topic are included from these interviews in chapter six (6).

[19] The word "lime" refers to an informal gathering of people to hang out. It may be planned, like a cookout at someone's house, or it may be spontaneous, like the gatherings that occur at street corners where young men get together.

Much to my surprise, I also did significant participant observations with individuals within the homosexual community in Tobago. Before going to Tobago, I assumed that there was a relatively large homosexual community on the island, but I envisioned a great deal of difficulty gaining entrée into this community due to the stigma and discrimination associated with homosexuality. I was wrong. Closer to the end of the six months, I made friends with several homosexual men, who frequently spoke with me, came to visit me at the offices and my home, and invited me to their homes.

5.0 THE EXPERIENCES OF PEOPLE LIVING WITH HIV

Research Question Answered In This Chapter

(a) *What Are The Pre- And Post-HIV Infection Experiences (Social And Cultural) Of People Living With HIV/AIDS In Tobago?*

5.1 WHY IS THIS IMPORTANT?

This section pays tribute to the individuals already living with HIV/AIDS in Tobago by allowing their expertise in the topic of HIV/AIDS to be acknowledged and explored. I believe that knowing and understanding the pre- and post-infection experiences of PLWHA is of utmost importance in HIV prevention in Tobago. Particularly, understanding the plight of PLWHAs identifies the circumstances that resulted in their HIV infections. When these circumstances are understood, they or similar circumstances can be incorporated into prevention programs because they may be applicable to other members of the general population. In addition, understanding post-infection experiences gives insight into how PLWHAs experience life in Tobago. Their experiences help in the development of effective HIV treatment and care programs. In addition, understanding their post-infection experiences also helps in the development of HIV prevention programs, since how PLWHAs are treated and how they experience HIV/AIDS may influence how other members of the community think about HIV/AIDS. To understand some of the social and cultural factors that influence HIV infections, I asked the participants to tell me a little about the situation(s) that resulted in them becoming HIV infected.

5.2 SEXUAL RELATIONSHIPS

5.2.1 Types Of Sexual Relationships

In Trinidad and Tobago, HIV is transmitted primarily via sexual contact. As a result, I wanted to understand the types of sexual relationships common in Tobago, and particularly within the PLWHA population interviewed. One issue that was continually echoed in the heterosexual relationships was the

illusion of being in a monogamous relationship. Several participants were either married, living in a common-law marriage or having a long-term visiting relationship when they became infected. In the majority of cases, the participants reported that they were faithful, however their partners were not. Eric talks about being out of the country for a couple months, and coming back to what he believed was a faithful partner:

> "I was involved in a relationship with a young lady, and I had to go to the United States. I was there for about five, six months. And shortly before I left, about two weeks, we had a falling out … When I got back I saw her and we started back having a relationship… Between the five months I was there [in the United States], apparently she had a sexual relationship with somebody else. Well it was not known to me at the time, and [we] started having a sexual relationship… As a result of that I contracted an STD, sexually transmitted disease … This was about 1994, 95 time so. So after about three months I did an HIV test and the results came back negative. And it wasn't until about 3 years later when I moved on with my life, I started seeing other people and stuff like that [when he discovered that he was HIV positive] …"

While most participants stated that they were being faithful to their partners, a few admitted that they were indeed the ones having affairs or having multiple sexual partners for several reasons, including economics, abuse in the primary relationship, and the need to feel loved. Sharon, for example, talks about the fact that she wasn't getting the type of love and affection from her children's father; therefore she had a sexual relationship with another man. She calls this man the "sweetman". This third party was also having sex with other females, he contracted HIV, and then infected her:

> "Well, my children father gave me everything. Plenty money, nice clothes and everything, but I had a little sweetman who showed me love. He didn't have nothing to give me you know, but when I was hungry he used to bring me food that he mother cook … you know these little things? … He was the one that show me the kind of appreciation that I really wanted my children father to show me… and then he get whorish[20], the sweetman, and he come and bring this disease …"

Although most of the participants were in relationships (either married, common-law or visiting), several identified the fact that they were being sexually promiscuous outside of conventional long-term relationships, which resulted in them contracting HIV. For example, Frank stated that he had a "freeloading" Carnival season, with several sexual partners; therefore to ensure that he was okay, he decided to get tested for HIV. At this point, he discovered that he was HIV positive. He does not know from whom or when he became infected.

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[20] From the word "whore." Whorish is a negative term used to describe having multiple sexual partners. It is frequently used to describe women; however it has recently transferred to describe males with multiple sexual partners.

5.2.2 Economics, Family Structure and Abuse in Relationships

Domestic, sexual, emotional and several other types of abuse were commonly raised throughout the interviews with the female PLWHAs. In many instances, the abuse (physical, verbal, emotional, and even sexual) was very common within their relationships at the time of infection and in previous relationships. As an example, Sharon describes one incident of physical abuse at the hands of her common-law husband:

> "… he is a dominating man. One day I went out with the neighbour[21], I went cinema cause I home in the house all the time, doing everything: cooking, cleaning, washing, doing everything. You have to get up in the morning, bath, cook breakfast, start lunch, cover it down and whenever he feel to eat, he eat. And a evening I was home and the neighbour say 'girl let we go down in town, and eat a little fried chicken and chips', I said 'alright' because I glad for the little out. I go in town, eat the fried chicken. She sponsored me you know, transport and everything. I come home feeling happy. Girl that man beat me. When I come he was home, and he beat me, all mi face swell, mi eye black and blue, if you see how I look mash up. And I never forget it and I will never forgive him."

Frequently, the women followed the descriptions of abuse with a rationale for why they stayed in the abusive relationships. Economics, and the need to maintain the family structure, were commonly stated reasons. Sharon, for example, stated that she would "give him [her common-law husband] a little wife[22]" because he gave her money for the children. Rebecca, on the other hand, stated that she has and at times currently exchanges sex for "curtain money[23] and all them kinda things." Likewise, almost in tears, Janice talked about the physical, emotional, verbal and sexual abuse that she endured while living with her common-law husband. She discusses the fact that she continued having sex with him because "it done happen[24]", and she describes why she stayed with a man who almost killed her on several occasions:

> "The relationship was abusive in the first place and in Tobago when you have kids, especially when you ent[25] grow up with a father you does try to get the best for you children. Whether it's a common-law relationship or a married relationship, and it not

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[21] The British spelling of the word "neighbor". I chose to use this spelling because British English is the official language of Trinidad and Tobago.

[22] To give or get "wife" is a term used to describe giving or getting sex.

[23] In Trinidad and Tobago Christmas is very important. It is customary and expected that all homes would be painted, fixed and new curtains, furniture, carpet and other artifacts be purchased and displayed. Families and homes that are not adorned with these new things are seen as an embarrassment because it signifies lack of money.

[24] "It done happen" refers to the HIV infection. She believes that she is already infected, so there was no benefit to leaving the relationship, or trying to find another partner.

[25] The word "ent" has two main meanings. In this context it is an alternative to "is not", "aint", "did not", "do not", and similar concepts. In the second context it is a term that mean "isn't it so" or "that is right, isn't it?"

working out you does stay because of the kids. I guess that was me, trying to make ends meet, just to make sure that they have a stable home, a father figure, a mother figure."

5.2.3 Condom Use And HIV Testing In Relationships

The participants overwhelmingly stated that it was not common to use condoms in "loving", or "trusting" relationships in Tobago. In fact, the suggestion of condom use was seen as signifying lack of trust, infidelity or suspicion of illness, and placed a strain on the relationship, particularly for women or individuals identified using the "female" gender. As Melissa looks back on her situation, she laments about being gullible and not wanting to disturb the relationship by demanding condom use:

> "I was too gullible if you could put it so… when you trust somebody, because I am saying 'yes we were in a relationship'. We were engaged, so I didn't see the need for me to use a condom at the time when he comes up or whatever. That was my mistake."

Like Melissa, none of the other participants discussed their partners' sexual history, nor did they confirm their HIV status before starting a sexual relationship. As expected, this provided a recipe for disaster since consistent and correct condom use was not common. The consequences of not getting tested were described by Natalie, who believes that her common-law husband was indeed faithful during their relationship, but contracted HIV from a previous relationship. She discovered her status after her common-law husband became very ill and died shortly after. Though Natalie believed that her common-law husband was not aware of his status, Richard firmly believes that his sexual partner was fully aware of his status, but chose to withhold that information from him. He cited the fact that his partner was older and was the breadwinner of the family as reasons why he did not insist on condom use.

5.3 LEARNING ABOUT THEIR HIV/AIDS STATUS

Studies have shown that how an individual reacts to a positive or a negative HIV test result depends on several factors, one of which is how that information was relayed [136, 137]. As a result, I felt it necessary to examine how this type of information is given in Tobago. This includes the presence or absence of pre- and post-test counseling, the professionalism of the person giving this information, in addition to the myths, legends and tales of how HIV results were given in the past to other individuals.

5.3.1 Pre- and Post-Test Counseling

I asked the PLWHAs about whether they were counseled before or after getting tested for HIV. Frank, who has known about his status for two years was the only PLWHA interviewed who was adequately counseled before being tested for HIV. Janice stated that when she was first tested 15 years ago in Tobago she received no counseling, but she did receive counseling at her second testing in Trinidad several years after. Camille, though she was somewhat prepared for a positive result due to her sexual history and her personal knowledge about HIV, stated with annoyance that she was not counseled at all three years ago when she learned her status. She stated that it seemed like "these people don't expect people to come in and be positive", so they did not prepare individuals for the possibility of a positive test. She describes her experience, which was very similar to other PLWHAs tested in Tobago:

> "I went in and I told them that I wanted to take a test, they took the blood and they told me that I could come back the evening."

5.3.2 Professionalism of Health Professionals

In addition to not being counseled, a recurring theme in the in-depth interviews was the lack of professionalism of the health care workers who told the participants about their status. When Camille returned for her results she was first told that they couldn't find any information on her. She was then directed to a third individual who stated "oh, I need to speak to you". Similarly, Eric was told to return for his results, and when he went back he was told to go to his doctor for the results. The lab was suddenly unable to give him his results. Due to her financial situation, Sharon decided to call for her results. The receptionist responded by hanging up the phone. She describes the situation below:

> **"**Well I didn't have no money to go, so I called on the phone. And when I called on the phone, the receptionist picked up. I said that 'I want to find out about this test that I took', and the receptionist hang up the phone on me. So I find that was so strange – how come she could just put down the phone on me? I called back again, she said 'best you come in'. So I went in and they gave me this letter. I took it, and I anxious to know the results. When I opened it I saw 'HIV positive'."

Janice did her HIV test at a health clinic, and had possibly the least professional response of the PLWHAs interviewed. From speaking to other community members, her experience represents what the general community sees as the norm in HIV status discussions between health professionals and PLWHAs. After being told to see a doctor by her abusive common-law husband, she was simply looked at by the doctor and told that she had six months to live. Having had 15 years to deal with her status, Janice can now laugh and joke about how the doctor told her that she was HIV positive:

> "… Ah still go by the health center. Next thing you know the doctor watching me and telling me 'you look like you get it [AIDS]', and I was like 'get what?' … He wouldn't tell me… well he [common-law husband] tell me that the doctor tell him that he get syphilis, so automatically I expect them to check me for syphilis… well they scrape mi inside …. And he send me to the nurse to take some blood. I gone by the nurse, the nurse just trickling out my blood, must be about five or six vials, and I was like 'nurse, what is all that blood for?' She telling me 'so the doctor ent tell you?' I said 'no, the doctor just tell me that I look like I get it, and I don't know what I get, and I would like to know what allyuh taking all that blood for'… So she start to explain to me that they have to take all this blood because they want to do some tests, to see how far the syphilis is, if I have HIV, if I ever had herpes, and everything…"

After that ordeal, Janice decided not to return for her test results. A few months later, however, she was contacted by one of the nurses at the health center, so she decided to go for her results. Again she was not counseled, and the session ended with the doctors asking "so you ent know you get AIDS?" Several other PLWHAs interviewed related very similar experiences. One gentleman, while caring for his ailing common-law wife, was told not to waste his money because his wife had AIDS.

An expected reaction to getting an HIV positive test result is to ask "what next?" Several of the participants recalled asking that question, and several of them got very negative answers from the health professionals. For example, Camille wanted to know about medications and so forth, but the health professional had no answers:

> "Well actually I tried to get information at the time but the lady had no information, the lab in Tobago here… I was like, 'so what about medication', [the health professional said] 'well we not too sure you know'. She knew about places in Trinidad, she know that they supposed to start in Tobago, but she not sure. She think there is the OASIS Foundation, but she don't know where it is."

5.4 WHAT HIV/AIDS MEANS TO PLWHAS

After talking about how they got infected, and how they received their results, I spoke with the PLWHAs about their views about being a PLWHA in Tobago. I wanted to know how they felt, how they viewed their lives, and whether there was a difference between how they viewed their lives now compared to when they just found out about their status. These questions are also important because the experiences of PLWHAs in Tobago directly and indirectly influence how other community members feel about HIV and living with HIV. For example, if the only examples of PLWHAs are people dead or dying, or people being discriminated against, these would negatively color how other members of the community view the disease, and possibly affect their willingness to be diagnosed and to disclose their status if infected.

5.4.1 HIV Happens To Bad People

The idea that HIV only happens to bad people (homosexuals, promiscuous individuals, etc.) is an idea that still exists in Tobago. Hence individuals expressed a sense of shock when they discovered that they were HIV positive, because they didn't believe that they fit into the categories of the type of people who get HIV. Some participants associate HIV with individuals who drink, smoke and party too much, people who are promiscuous, are homosexuals, or otherwise live a "bad lifestyle". Janice explained how shocked she was when she discovered that she was HIV positive, because she was "a good girl":

> "Well I never really thought that I could get AIDS, because AIDS was something where you looking at people out there and you saying 'she have two and three man' you know? 'She out there [being promiscuous] and she go get AIDS', but it never dawn on me that AIDS coulda come home to me"

The Tobago OASIS Foundation office is located in a small plaza in the capital of Tobago. It is on the first floor of the building next to a couple of boutiques and stores. On the ground floor there are clothing stores, beauty supply stores, etc. One day after being seen going in and out of the OASIS office I went to purchase something at the beauty supply store. As I entered the store, I noticed a close family friend talking with one of the service ladies in the store. She saw me, but I pretended not to notice. Because she had not seen me in over a decade, she wasn't certain about my identity, so she started asking the other service lady if I was my mother's daughter (she used my mother's name). The service lady said "no, she can't be, she does be upstairs with them AIDS people". The family friend then stated "ok, it's not she then, if that person does be upstairs, its not mi friend's child." At that point I looked at both of them and stated "yes, its me." Both were very surprised, but because they didn't know that I had overheard the conversation, they greeted me normally.

This made me very aware of several issues. One, because they knew that I was in the United States studying and I had come from an upstanding family, they assumed that I could not be associating with "them AIDS people". The second issue relates to the lack of privacy and labeling that happens to any individual who goes into and out of the OASIS office. This second issue is discussed in the confidentiality section of this manuscript. When I returned home I told my mother the story and admonished everyone in my family to refrain from confirming or denying my HIV status if asked about it. The appropriate answer should be "and what if she is?"

5.4.2 HIV Is Synonymous With Death

At the time of diagnosis, the idea that HIV was synonymous with death is a theme that resonated among the participants, particularly those who were diagnosed five or more years ago. Eric's recount of how he felt after getting his diagnosis exemplifies the consensus of participants' feelings at that time:

> "He [the doctor] said 'Mr. [participants surname] you are HIV positive', and then like everything around me just collapse. There was this feeling of total despair. The first thing I started to hear was death, death, death! Because at that time, that is what HIV was being publicized as. You have HIV, you going to die. There was nothing about treatment or anything like that. They used to show plenty picture[s] of people dying from HIV. So that's all that went through my mind."

In addition to their personal views about HIV meaning death, several participants talked about how their family and friends reacted similarly when talking about HIV. As in Natalie's case, the first question that several friends and family asked after disclosure was "'you going and die just now?'" Camille, with great pride, describes the reaction that she gets from individuals in her home village who are genuinely surprised that she currently looks healthy:

> "But when I go [name of home village] I does get a reaction, some ah them does actually look surprised to see me because I still looking good. The rumor did reach so far, that they say that I was on my deathbed. So when they see me they does [she makes a gesture of surprise on her face]."

As I stated before, the individuals who discovered that they were HIV positive greater than five years ago tended to have very negative views, particularly the view that they would die soon. Those participants who recently found out had relatively positive responses. Andy, who discovered that he was HIV positive two years ago, represents a good example of their response:

> "I was actually normal, because of the fact that when I found out, it was what, this week would make it two years. So by then everybody, it was like if you have high blood pressure or you have diabetes."

5.4.2.1 What Will Happen To My Children When I Die?

Those women who were mothers at the time of their diagnosis also had the fears of HIV meaning death. This fear was exponentially increased, however, when they thought about what would happen to their children after they died. Though the men interviewed did not express any fears about their children, if they were fathers, the women feared that their children would be separated, would be mistreated or abused, or would not be taken care of at all. Others expressed anger that their children would be forced to grow up without a mother. Natalie for example, angrily wondered about who would take care of her children when she died:

> "I was mostly angry because mi kids and them ent grow up as yet, and to find out that you are HIV positive and you are going to die just now. Who is going to take care of them?"

Sharon on the other hand didn't "want no social welfare officer come and say that they taking [her] children and put one here and one there." Janice presented an extreme case. She experienced domestic abuse at the hands of her children's father, and verbal abuse at the hand of her in-laws. As a result, she was so afraid that her children would be mistreated if she died that she developed a plan to ensure that she killed her children before she died:

> "The actual thought I had when I first find out about dying was like 'you see me, me ent going and leave my children them now'. And to be honest with you, I really bought a bottle of Gramazone[26] … And I not leaving my children to suffer so when I going to die all three ah we dying together."

5.4.3 How HIV Affects The Daily Lives Of PLWHAs

I believe that how HIV affects the daily lives of PLWHAs affects their ability to cope with the disease, in addition to influencing how other individuals view HIV. As a result, I asked several participants how HIV affected their general well being. In most cases individuals stated that they continue to work and live relatively "normal" lives.

5.4.3.1 Economics, Work And HIV

The only time HIV significantly affects their daily lives is during periods of illness, which prevents them from working, taking care of their children or their other family members. Sharon's example highlights the direct connection between HIV infection and economics, since she was recently awarded a job, but was unable to do it because she fell ill:

> "… I finally get through with the 10 days[27] and I get sick, so I couldn't go to work. You feel them studying me to give me a 10 days again? They go say 'why you didn't come and do your 10?' … Two days before the 10, I [got] sick, [and ended up in the] hospital"

[26] Gramazone is a popular pesticide used in agriculture in Trinidad and Tobago. It is also publicly known as a suicide method.

[27] The government of Trinidad and Tobago has implemented several types of unemployment relief programs. One such program is locally known as "10 days". This is a beautification project where workers are employed for alternating 10-day period (10 days on and 10 days off), to clean the roads, beaches, parks, and other areas.

Several studies identify a correlation between HIV and economic status, where poor individuals are more affected by HIV and individuals who become infected with HIV become poorer [35, 36]. I felt that it was important to understand the current economic status of the PLWHAs interviewed. As an introduction to the interviews, where demographic information was collected, I asked the PLWHAs about whether they worked outside the home and their average monthly income. The average income reported by the female PLWHAs was $1669TTD (range of $550 to $3000 TTD), while the average income for the men was $4500TTD (range of $2000 to $9000 TTD) per month. The females generally have maintenance or laborer jobs, while the males generally have jobs in the protective service or the hospitality fields. At support group meetings, several members requested that the organization organizes skills training workshops for them, which would then allow them the opportunity to make items (bandanas, t-shirts, crocheted items, etc.) for sale.

5.4.3.2 Sex After HIV

Though several study participants seem to have normal, healthy sex lives, several of them expressed the fact that they have not had sex since becoming infected. One common reason for not having sex involved not wanting to disclose their HIV status. They believed that their partners would start asking questions if they insisted on condom use. A second reason involved the fear that they would be blamed for infecting others if their status was discovered. In fact, Sharon stated that she had one sexual partner since her diagnosis, however he has since accused her of infecting him, therefore she is now abstinent. Janice similarly explained that she was once almost run over by a car driven by the friend of a boyfriend who had recently died. The friend driving the car screamed, "you kill him, you give him AIDS!"

Though the other PLWHAs explained to some degree why they avoided sex after becoming infected, I think that Camille voices what they may have been afraid to say. She does not like having sex with condoms because of what condoms represent. In addition, even if she uses a condom, she is afraid to have sex without disclosing her status for fear of infecting others. Her example expresses the fears of the other PLWHAs interviewed who refrain from sex:

> "Yes, (laughing nervously), sometimes I don't know how to say it. It is certainly affecting me, I try to stay away from it, because well most of the times that I have sex now it is with the boy that I was living with because he already knows the situation. I find that having sex with people, whether I use the condom or not, I don't feel comfortable, having sex with somebody and they don't know my status. Even if I am using a condom I don't like the idea of them not knowing, because if the condom burst, and they find out this thing after, and they want to come and kill me. So I, besides that I feel like I am missing something, I don't really feel for sex anymore. I feel its because I stayed away for so long. I just feel like I missing something. Not missing something in the sense that I want it and I can't get it, its just that I don't feel for it. I feel like if something is wrong with me… I don't know.
>
> I think is something psychological because when I was living with mi boyfriend, and when we would have sex, sometimes he wouldn't use a condom, and the times that he didn't use

> a condom I used to be really aroused, … Like if I think that he not wearing it I does have a real good time, but from the time he pull the condom I does be like [she stueps[28]]. Sometimes it does be, I think that it is psychological in truth because I really feel like I missing something."

Since safe sexual activity is important in the lives of PLWHAs and the general community, I asked the PLWHAs whether they had been counseled on issues pertaining to healthy sexual activity. This included the fact that a person's sexuality does not halt after an HIV diagnosis, and the importance of condom use to prevent re-infection or the infection of other parties. None of the PLWHAs remembered their physician specifically talking with them about healthy sexual activity. In fact, one PLWHA was pregnant at the time of the interview. She stated that her sexual partner was HIV negative, however they continue to have unprotected sex. She did not seem to understand the ramifications of having unprotected sex as a PLWHA. Those who were aware of the need to protect their sexual health and the need to use condoms stated that this information was given at other venues, including support meetings at the HIV related organizations or workshops sponsored by these organizations. For many study participants, particularly those not attached to an HIV related organization, their sexual health is something that has never been discussed.

5.5 HOW PLWHAS COPE WITH HIV IN TOBAGO

What are the coping techniques used to deal with being a PLWHA in Tobago? Though I didn't explicitly ask this question, as the participants talk about living with HIV, several of them identified coping strategies.

5.5.1 Belief In Higher Powers

According to the 2000 census for Trinidad and Tobago, of the 44,190 people from Tobago who answered the question about religion, only 2,602 stated that they had none. Of those who identified a religious affiliation, 90% identified some form of Protestant Christianity, 7.5% identified Catholicism, less than 1% percent identified Hinduism, less than 1% identified Islam, and less than 1% identified Jehovah's Witness

[28] When someone stueps they make a hissing/sucking sound with their mouths. It usually represents anger, frustration, or disgust. In this context it represents a combination of those feelings.

[138]. Many of the study participants referenced their belief in God[29] as a method of coping and treatment. Robert, for example, stated that even though he knew that there is no cure for HIV, he is still putting all belief in God for his healing:

> "… God don't give you more than you can handle… And I say 'that it's not me, it's God, he can cure everything.' Even though they don't have no medical cure for this thing, I know it have no sickness that God can't cure, so I putting all my belief in he."

Even though I was raised in Tobago, I was still surprised at the degree to which religion, and particularly Christian religious philosophies, are entwined within all aspects of daily life. For example, the beginning of broadcasting for both radio and television stations in Tobago is done with a prayer; both public and private schools begin with, and in some cases, end with prayer; and religious pictures or writings can be found on the walls of business places and other public places. There is also an automatic inclusion of God in the recommendations for dealing with HIV by the health professionals on the island. For example, when Rebecca discovered her HIV status over ten years ago, her doctor explained that he could do nothing to help her. He then suggested that she needed to "make [her] path right with God".

Another example of the belief in a higher power (or the belief in the supernatural) occurred when Janice's husband began getting sick. In Tobago, although a large portion of the population identify with either Protestantism or Catholicism, intertwined in these beliefs is the idea that individuals can communicate with the devil or the dead and bring harm to other individuals. Therefore it is common to blame an enemy for the illness or downfall of another. Initially, instead of seeking medical advice, his family and friends quickly blamed Janice, and stated that she was trying to get back at him for how he treated her by working obeah on him. Similarly, when the women that he was cheating on Janice with also became sick, they again blamed Janice.

5.5.2 Support After Getting Infected

In an effort to understand the lives of PLWHAs I wanted to know a little about their support systems. While most PLWHAs spoke about God, all mentioned the support of other social systems including friends, family, social services, and HIV related organizations.

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[29] In this context, when individuals talk about God, they are referring to the God of the Jews, as identified in the Kings James version of the bible. God is the father of the triad that is the Father, Son and Holy Ghost.

5.5.2.1 Friends and Family

The importance of support from friends and family was discussed by several of the participants. Several PLWHAs stated that their HIV infection had positive effects on their relationships with family and friends. These individuals assured them that an HIV status was not synonymous with death, that they could still live very normal, healthy lives, and that they could come to them when needed. Janice also describes the support she got from a neighbor who allowed her the time and space to cry when needed:

> "But I had this lady friend, I used to go and get water by, and everyday she see me coming for the water. And I used to be behind the house by myself, when I think nobody ent watching me, sometimes she inside watching. But you know she ent saying nothing because she don't know what happen. And I used to be like, everyday I go for the water, it's the only time I could let out how I feel. I used to be real crying. And then one day she come out and she say 'girl, everyday you coming behind here and you crying. What is it?' I ent tell she the same time, but I go home and come back. Because it's a woman that does give me anything, so I feel I could trust she and tell she. And is so I come and I tell she. Well she and all didn't know what to do. So when she see mi come she ent go disturb me. But she ent go let me overdo it."

5.5.2.2 HIV-Related Organizations

One point that kept coming up over and over again was the importance of meeting other PLWHAs. When PLWHAs realized that they were not alone, or that other PLWHAs were living normal lives, they were encouraged and supported, so they continued living "normal lives." As Janice stated, for several years she felt like she was the only person in Tobago living with HIV. After she was introduced to an HIV-related organization, and she saw that the hundreds of people there were also PLWHAs, she felt the courage to walk with her head raised high, without the burden on HIV on her shoulders:

> "And I used to feel like I alone in Tobago have AIDS. Until it was about 1999 that Dr. [health professional] call me and ask me if I want to go to a workshop. She didn't really tell me what it was all about, but she told me that it would be a really good experience... It was in the Cove, and the first day of the workshop I was shocked. There was doctors, teachers, there was ordinary people like me. And by the end of the first day I realize that everybody in this room, the hundred and how much people in this room except for a few of the facilitators were HIV positive. And I say 'why I have to live like this in Tobago?' ... Eventually I started going to Trinidad every Wednesday because they had meeting by CARe[30], they had a support group there. It had people living with the disease longer than me. So I used to go down every week and I start building up myself."

The most obvious place to meet other PLWHAs is at organizations that provide support and services relating to HIV/AIDS. In Tobago there are three organizations that specifically deal with

[30] The acronym CARe stands for Community Action Resource, an HIV/AIDS support group in Trinidad.

HIV/AIDS - the Tobago AIDS Society, Friends of the Tobago AIDS Society and the Tobago OASIS Foundation.

(a) Tobago AIDS Society (TAS)

The Tobago AIDS Society was the first HIV/AIDS related organization in Tobago. It was started in 1996 by a health professional who noticed an upward trend in the number of HIV and AIDS cases in Tobago. She believed that a support system was necessary to help PLWHAs and their families, in addition to providing HIV education to community members. TAS has since expanded to provide a large range of services to PLWHAs and their families. These include providing food vouchers of about $200 to $250TTD per month to approximately 40 PLWHAs, providing the dietary supplement "Ensure", helping with funeral costs when necessary, providing school books and uniforms for children of PLWHAs, paying rental expenses for a limited number of families, and giving Christmas food hampers. The educational programs include having lectures at primary and secondary schools geared to the teachers and parents and having information booths at various events throughout the island.

TAS is run from a small office, via an administrative assistant. According to representatives, none of the administrative staff are PLWHAs, however there are board members who are HIV positive. Other non-TAS members believe that TAS has an unofficial policy of non-disclosure, therefore PLWHAs are not encouraged to participate in workshops or other venues where their HIV status may be disclosed. I was not able to interview any PLWHA solely associated with TAS because of this policy. This TAS office is very small, but is filled with brochures and other types of information about HIV and diabetes (the office also houses the Tobago Diabetes Association). There are plans to build a health facility, which includes a hospice for HIV and other chronic disease patients.

(b) Friends of the Tobago AIDS Society (FOTAS)

The Friends of the Tobago AIDS Society is an adjunct organization that was created by several Trinidad and Tobago nationals living in the United States. According to a current board member, the founder is a Tobagonian whose adult child had died from AIDS related illness. In an effort to reduce the suffering of other PLWHAs, and in an effort to help in her healing, this organization was created. FOTAS is purely a charitable and educational organization with the main purpose of providing financial, medical, professional and other resources for persons infected with and affected by HIV/AIDS. They raise funds in the United States and London, which is used to fund the yearly five-mile FOTAS AIDS Awareness Walk in Tobago. Each participant in Tobago purchases a package (approximately $60TTD), which includes a t-shirt, a small bag, HIV information and other trinkets. In 2006 the largest turnout thus far surpassed 1000 participants. FOTAS initially divided and gave the proceeds to both TAS and OASIS, however due to alleged mismanagement of funds, it was recently announced that each organization is now required to write proposals for future funding. FOTAS has recently started directly supporting PLWHAs and their

families within the community, and they are interested in facilitating training sessions for physicians and other health professionals in HIV.

(c) Tobago OASIS Foundation (OASIS)

The Tobago OASIS Foundation is the only HIV-related organization organized and run by People Living with HIV/AIDS in Tobago. It is an offshoot from TAS, where the PLWHAs decided that they needed a place where they could meet and voice their fears and concerns without the presence of non-PLWHAs. It was founded by three PLWHAs in 2002, and it is officially a part of the Caribbean Regional Network of HIV Positive People (CRN+). OASIS offers a host of services to PLWHAs in Tobago. On the 2nd and 4th Wednesday of each month, support group meetings are held. These support group meetings include health-related lectures from physicians and other health professionals. In addition, members of OASIS are encouraged to attend sponsored workshops and conferences nationally and internationally. OASIS members are frequently asked to give presentations about HIV/AIDS and being a PLWHA in schools, churches, and other community organizations. The members of OASIS recognize the need for pre- and post-test counseling, as a result, community members who are interested in getting tested at the private laboratories can be counseled at OASIS. OASIS does not offer HIV testing. OASIS also organizes celebrations for World AIDS Day and the International HIV/AIDS Candlelight Memorial. Financial and social support of also offered via food hampers, transportation money and other necessities when available.

A board of directors, consisting of health professionals, clergymen, community members and PLWHAs, runs OASIS. The office is relatively big, and it is located on the upper level of a small mall in Scarborough, Tobago. There are signs on the outside, and the first floor of the building indicating the types of services offered in the office (figure 3 below). Due to the stigma associated with HIV, it is assumed that all individuals who go into and out of this office are HIV positive. This prevents individuals (PLWHAs and community member) from visiting the office; therefore OASIS members make frequent home visits. An office manager and her assistant run the office. There are computers, a new large laser printer, a television and DVD player. In addition, there is a library with books, brochures, flyers, and medication information cards. OASIS has been awarded funding to develop an internet café and a wellness center. These projects have not officially started however, due to lack of commitment and internal frictions within the organization. To help resolve this issue, a push was being made to include more PLWHAs on the board of directors. An annual general meeting was being organized as I prepared to leave Tobago.

The atmosphere at the OASIS office is very welcoming. PLWHAs spend a great deal of time there. They come to socialize, watch television, talk about issues surrounding medications and side effects, ask advise on obtaining different types of social support, their children visit and spend time doing home work,

eating lunch, or just hanging out. It is definitely an oasis, a fertile spot in a barren land, or a spot refreshingly different from others around it.

Figure 3: The Tobago OASIS Foundation sign
This sign is located on the first floor of the mall (hanging from the ceiling), indicating the presence of the Tobago OASIS Foundation office. It states that it is an "information and counseling centre for HIV and AIDS."

(d) Relationship Between HIV-Related Organizations

I sensed some degree of tension among the HIV-related organizations in Tobago. For instance, I have been told on several occasions that FOTAS is not an arm of TAS, but it aims to help **ALL** PLWHAs in Tobago, and "stay away from all the politics and fighting in HIV in Tobago." From speaking with various community leaders and health professionals, when the founder of FOTAS tried to contact HIV-related organizations in Tobago, they were told that TAS was the only organization; therefore it made sense to present themselves as Friends of the Tobago AIDS Society. They have since tried to distance themselves and support all HIV-related organizations. As another example, PLWHAs in OASIS believe that TAS's non-disclosure policy negatively affects HIV in Tobago. They believe that Tobago's general population needs to see healthy PLWHAs who are not ashamed of their HIV status. This disclosure would give HIV a face, and in the long term reduce HIV-related stigma and discrimination. The PLWHAs believe that their voice would be stifled if they were members of TAS.

(e) Views About HIV-Organizations

Of the PLWHAs interviewed, only three were not directly attached to one of these organizations. The support and services provided by these organizations were cited as extremely important to the individuals who use their services. Many individuals likened these organizations to their families, and in many cases other members of TAS and OASIS were identified as the only true friends of the PLWHAs interviewed. TAS and OASIS provide a place for individuals to just be themselves, where they do not have to worry about anyone seeing them take their medication or anyone talking about the rash or spots on their skin. In addition to these attributes, Melissa talks about the comfort that she feels at OASIS because she is with other PLWHAs, people who are "positive and going through the same thing":

> **"**Well OASIS has done a great deal for me, [in] that you feel at home. Even with the programs they send you on. It's with people of similar status, so you don't have to hide from nobody or hide to take your tablet or anything. People ent watching your skin, because everybody come like one. So I really does enjoy the sessions here, coming to meetings, where everybody talk and laugh. So I really enjoy it because you see, despite what people who are HIV negative, they can just imagine what you are going through, but when you deal with somebody who is actually in it, it's a difference. HIV negative people they would try to comfort you or give you a word of cheer or something, but they don't actually know. And you are going through things that you can't tell them, you would be able to open up to like somebody who is positive and going through the same thing."

According to clients at OASIS and health professionals at TAS, TAS has an unwritten policy about discouraging individuals from disclosing their status unnecessarily, therefore it was difficult identifying and interviewing the individuals who are PLWHAs and solely utilize the services of TAS. This policy, along with the fact that TAS is run by non-PLWHAs, was given as reasons why the individuals choose one organization over the other. In addition, there is a view that the organizations did not welcome individuals being members of both organizations. As Rebecca explained:

> **"**… because I know it have people who when they back against the wall, they run by TAS and TAS give them thing and they come back here and bad talking TAS. So, TAS does say that if you here you can't be there, and no jumping jack."

Due to this non-disclosure policy of TAS, the participants that I interviewed were primarily from Tobago OASIS Foundation. In fact, I also spent a large percentage of my time at the Tobago OASIS office. This provided me the opportunity for extensive participant observation. One observation was the endless number of workshops, conferences and other learning opportunities available to PLWHAs in Tobago. At one point there were three different learning opportunities within the space of two weeks. Since most of these were outside of Tobago, and required being away for several days, some of the members were not able to attend these activities. One such activity was a weeklong Peer Treatment Counselor (PTC) workshop, organized by Caribbean Regional Network of Positive People (CRN+) and the International

Alliance for HIV/AIDS in the Caribbean (The Alliance). The Alliance requested at least five individuals from OASIS for this completely expense paid workshop. Since several other members were away at other workshops or conferences, I was asked to join the group and represent OASIS at this workshop.

This workshop was very extensive and included information about how the immune system works, how HIV affects the immune system, the different classes of medication, how these medications affect the viral load and CD4 counts, and who when and why individuals should or shouldn't start HIV medication. In addition, information about who a PTC is, including the roles of helping with treatment plans, answering questions, and supporting adherence was discussed at this workshop. In addition to the knowledge gained at this workshop, there are also economic incentives for participating. There is a general policy of providing economic incentives for participation in these types of events; as a result, even though most lodging and meals expenses were paid, an additional, substantial per diem was given to each participant.

5.5.3 Social Support Services

The social welfare system in Tobago provides services to anyone in need. These include providing food, paying for additional medical needs, and giving monthly stipends when needed. The HIV related offices always advocate that their client access these services, however one downfall is the need to provide a medical reason why you are unable to work. Several PLWHAs talked about being asked very personal questions about how they contracted HIV and other issues that were not relevant, when they tried applying for assistance. Another PLWHA suggested that on the medical documentation needed for social services, all health professionals should state that the client has an "auto-immune related disease." It was also suggested that the client emphatically state that any additional information is not relevant, and therefore they would/should not answer those types of questions.

5.5.4 Denial And Finally Acceptance

One common method of dealing with HIV as described by the PLWHAs was denial. Several PLWHAs interviewed stated that their initial reaction was of denial, particularly since after a while they regained their strength, were no longer "feeling sick", and obviously had not died as predicted by their physicians. Eric talks about being in denial for several years after learning about his HIV status, particularly since his ex-girlfriend was not HIV positive and was having a baby. He believed that since he was having unprotected sex with her for several years then she must also be positive. Since she was pregnant he assumed that she was not HIV positive, which implied that he was HIV negative. Janice had the same reaction, particularly since she was given six months to live by her doctor. She however was rudely awakened when a second HIV test, several years later, proved that she was indeed HIV positive:

> "First to begin, they give me six months to live. Six months was mi death sentence. I looking at six month, and the six months come, the six month go and so on. And I just keep putting on weight, I ent looking sick, I ent feeling sick, and I normal. So I tell mi sister 'I want to go and do a next test because I feeling good', because the way I see people dying and the way they talk about AIDS, I say I woulda dead already… It was really stress, until one day they call me and tell me that the results come back. And I keeping mi fingers cross, because if it come back positive it go be very difficult. And when I gone, it was like if the end of the world was just there again. To hear that you are HIV positive! It was terrible. I feel like mi life was over then. If I didn't cry before, the nurse and all did feel sorry for me because I was bawlin' down the place … It took me a little time to adjust and realize that my status would not change."

Camille continues to experience that same type of denial. Though she says that she is learning to accept her HIV status, she has taken several HIV tests, hoping that the results would change. Robert was (and in my opinion is still) in denial about his status. He claims that he understands his status, however he refuses to visit a doctor or be treated for HIV. He attends the support meetings, and is very active within OASIS, however he does not believe that he needs medication even though he is beginning to show symptoms of advanced HIV disease (he is beginning to get boils on his skin).

Though this initial response of denial exists, the PLWHAS have all expressed a sense of acceptance, and in several cases an understanding that this has probably happened to them for a reason. Given this evolved view, most of them are now thankful that they have the experiences that they now have, because of being a person living with HIV in Tobago. They have traveled extensively, have earned or been given things, and have experienced several "blessings" that they believe would not have happened if they were not HIV positive.

5.6 HIV CARE AND TREATMENT IN TOBAGO

I believe that if HIV is effectively treated, and other community members see that HIV is no longer a death sentence but a chronic disease, individuals will be more willing to learn about their status, which is an important arm in general HIV prevention. As a result I asked several questions about the treatment and care options in Tobago. I also wanted to know whether the PLWHAs were satisfied with these services, in addition to possible recommendations for improving them.

5.6.1 Treatment Facilities

Trinidad and Tobago has a single payer health care system. As a result, any citizen can access medical treatment, in addition to prescription drugs free of charge at any government health center, hospital or

dispensary. The governance of the health system has been decentralized, and therefore administrative responsibilities are delegated to Regional Health Authorities. Therefore the Tobago Regional Health Authority (TRHA) is responsible for health care in Tobago. The Tobago House of Assembly (THA), the governing body of Tobago, however, has been granted authority over certain sectors of Tobago, including health care. If this seems confusing, that's because it is. While the TRHA board of directors is functional, the actual administrative and treatment arms of health care in Tobago is funded and run by the Secretary for Health, under the THA. There is one government hospital in Tobago and 18 community health centers throughout the island [139]. There are STD clinics at the hospital and the health centers where other STDs are treated; however, individuals with positive HIV diagnoses are referred to the Tobago Health Promotion Clinic (HPC).

The HPC can be seen as the treatment arm of Tobago's HIV response. The National AIDS Coordinating Committee (NACC), a body comprising of key stakeholders relating to HIV, was commissioned out of the office of the Prime Minister to coordinate a sustainable response to HIV in Trinidad and Tobago. This body has recognized the autonomy of Tobago, and has therefore commissioned that a similar entity be formed out of the office of the Chief Secretary of the Tobago House of Assembly. This body, the Tobago HIV/AIDS Coordinating Committee (THACC) is similarly comprised of key stakeholders, and is operated via the Tobago HIV/AIDS Secretariat. The Tobago Health Promotion Clinic also falls under the THACC.

The Tobago Health Promotion Clinic was opened in 2004, with the aim of providing "holistic HIV/AIDS care, prevention and education to the Tobago public within the context of concomitant patient friendly chronic disease care and education." It is located in the Calder Hall area. As the aim alludes to, this facility provides treatment for all chronic diseases, including HIV/AIDS. The services currently provided include (1) HIV Treatment, Care, Prevention, (2) Mental Health Counseling, (3) Chaplaincy, (4) Research Monitoring And Evaluation, (5) Social Services, (6) Substance Abuse Counseling, (7) HIV Testing, Voluntary Testing, (8) Mobile Health Services, and (9) Community Outreach Services [7].

The clinic is not equipped with a laboratory; as a result all laboratory work is sent either to the Tobago Regional Hospital or to Caribbean Regional Epidemiological Center (CAREC) in Trinidad. The clinic also does not have a pharmacy, therefore individuals must take their prescriptions to the drug dispensary at the Tobago Regional Hospital, where they are filled free of charge. To help protect their privacy, those individuals who are HIV positive have the option of having their prescriptions taken to the pharmacy by a nurse from the HPC, who brings the medication back to the clinic for pick up.

According to the latest clinic reports, as of November 2006, there were 1,235 registered clients, of which 206 were HIV positive clients. Of those HIV positive clients, 189 were on HIV related therapy. In 2006, 114 new HIV positive clients were seen at the clinic. Since the clinic opened, there has been an approximate decrease in HIV related mortality by 82%, a decrease in HIV related morbidity by 73%, and a

decrease in HIV related hospital admittance by 68%. Medication adherence is averaged at about 85%, according to this report [7].

Before the Health Promotion Clinic was opened in Tobago, PLWHAs from Tobago traveled to Trinidad to attend the Medical Research Foundation (MRF). The MRF was officially opened in 1997, representing the collaboration of the University of the West Indies (UWI), CAREC and local physicians to help fight the HIV epidemic. According to several of the clients who visit MRF, the services there are very comprehensive and they include testing and treatment options. MRF is also equipped with a laboratory and a pharmacy [140].

5.6.1.1 Views About Treatment in Trinidad

The participants were asked about the quality of their treatment and care as PLWHAs living in Tobago. One point that continued to be repeated was the fact that most of them were in-fact treated in Trinidad. This was due to several reasons, one of which is the fact that the HPC was only opened in 2004, so going to MRF was their only option for several years. All of the participants who've attended MRF in the past, or continue to be clients there have very positive reviews about the quality of service there. These clients cite the professionalism of the health professionals at MRF as a major contributing factor to them continuing their treatment in Trinidad even though treatment is available in Tobago. According to the PLWHAs interviewed, professionalism refers to how the clients are treated, and the confidentiality with which their information is treated. There is also a feeling that the general quality of treatment in Trinidad is better. One client stated that when she wants "ole talk[31]" she goes to Tobago, but when she needs "the real thing" she goes to Trinidad. Finally, MRF has recently implemented a 24-hour hotline that the clients seem to really appreciate.

Let me use this opportunity to describe transportation between Trinidad and Tobago. Trinidad and Tobago are approximately 21 miles apart. There are no land bridges between the islands, therefore transportation is limited to air or sea travel. Air travel takes approximately 15 minutes and costs $300TTD (about $50USD) round trip. Sea travel takes either six hours or two hours depending on the type of ferry used, and costs $50TTD (less than $9USD). When traveling either by air or sea, a PLWHA from Tobago can go to Trinidad for an early morning appointment and be back in Tobago by the end of the day. It is customary to travel between the islands for shopping or medical purposes. The cost of sea travel is within reach for most citizens of Trinidad and Tobago

[31] In this context, "ole talk" is a phrase used to describe being given information that is perceived as being useless, irrelevant or sometimes incorrect. It highlights a sense of frustration because the discussions are not useful to the PLWHA. In addition frustration is experienced in situations where additional action is promised by the health professional and not acted upon, again rendering the conversation useless to the client.

5.6.1.2 Views About Treatment In Tobago

According to several of the study participants, there are more Tobagonians being treated in Trinidad, compared to those being treated in Tobago. As a result, the figure of 206 HIV positive clients at the Health Promotion Clinic at the end of 2006 does not adequately represent the number of individuals infected in Tobago. One HIV-related health professional is in the process of using PLWHAs to identify other PLWHAs who are treated in Trinidad, with the hopes of determining what causes them to choose to go to Trinidad instead of utilizing the treatment options in Tobago. Several of the PLWHAs that I interviewed answered this question. The majority of the clients highlighted discomfort with a particular health professional working at the clinic. Apparently he does not have the compassion and tact needed to deal with this type of vulnerable clientele. One PLWHA stated that she believed that he should be on "the farm to see bout animals and things. Pig and horse and them kinda thing… He very grumpy." Another popular reason was the lack of technology available at the Tobago HPC. According to one client, she was being treated at the clinic without obtaining adequate lab tests including viral loads and CD4 counts. Since she received this type of information in Trinidad, she no longer feels that the clinic in Tobago is well enough equipped to safely treat her. Another factor highlighted is the inconvenience of going to the hospital dispensary for medications and the potential for disclosure at the pharmacy.

The overwhelming issue of concern to many of the clients is the fact that the clinic is locally known as the "AIDS clinic", therefore it is assumed that anyone who gets services there is HIV positive. Like the aim of the clinic states, this is not the purpose of the facility, however several community members that I spoke to refer to the facility as the "AIDS clinic", thereby confirming the fears of the PLWHAs who received treatment in Trinidad instead of Tobago.

While several participants have decided against being treated in Tobago completely, a few PLWHAs get services from both Trinidad and Tobago. These clients use the services in Tobago when their medications have run out or if there is an emergency. Otherwise they also prefer being treated in Trinidad. Of the 14 PLWHAs interviewed, only two are treated solely in Tobago. One of these clients stated that she became very ill while traveling to Trinidad once, so she has just decided to deal with the potential status disclosure and be treated in Tobago. Sharon, the other PLWHA who is solely treated in Tobago, believes that the clients in Tobago are treated a little better than those in Trinidad:

> "And then when I was really down, there is a nurse there, Nurse [Name], she used to give me home visit. And Dr. [Name] himself came home a day, to see how I was feeling. So I have no complaints about there [Tobago HPC]. I think that we in Tobago does get more care, that's what I think, I am not sure, because I don't think that in Trinidad does get home visits. I have no complaints. I don't think that I would transfer mine to go to Trinidad, I can't take that up and down to travel."

One unique thing that I discovered about being treated in Tobago was the possibility of new drugs being offered to the clients there. Natalie, who currently is not taking ARVs due to her CD4 and viral load, describes being offered a new treatment that includes placing a light on the tongues, which reduces the viral load. She intends to comply if the doctor thinks that it is a good idea:

> "But Dr. [Name] was telling me about this thing that he wants to bring in January, this light that you put on your tongue for one hour everyday, which will carry it down [her viral load]. And you wouldn't even see that its there in the blood… he asked me if I was on medication and I told him no. So he wanted to try it out on the patients who are not on medication as yet to see if it would work."

The Scarborough Regional Hospital is an option for treating emergency illnesses of PLWHAs. While a few clients are comfortable being treated at the Regional Hospital, the majority are very uncomfortable with that option and would do anything not to be taken there. For example, Sharon describes an incident where she was given the wrong HIV combination while in the hospital for a kidney infection approximately 2 weeks before doing the interview:

> "Infecting the kidneys. I went to the doctor in the hospital, that's last two weeks ah talking about, and when I went in the hospital they put me on ATZ and 3TC. Yesterday I went in the clinic and I tell the doctor what they put me on and he quarrel because he say that is not my combination."

Both PLWHAs and health professionals working in HIV echoed this issue about health professionals at the hospital being ill equipped to deal with HIV. Via participant observation I've heard about other individuals who were HIV positive and taken to the Regional Hospital who were not adequately treated for the HIV. In fact, in one instance it was recommended that the health professionals at the hospital contact the physicians at the Health Promotion Clinic, and this suggestion was not adhered to. Apparently offers for HIV training for physicians at the hospital have also been repeatedly turned down. According to the PLWHAs and health professionals interviewed, there is a sense of individualism at the hospitals in Trinidad and Tobago, where working in groups is not encouraged. Therefore physicians are reluctant to call other physicians and consult on cases when there is uncertainty. It must be noted that these are the views of PLWHAs and health professionals not attached to the hospital. I was unable to substantiate these claims by speaking with health professionals at the hospital.

5.6.2 HIV-Related Medication

5.6.2.1 Antiretroviral Medication

As part of the single-payer system, all antiretroviral (ARV) medications are now free in Trinidad and Tobago. Though this is now the case, for several participants who were diagnosed earlier in the course of the disease, they were faced with bearing the total cost of the medications. Eric explained his experience when the cost of the medication represented 83% of his monthly salary, and therefore he used to take the medication incorrectly because he wanted to stretch them out. This resulted in him becoming very ill:

> "The bombshell was the cost of the medication. He was saying that he had to bring the medication in from Puerto Rico and it wasn't really available here. At that time there was no place giving out free medication in Trinidad and Tobago, at least I don't think so. The bombshell was that the medication would cost me $5000[TTD] a month. He looked at me and said that he could probably give me a difference combination for about $3500[TTD] … Anyway, I got the medication and I started taking it, but it was only one month's supply. I wasn't familiar about how you should take the medication at that time, and I wasn't a fan of taking tablets, so I would take it for two week, and I started feeling much better. As in everything else in our local thing, when you start feeling better you stop taking the medication, so I stopped, and started taking it once every two day, once every three days. I was also trying to stretch out the medication because, I know I wasn't getting anymore in a hurry."

Though most of the participants are currently taking antiretroviral medication, several of them were hesitant because of real or perceived side effects of the medication on other PLWHAs. Many expressed sincere fears about the negative effects of the medication, primarily those PLWHAs who were diagnosed 10 or more years ago. For example they stated that several friends had died shortly after taking ARVs, while others became deformed or experienced other forms of unbearable illnesses. After their CD4 continued to decrease however, or they became very ill, they were persuaded to take ARVs.

As expected with HIV related medication, several of the participants experience side effects, which discouraged them from taking the ARVs. Melissa explains why she has since stopped taking the prescribed ARVs, because of their side effects, which include losing weight, vomiting, diarrhea and not being able to take care of her son and other daily functions:

> "I got thin, extremely thin. And I was having constant diarrhea, for a month going on two months. Vomiting. Like you in a different world. If I take the tablets now, and again mi body start to reject it, because if I take them about half come back up. Then you bloated, you have to sit down there for about an hour before your belly settle. I couldn't live like that, because I had to see about my son, and I was always on the go… I tried all how to take them. So I came off…"

While Melissa has not been able to deal with the side effects, several other PLWHAs have learned to live with the side effects because they believe that without the ARVs they would die. Other PLWHAs have complained about the side effects and since have been placed on other combinations that seem to work. Most of the PLWHAs interviewed however are compliant. Health professionals at the clinic state that individuals are not prescribed ARVs unless they are emotionally and physically ready to comply.

5.6.2.2 Herbal Or Natural Remedies

The majority of the PLWHAs interviewed only use ARVs to treat their HIV infection. Many stated that they did not believe in herbal medicines, and therefore would not take them. Others have experienced very positive results from the ARVS and therefore are not interested in using other treatment methods. A third subsection of the PLWHAs interviewed have seen the negative effects of herbal medication when mixed with ARVs or when they replace ARVs and are therefore very afraid to even try herbal medicines.

A couple of the study participants admitted to trying herbal medicines for HIV. One lady stated that shortly after being diagnosed she used to pray and ask God to direct her to the types and combinations of herbs to pick, brew and drink. As her situation worsened, however, other PLWHAs have convinced her to start taking ARV medication instead of the herbs. It has been rumored though that she is not adhering. Another PLWHA admits to recently going to a herbalist to treat the boils on his skin:

> "Just recently, last week or the week before I went by the herb shop there and buy some herbs because I had a problem.... I went by the herbs man and explain to him about the boils. And he tell me that me blood want to clean, so I just went they and he give me some things to clean out mi blood. He give me something to boil and drink everyday. A spoonful everyday, three times a day. Ah drinking that now, so I don't know if that would work."

It must be noted that there is a push by several herbalists to discredit conventional, modern medicine. They state that the ARVs are not working. In one workshop that I attended, a young man brought a packet with material that discredited the medical profession, and stated that HIV was a conspiracy by the medical and pharmaceutical industry to control humans, and particularly humans of African decent. Also, I've noticed that there are several radio and television advertisements with testimonies of individuals being cured by herbal medicines. Their illnesses include diabetes, heart failure and erectile dysfunction, and as a result they have stopped taking their prescription. One PLWHA also stated that he has been personally solicited to test herbal remedies to cure HIV. One requirement though was the discontinuation of ARVs, and he was not willing to do that.

One important distinction, however, is the fact that several PLWHAs see a difference between taking herbs as medication and using natural remedies to combat side effects. For example, PLWHAs

have identified rough lemon, clove, orange juice, olive oil, sea baths and similar items/rituals to help maintain general health and to help deal with the sides effects.

5.7 DISCLOSURE OF HIV STATUS IN TOBAGO

Disclosure (either voluntary or involuntary) is a very important issue in Tobago because of the reaction by family, friends and other community members, and the effect that has on healthy outcomes. As a result I wanted to know about how PLWHAs' status has been disclosed in the past, and the responses to that disclosure.

5.7.1 Confidentiality

The concept of what is confidentiality, and whether confidentiality exists or can exist in Tobago was discussed at length by all PLWHAs interviewed. It was generally believed that confidentiality does not, and will never exist in Tobago. One reason for this is the size of the island. With a population of approximately 54,000, as the locals put it, "everybody know everybody business." Most of the PLWHAs interviewed had their status disclosed to others without their consent. Let me use Camille's experience as an example. Camille's boss confronted her after he heard that she was HIV positive. He was very supportive and has actually helped her deal with her infection, however the fact that he heard that she was HIV positive is very common:

> "He call and was like "ah hearing something'. He call me a night, late - I was almost ready to sleep. He say 'I want you to be straight with me, I hear you HIV positive', I say 'and what if I am? how does that relate to you? How does that affect my work?' he said 'no, I just concerned about you, so I just wanted to know what's up with people that I care about. I just want you to be ok'. I said 'ok'."

Similarly, Janice talks about going out with friends and having other people whisper and pull the friends aside and ask them "you know she have AIDS?" This issue of confidentiality is given as a reason why individuals are reluctant to come to the OASIS office. Given my experience with the close family friend who had seen me on the ground floor of the OASIS office building, I understand why individuals would be reluctant to come to the office. Robert explains this very phenomenon – that every one assumes that individuals who visit the OASIS office are all HIV positive:

> "Well everybody downstairs know that up here is a place for people with HIV. So some people does just tell themselves that if they come up here, the mere idea that they coming up here, people go say 'that girl they get AIDS boy? Or that boy get AIDS?' Because he

> gone up by the AIDS place. And you may just come to get a message or something. But that the fear that plenty people does have coming up here."

This lack of confidentiality also exists in the hospitals and health care facilities. A community leader told me this story. This person had a sister who was HIV positive and in the hospital because of her illness. The HIV positive sister asked the community leader to braid her hair. The community leader said that she agreed to do it, and proceeded to comb the PLWHA's hair. A nurse on the ward seeing this called the community leader to the side and asked "you know she have AIDS?" The community leader said "Yes, she is my sister. What is your point?" The nurse then quickly apologized and begged her not to tell her supervisors about what occurred. The community leader did not pursue the issue, but returned and continued combing her sister's hair.

As stated earlier, some individuals are very reluctant to go to the clinic in Tobago because of this lack of confidentiality. It is believed that either medical professionals or other individuals who see you going into or out of the health facility would disclose your status. When talking about specific incidences at the clinic, there are many stories to back up the idea that there is no confidentiality there. One PLWHA reports having seen a worker at the clinic "throwing an eye[32]", while Robert talks about news reports made on the local media. Other clients reported that workers were eavesdropping on conversations between the client and the doctor, and then looking through the medical records at the clinic:

> "And then a time I hear this on Tambrin I think, that somebody did report the cleaner. Like this is the doctor room, it have a room close by that she does go in and listen to hear what you and the doctor saying. And like when she going to clean, me ent know if they doesn't lock the cabinet or not, like she now does just go in the cabinet and getting all your information, and like nobody can't tell she nothing. Well it had to have some truth in it, because is nuh one person I hear say that, and it even reach on the news."

In an attempt to give examples of the levels of disrespect and the lack of confidentiality at health facilities, Camille describes a situation that occurred at a health facility in Trinidad. She was hospitalized there for an HIV related illness, and she overheard her status being disclosed to the nurses and other individuals who were not dealing with her case. Several years after leaving that hospital, she returned to visit her sister who was having a baby at that hospital. As she walked through the ward, she again overheard the nurses pointing her out, while disclosing her HIV status. Though this experience didn't happen in Tobago, it serves as an example of the level of confidentiality in the health care systems throughout Trinidad and Tobago, not just Tobago. As Camille explained:

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[32] The term "throwing an eye" refers to the use of the eyes to identify someone. Usually it is used when individuals have been speaking about a third party who isn't known to all parties. In an effort to identify this third party without being obvious, the eyes are used.

> "And another thing too, my sister was making a baby, so she went in the same hospital that I was in. So I went with she, and two of the nurses who were on the ward while I was there. They went and sit down and shushuing[33], I watching them, but I pretending that I ent seeing them… But one of the nurses recognize me but the other one didn't know, so the one that recognize me was informing the other one. So when I pass to go with my sister, I hear them saying 'oohh that is she?' and if you see them. I say ' ah ha'. And they supposed to be the professionals."

This idea that everyone knows everyone else's business can been seen as a positive thing, because it presents an informal method of tract tracing for HIV/AIDS. Janice describes how she may have avoided getting infected if she had heeded the warning that someone breaking confidentiality had given her. She, like many others, did not understand how HIV was transmitted and therefore she did not understand how the other woman's HIV infection would have affected her life:

> "Well my cousin, she was a nurse in Trinidad and she had known about this girl - from she coming to the clinic. When she come home she say 'girl, I see your children father down the road with this girl, he know what he doing?' … I think that she told me in good faith and hoped that I wouldn't say anything because knowing the kinda work she doing, she could lose she job. So when she tell me that I was like 'so what you telling me that for. That ent have nothing to do with me. If she get AIDS that ent have nothing to do with me'"

5.7.2 Disclosure

This issue of disclosure is very important to HIV preventions for various reasons. Therefore I asked the PLWHAs whether they had disclosed their status, to whom, and probably most important, the reaction of these individuals. For those who choose not to disclose I also wanted to understand their rationale for not disclosing.

As part of my participant observation, I was a member of a planning committee working on the World AIDS Days celebrations in Tobago, and this issue of disclosing, particularly public disclosure, was extremely contentious. The group planning the events wanted to have a concert, which focuses on all aspects of HIV. The concert would include performing artistes, and in the midst of the performances it was suggested that PLWHAs make public disclosures about their status as a method of giving HIV a face in Tobago. The issue was the reluctance of PLWHAs to disclose in such a public forum. The committee found one person to disclose, because she was already very open about her status. One PLWHA was somewhat willing to do it, but after second though he decided against it because of his current employment situation, and the potential ramifications.

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[33] To shushu is to whisper or gossip about someone else.

In addition to PLWHAs disclosing their own status, other community members continually disclosed other individual's assumed HIV status to me. I may simply state "oh, I saw [name] today", and the response would be "he name was calling up in the thing too you know?", or "they say that she have the AIDS too."

5.7.2.1 Disclosing To Sexual Partners

I spoke with the PLWHAs about whether they had disclosed their status to their sexual partners or significant others. In my view, Eric's response highlights why individuals are hesitant to disclose. He was very afraid to disclose for fear of losing his then fiancé. As a result, he did not disclose for several months after his diagnosis. When he finally was able to disclose to her, his worst fears came true, because she ended the relationship:

> "I turned to her and I started crying… and I said to her 'supposed I'm HIV positive now?' I just blurted it out, because I couldn't even remember what was going through my mind at that time, because she was showing general concern. So I asked her 'supposed I'm HIV positive?' well that hit like a ton of bricks I supposed because she stepped back and I could see it in her face, utter dismay, shock, how could you do this to me and this kinda thing. Anyway she left that day and she never came back. I tried calling and she never answered."

Janice was in a relationship with a young man who was aware of her status. He ended the relationship however because his family and friends were telling him that he shouldn't be with someone who is HIV positive. They have remained friends and she believes that they truly loved each other, but the pressure being placed on him "brought problems"

Camille on the other hand had a positive experience when she disclosed to her boyfriend. They had recently moved in together, and after reading a magazine about HIV, she decided to get tested. When she was diagnosed as positive, she was relatively calm, and went home to tell her boyfriend. He was scared at first, and he initially thought that she had known about her status before. He was tested HIV negative the following day and they stayed together for several years after. Since that relationship didn't work out (for other non-HIV related reasons), Camille has been communicating with another gentlemen, whom she has also disclosed her status to. She wanted to give him the opportunity to end the relationship, and didn't want to be accused of "leading him on." Janice, another PLWHA interviewed states that she discloses her status to her sexual partners, however she believes that most PLWHAs are having sex without disclosing their status.

In some instances, the clients believed that their sexual partners knew about their status but did not disclose to them, which is why they got infected. Richard, who is homosexual, firmly believes that his partner knew about his HIV status, or at least suspected it, since his partner's former boyfriend was dying

from HIV. Richard decided to get tested because a friend of his boyfriend, and his boyfriend's former partner told him that the former partner was indeed dying from HIV. Melissa stated that her son's father broke down in tears and told her "sorry" when she told him her status. He refuses to be tested.

Health professionals working in HIV state that in Trinidad and Tobago HIV is not a notifiable disease; however health professionals encourage disclosure to at least sexual partners. They have stated however that on several occasions this does not actually occur. Newly diagnosed clients are also asked to provide a contact person, just incase something happens to them – they usually do not provide a contact person. One example is given of a young man who asked if his medication could be given in vitamin bottles, so that he wife would not find out. The health professional asked what he would do if the wife asked for some vitamins, and he stated that he would just give her a couple. To help deal with this issue of non-disclosure, one community leader discussed the fact that he was in favor of criminalizing the act of infecting others without disclosing your status. He believes that since HIV medications work very well, individuals can now look "normal."

5.7.2.2 Disclosing To Other Family And Friends

All of the PLWHAs that I interviewed stated that they had disclosed their status to their close family and friends. Some of them did it immediately after the diagnosis, some waited days, months or even years before doing this. The PLWHAs were very selective in deciding which family and friends to disclose to, and in most cases the response was very positive. In fact, several PLWHAs stated that disclosing to family and friends improved their relationships with those people. One PLWHA stated that her mother reacted very negatively and for a long time did not want her to eat at her house, or spend any time there. However after several years, the mother is beginning to understand the disease and accept her.

5.7.2.3 Disclosing At Work

A few of the participants have disclosed their status at work. Generally the response to this disclosure was positive, which included having their co-workers praying for them, or supporting them in other ways. Donna identified one situation where one of her co-workers started questioning why the company allowed her to continue working. The superior who she was complaining to simply stated that Donna had the right to earn an income like everyone else:

> "My boss know, and the corporal know alone. Because she come and she ask me, and I didn't want to tell her no lie. And she ask me where I does go to clinic and I tell she Trinidad and she tell me if ever I have an appointment to go down, let me call she and she go schedule me for it [they will accommodate her clinic appointments while scheduling her to work].... and a girl who [working] there go and tell the sergeant if they know I have it, why I working in the company? The sergeant tell she to mind she business, because if was she, she woulda be still working and earning her money"

5.7.2.4 Involuntary Disclosure

This issue of voluntary versus involuntary disclosure is very real in the Tobago setting due to the size of the population. For example, on several occasions during casual conversations with my friends and family I had to continually sensor my speech because of the threat of involuntarily disclosing the HIV status of the PLWHAs interviewed. Since the population is very small, and literally everybody knows everybody, a simple description of a person's appearance, employment status, or family history can be used to identify the individual being spoken about. This coupled with the fact that my friends and family knew that I was working within the HIV positive population would allow them the opportunity to make the connection that the person being spoken about was HIV positive. One health professional explained a similar situation where she was in the presence of another health professional when they met one of his clients who was HIV positive. The health professionals started a casual conversation with the client, and at some point identified the PLWHA as a client, which indirectly identified the client as a PLWHA.

Since the HPC does not have its own pharmacy all prescriptions are taken to the hospital dispensary. In an effort to prevent disclosure a nurse from the clinic takes the prescriptions to the dispensary for filling. At times several questions are asked about why a certain drug is requested, etc. Health professionals have suggested having a pharmacist specifically trained in HIV to deal with these medications. This would improve the quality of service since that pharmacist would be aware of the different types of drugs, and therefore would not ask those types of questions. In addition, it will improve the confidentiality issue because only one person would see the names on those prescriptions.

5.8 STIGMA AND DISCRIMINATION

Another important factor in the experiences of PLWHAs that directly and indirectly influences HIV prevention is HIV-related discrimination. To my surprise when I asked PLWHAs specifically about whether they had experienced stigma or discrimination, most of the participants told me that they did not experience stigma or discrimination because of their status. After continuing the conversation, however, many participants related experiences that they themselves classified as stigma or discrimination, or I would classify as stigma or discrimination. Janice talks about people literally pointing her out as she walked through the capital city of Tobago. As she stated, for years she felt that she was the only person in Tobago with HIV:

> "People used to just watch me and point me out in the road in town. I always looking over mi shoulder to see who watching me funny, who pointing at me. And I used to feel like I alone in Tobago have AIDS."

Other forms of discrimination were described by other PLWHAs. For example, Sharon remembers working in a maintenance program cleaning schools, and she was told to only clean the outside of the school because she would "infect the children". Rebecca could not go to her mother's house for several years, and whenever she was allowed in the house, she was not allowed to use the bathroom, or eat using regular utensils. Camille remembers the plight of an HIV positive friend who was only allowed to eat from disposable utensils at her family's house. Eric also related the situation of a young lady who moved to the United States with her family. When they learned that she was HIV positive she was forced to leave and return to Tobago. At that time medications were very expensive and the girl died shortly after.

In many cases the children of female PLWHAs were discriminated against. Janice remembers her children coming home in tears telling her, "people say you get AIDS", and that their mother would die soon. The discrimination became so overbearing that the children sometimes experienced nightmares. For many years, Janice denied that she was HIV positive to her children, but as they grew older she realized the need to disclose to them. As another example, Natalie's son, who is also HIV positive but does not know about his status, is discriminated against in school even though he doesn't fully understand what is happening to him. His mother describes a situation where parents of other students demanded that he be removed from the classroom:

> "I can't tell him right now [her son who is HIV positive, that he is HIV positive] because some day we was at home and mi daughter came in and say 'mummy, them children saying that [son's name] have AIDS'. At the time he had some little things come out on his skin. Well I did disclose to the principal his status, and some ah the parents she said came in and complain that he not supposed to be in school with those things on his skin. So she tell to get a letter from the doctor stating that it was ok for him to come to school. I did carry the letter to school, and that stopped…"

Janice also related an experience about what happened to her a couple years ago. Since she is one of the longest living PLWHAs in Tobago, and because she has disclosed her status at various occasions, many individuals know who she is, and know that she is a PLWHA. She applied to work at a store once and was given the job. A couple days later, the lady who hired her told her that the position was no longer available, possibly because she had just learned about her status. Coincidentally Janice's cousin later applied for that same job and got the position. One day Janice happened to walk into that store to buy something. Seeing Janice come in, the owner of the store called a couple of the other workers, including Janice's cousin and told them "you see she (identifying Janice), that is the one with AIDS". As the other workers responded by laughing and so forth, Janice's cousin told the owner that she was indeed related to her, and that she was disappointed by her behavior.

In the early stages of the epidemic, before HIV treatment was available in Tobago, PLWHAs used to take other newly diagnosed PLWHAs to Trinidad. While traveling on the boat, community members frequently cursed at them, shunned them and threatened to beat them up.

Though most of the participants interviewed had disclosed their status to the important people in their lives, they believed that disclosure is generally not common in Tobago due to the perceived and real discrimination that others have experienced, and their personal belief about the type of discrimination they expect. As Janice emphatically stated, "people so afraid to talk about their status …", which was again echoed by Sharon who agreed that "…because of discrimination people will hide that they infected …"

5.8.1 PLWHAs Discriminating Against Other PLWHAs

One alarming factor that was unearthed was the idea that PLWHAs discriminate against other PLWHAs. According to one health professional, there is a need for people generally, including PLWHAs, to separate themselves. This separation creates a sense of superiority, where "I have AIDS, but at least my skin ent have sores." Rebecca talks about a specific situation when she discriminated against another PLWHA in that same manner:

> "I was in Trinidad already at a seminar or something with HIV, and the fella next to me, then time mi skin didn't have so much a break out, his was broken out, and I didn't want to sit near he, and all ah we have AIDS."

5.9 ANALYSIS - LIVING WITH HIV IN TOBAGO

An HIV positive diagnosis changes your life. It changes the way you view the world, it changes how you respond to stimuli and it changes how the world responds to you. The PLWHAs in Tobago experience these changes, and in some situations the HIV diagnosis was emotionally, physically, economically, and socially detrimental. For other PLWHAs the diagnosis brought growth, strength, and some even say that "it saved them". In this section I would like to discuss the lives of PLWHAs in Tobago, and specifically discuss how their lives may inform and affect HIV prevention in the general population of Tobago.

The most obvious issue relates to how these PLWHAs became infected with HIV. Approximately half stated that they were in "monogamous" relationships, where their partner was unfaithful. As is common in Tobago, these individuals believed that they were in committed relationships; therefore condom use was either discontinued or never occurred. This is extremely important with respect to HIV prevention, since the conventional theories and models that encourage condom use focus on several

factors that are viewed in Tobago as contrary to being in "loving", "trusting", or "committed" relationships. The philosophy that condoms are used to protect an individual from infection implies one of several assumptions: (a) your partner is unfaithful, (b) your partner is sick, (c) you are unfaithful or (d) you are sick. In Tobago, a relationship where any of these assumptions is made is seen as a failing relationship. Therefore to prove that none of these assumptions is being made, condom use is quickly discontinued in "primary relationships." This practice has been verified in different communities throughout the Caribbean [40, 81, 92]. Given the implications for relationships, HIV programs that simply suggest condom use may prove ineffective, particularly when dealing with individuals in long-term, committed relationships. Two new approaches may be needed: (a) redefine the meaning of condom use and (b) reemphasize the importance of fidelity and/or safe sex.

The flip side of this coin involves individuals who are indeed unfaithful or sexually promiscuous and therefore contracted HIV outside of their primary relationships. This type of sexual behavior, previously identified as sexually permissive, is also very common in Tobago. In fact, several PLWHAs, community members, community leaders and health professionals identified having multiple sexual partners as a norm in Tobago, and therefore a factor that influences the HIV rates on the island. Given this fact, HIV prevention programs must consider the norm of having multiple sexual partners, and be willing to openly and honestly discuss the sexual practices of the average Tobagonian male and female.

Like the issues relating to condom use, the issue of getting tested or not getting tested for HIV is another factor that influences the HIV rates in Tobago. None of the PLWHAs requested that an HIV test be done before a sexual relationship was started. In some cases, it is believed that this would not have directly prevented the HIV infection, since some PLWHAs believe that their partner became infected after the relationship started, but in other cases it may have prevented the infection. Being tested, or requesting that your partner be tested, again implies a suspicion of infidelity or illness, which are assumptions that are detrimental to relationships in Tobago. In addition, and in their defense, several PLWHAs became infected during a period where HIV testing was not common and was very expensive, therefore it may not have been practical to request an HIV test. That was then, however, and this is now. An important arm in the fight against HIV is early detection followed by treatment. Therefore current HIV prevention programs must stress the need for testing. Like condom use, the programs that promote HIV testing will need to redefine what an HIV test means - not just the medical meaning, but also the social and psychological meanings of HIV testing.

As identified in other studies in the Caribbean [26, 27, 57, 99], economic need and the need to maintain social relationships have influenced the decision of Tobago PLWHAs' to stay in abusive or otherwise unsatisfying sexual relationships, or to continue having unprotected sex when the risk of HIV infection is present. Very similar to the reasons given in other studies, the real, tangible threat of starving children or losing a relationship far outweighed the abstract, intangible threat of contracting HIV. This is particularly the case since many of the PLWHAs became infected during a period when little was known

about HIV in Tobago. In today's world, however, it is believed that similar decisions will be made if members of the community, particularly female or feminine members of the community, are faced with the same decision. I use the term female or feminine members of the community in an effort to include the male participants who can be identified as playing the feminine parts in homosexual relationships. For example, one young dependent male in a homosexual relationship stated that even though he knew about condoms and HIV, his partner, who was older and the breadwinner, did not want to use condoms, so he agreed to have unprotected sex. This resulted in him becoming HIV infected.

According to the Central Statistical Office of Trinidad and Tobago, in all areas of employment the average woman's income ranged from 52.8% to 87.8% of the average male's income in 2000 [138]. The average income reported by the female PLWHAs was $1669TTD per month, while the average income for the men was $4500TTD per month (women's income approximately 37% of men's income). For many of the women interviewed, their economic status had improved or at least remained the same compared to when they became infected. Given this fact, it can be understood why female/feminine individuals in Tobago may be forced to remain in sexual relationships, or directly exchange sex for money, as a means of survival. This directly affects HIV prevention since simply advocating condom use may not be seen as practical for these individuals. The social and economic situations that force individuals to make detrimental sexual health decisions will need to be addressed as part of a wider HIV prevention regiment if success is to be seen in future programs. For example, the implementation of shelters or half-way homes, in conjunction with trade or skills training, would improve the general outcome of HIV prevention programs, since improved general education and economic status of females/feminine individuals have been known to improve sexual health [93].

Though the effectiveness of pre- and post-test counseling for secondary prevention and health outcomes have been debated in the United States [141, 142], several studies have shown that in resource-poor Caribbean countries, having effective pre and post-test counseling positively affects the general outcome of HIV positive clients. In many cases, this counseling is used to provide information, distribute condoms, identify individuals who are depressed or otherwise negatively dealing with their diagnosis, and gauge the ability of individuals to adhere to the required HIV medication regiment [143, 144]. Given this fact, it is very disturbing that the majority of PLWHAs interviewed were not adequately counseled pre- or post-test. The initial denial relating to their infections may also have been a direct consequence of the inadequate pre- and post-test counseling received. In contrast, those individuals who were adequately counseled, or who knew a great deal about HIV seemed to be dealing with the diagnosis relatively well. This is important because secondary prevention is very important for HIV prevention in the general population [106]. Obviously, PLWHAs pass HIV to other community members. Therefore PLWHAs who understand and accept their HIV status will be better able to practice safe sex, disclose their status, take their medication and generally help in the reduction of HIV infections. This study highlights the need for health professionals to be adequately trained in basic HIV-related knowledge, which should include references and referrals for additional information.

The PLWHAs interviewed had varied responses to their infection; however, there were some common themes and common predictors of positive or negative responses. A common theme was the general belief that HIV only happens to bad people. This belief stems from the introduction of HIV to Trinidad and Tobago, along with common moral judgments about certain groups of people. The first documented cases of HIV in Trinidad and Tobago occurred in the homosexual community, closely followed by other "high risk" groups including drug users and prostitutes [14, 19, 73]. As a result, HIV has always been presented as either punishment for religious wrong or moral wrong. This has resulted in "normal", "moral" and "religious" individuals not being aware of their risk of contracting HIV, which is an obvious hindrance to HIV prevention. Prevention programs therefore must redefine HIV, and highlight the vulnerability of all sexually active individuals, regardless of their moral or religious standings.

The idea that HIV is synonymous with death, a concept continually echoed by the PLWHAs, was also due to the initial and continued portrayal of HIV in the media and other venues. Those PLWHAs who were diagnosed many years ago were told by their physicians and other health professionals that nothing could be done, so many of them believed that they would die soon. In addition to having health professionals proclaim death, PLWHAs stated that the only images of HIV on the television or posters included people in the last stages of AIDS; therefore they all assumed that a horrible death was their only option. This presented several hindrances for HIV prevention. First, the PLWHAs gave up hope in life, and several believed that if they were going to die anyway, there was no need to protect themselves from other infections. The second hindrance occurred when the individuals did not die in the time frame given by the physician, and because they began feeling well again, they convinced themselves that they were HIV negative. Believing that they were HIV negative may have resulted in the PLWHAs participating in unprotected sexual intercourse, again increasing the risk level of their sexual partners.

After spending some time readjusting to their HIV diagnosis, most study participants stated that they continue to live relatively normal lives. Normal living has been affected only during periods of illness or periods of adjusting to medications. This is very important because it highlights the fact that HIV is not a death sentence and in fact, if managed correctly, can be seen as a chronic illness similar to diabetes or heart disease. With reference to HIV prevention, it is important for the public to see HIV as a chronic disease and for them to have healthy examples of PLWHAs, which may alleviate some of the fears surrounding the disease. In many years past, the only images of PLWHAs were at the end of their life spans, which meant that they looked very ill. In addition to alleviating the fear about HIV being a death sentence, it is also important that community members understand that someone does not have to "look sick" to be HIV positive. The fact that individuals can look and live healthy lives is important in stressing the importance of testing and condom use in the general population.

One factor worth mentioning with respect to how HIV affects the daily lives of PLWHAs is the influence on their sexual health. Less than half of the PLWHAs interviewed stated that they have healthy sexual lifestyles; a large portion of them either do not have sex or are very dissatisfied with their sexual

lives. Addressing the issue of sexual health, by stating that is it neither expected nor practical for individuals to simply stop having sex, may in fact change how PLWHAs view sex, and therefore influence their decision to experience healthy, safe sex.

To my surprise, the PLWHAs interviewed all seem to have very good support systems. These ranged from the support of god and the church, to the support of friends, family and HIV-related organizations on the island. Though they all know someone, or know of someone who does not have that support, they have been able to have relatively positive experiences. The fact that they all knew someone or knew of someone with a negative experience is, however, very important for prevention. In many cases, the only stories discussed in the general population are the negative stories, therefore individuals may be unwilling to disclose their status for fear of being rejected. In addition individuals may choose to not get tested for fear of their results being involuntarily disclosed due to the size of the population.

The importance of HIV-related support organizations became very apparent from these interviews. Many PLWHAs felt isolated, rejected and dejected after learning about their HIV status. For many of them, HIV was a disease that you died from. Their interaction with other PLWHAs, however, changed their views about their lives and their ability to actually "live with HIV". The organizations provided emotional and social support, however they also provided practical support including education, referrals, and sometimes money. The types of support provided by the organization also helps with secondary prevention, since most of the information about condoms, treatment or other STDs came from associations with HIV organizations.

I was pleasantly surprised about the level of treatment and care available to PLWHAs in Tobago. This fact has not been reported in the literature, and as a result, many academics, and health professionals in Tobago are unaware of the services available to PLWHAs. This lack of knowledge has affected their ability to provide effective referrals, which in turn influences how PLWHAs deal with HIV, and whether they are treated correctly and effectively. The differences in perception of treatment in Trinidad versus Tobago seemed to be determined by the quality of care available (professionalism of workers, availability of laboratory equipment, a pharmacy, etc), and the perceived confidentiality (or lack thereof) within the healthcare setting.

The issue of confidentiality is very important when dealing with HIV in Tobago. Confidentiality is important in other communities; however, I believe that the geographical and population size of Tobago creates an additional hindrance to maintaining confidentiality. With only 54,000 people living on the 116 square mile island, the situation where "everybody knows everybody" is not just a cliché. It is a reality. As a result, involuntary disclosure is very common. Since HIV has been associated with negative characteristics or moral values, it is believed that individuals who are HIV positive are also seen in this negative light and are discriminated against or stigmatized. As a result, HIV status disclosure is highly feared. The PLWHAs gave several examples of positive reactions to their disclosure, but their experiences also included negative reactions to the HIV status of themselves or others. This is very important, since

the stories of PLWHAs are repeated throughout the island, and the negative reactions may prevent other community members from wanting to learn about their HIV status, or from wanting to disclose their status to sexual partners or other family and friends.

6.0 FACTORS THAT INFLUENCE HIV INFECTIONS

Research Questions Answered In This Chapter

(*b) What are the major cultural and social factors that influence the high HIV/AIDS rates in Tobago?*

(c) How do these factors influence community norms and therefore individual behavior patterns with respect to HIV prevention strategies in Tobago?

6.1 WHY IS THIS IMPORTANT?

The fact that HIV infections in Tobago have been attributed mainly to sex (mainly heterosexual sex), it can be extrapolated that in Tobago successful HIV prevention should entail one or more of four human behaviors: (a) abstaining from sex, (b) being faithful with one HIV-free partner, (c) using a condom correctly and consistently, and (d) getting tested and ensuring that your sexual partners are tested and are HIV-free. An individual's ability to do each of these behaviors is influenced by a host of emic and etic factors. As a result, if HIV prevention programs are to be effective, these emic and etic factors must be known, understood, and incorporated into HIV programs. This section identifies the factors that influence sexual health in Tobago.

6.2 OVERVIEW OF TOBAGO

The island of Tobago is located 21 miles northeast of its sister island Trinidad, nested in the Caribbean Sea and the North Atlantic Ocean. Tobago is approximately 116 square miles. According to the 2000 official census, the population is 54,084, with a 97.99 male/female ratio[34]. The ethnic composition includes 88.9% Afro-Caribbean, 2.5% Indo-Caribbean, 0.1% Chinese, 0.1% Syrian/Lebanese, 0.6% Caucasian, 0.6% mixed, 0.1% Other and 1.2% Not stated. The age distribution includes 26.48% 0 – 14 years, 18.99%

[34] Sex ratio calculation = (Male/Female) x 100

15 – 24 years, 29.91% 25 – 44 years, 13.61% 45 – 59 years, and 11% over 60 years. The census states that 8% of the population identifies with Catholicism, 60% with Protestantism, less than 1% with Islam, less than 1% with Hinduism, and approximately 22% with another or no religious affiliation. The currency of Trinidad and Tobago is the Trinidad and Tobago dollar (TTD), which has a United States dollar (USD) exchange rate of approximately 6.25TTD = 1.00USD. The GDP (purchasing power parity) of Trinidad and Tobago is $21 billion USD, and the per capita GDP is $19,700USD. Education is free for all citizens and is compulsory up to age 12. Recently, tertiary education has become free for all qualified citizens. The literacy rate is approximately 98% [4, 145].

Trinidad and Tobago has a democratic republic political system, with a central government that comprises of a Senate and a House of Representatives. According to the Tobago House of Assembly Act No. 40, of 1996, the Tobago House of Assembly (THA) predominantly governs Tobago. The responsibilities of the THA are numerous and include health, tourism, community development, agriculture, arts and culture, food production, and education including curriculum. The THA is not responsible for other aspects including national security, foreign affairs, immigration, judiciary, and service commissions [146].

Tobago's official HIV infection rate is 40.12 per 10,000 people (approximately 206 people infected and being treated at the Health Promotion Clinic). In this analysis the entire island of Tobago is compared to counties in Trinidad. Tobago has the highest rate compared to the other counties. The second highest rate is 32.43/10,000 in St. George County and the lowest rate is 5.97/10,000 in Nariva/Mayaro County [7]. Discussions with both health professionals and PLWHAs indicate that these reported rates are inaccurate, with the actual infection rates being much higher, since it is believed that a large percentage of the individuals with HIV do not know that they are infected. In addition, it is also speculated that at least 50% of the individuals who know their HIV positive status in Tobago are treated either in Trinidad, the United States or other countries, therefore their statistics are not counted.

6.3 INFORMATION AND VIEWS ABOUT HIV

6.3.1 HIV Equals Death

Very similar to the initial reactions of PLWHAs, the majority of the community members that I interviewed associated HIV with death. In several instances during my ethnographic interviews, I asked community leaders and community members what would happen if they discovered that they were HIV positive. Almost all of them responded with a resounding, "I will die!" I would normally follow that response with a question about what they meant by that. Many, out of fear, would simply repeat "me, I go just drop dead!" or "nah, I can't deal with that. I go dead". One male community member said that he

would no longer think about life, and that he would prepare for his death. A second community member, when asked what she would do if she tested positive, stated that she would kill her boyfriend. Another female community member stated that she believed that the shock of learning the diagnosis would kill her. Particularly since she doesn't know anyone with HIV, but she had heard the horror stories of other PLWHAs:

> "Die! I believe that even the shock alone of it might just, that might just [kill me]. I never deal with no body with it, to say that I know how to react and thing. So it's just the stories that you does hear. That people getting scorned or people talking and laughing at you. If I get that I feel I go just disappear."

Those community members or leaders who had been previously tested for HIV, had friends who were HIV positive, or were aware of the possibilities of treatment, however, responded with more positive answers. As one female community leader explained, she knew that it would be very hard to live with HIV, however she knew that there were things that would allow you to live a "normal life":

> "I would be fine. It would be kinda hard, but I know that it have things that they could give you to make you live a normal life."

6.3.2 Lack of Information, Misinformation and Myths About HIV/AIDS

I've always been honest with my friends and family about the focus of my research while in Tobago. As a result, they all knew or assumed that I knew a great deal about HIV. Consequently, I was approached continually with questions about HIV. For example, several community members asked about whether HIV could be spread via insects and/or kissing. Many did not know about the methods of testing for HIV, and almost none of the community members interviewed were aware of the free HIV testing and treatment available to citizens of Trinidad and Tobago. Yes, they knew that the "AIDS clinic" existed, but they did not know about the types of services offered there. Several did not know where the clinic was, but had heard many negative stories about the clinic, including the lack of confidentiality at the clinic, and the dissatisfaction of PLWHAs pertaining to services received at the clinic.

This lack of knowledge about the services and medication available to citizens caused me to speak with health professionals and community leaders about the perceived impact of giving this type of information. Though I never directly asked why this information was not given, one community leader summed up the views of others (and answered that question) by stating that he was concerned about talking about the availability of treatment options for fear that this would cause individuals to increase their risky behaviors. He related a frustration about not knowing what would constitute "too much information", and what would impede Tobago's fight against HIV.

Another example of misinformation occurred at a talk at one of the religious tertiary education institutions. A PLWHA was asked to give a talk about living with HIV at a class one evening, and she

asked me to accompany her. The process was very interactive and eventually a question about the PLWHA's sexuality was raised. The PLWHA stated that like any other person she still has a sex life, however she consistently used condoms. Another student then asked about the safety of condoms. The student stated that a teacher once told them that since condoms do not cover the entire pelvic area, it was not protective against HIV. According to the student, the teacher explained that the rubbing and friction that occurred during sex caused bruises throughout the pelvic area and therefore HIV could/would still pass from one party to the other, even if the male was wearing a condom. The PLWHA responded by jokingly questioning the rigor of the sexual contact, and then she corrected the misconception about HIV passing via bruising. She finally stated that that was a perfect example of individuals using scare tactics to prevent young people from having sex. In the end, I do not believe that the student was convinced about the safety of condoms, or how HIV was transmitted.

One PLWHA whom I interviewed shared a story about a friend who was convinced that since his girlfriend had tested negative for HIV that he was safe and did not need to be tested. Another community leader asked about the origin of HIV. She stated that a doctor once told her that semen mixed with faeces contributed to HIV transmission, which explained why HIV was mainly rampant in the homosexual community. A third community member stated that a white woman told her that a man had to have sex with a monkey for the virus to move from the monkey to humans. Sharon, a PLWHA, asked about the correct way to deal with the body of a person who died from HIV-related complications. She related a conversation with a close friend. Sharon was sure that a person with HIV who died could be buried or cremated, depending on the wishes of the deceased, however the friend was convinced that "when an HIV and AIDS person dies it is not good to bury [the] body, it supposed to be burned."

Another example of misinformation about HIV is the view that HIV positive individuals look sick. On several occasions when PLWHAs disclosed their status at educational sessions, community members would gasp because the PLWHA "didn't look like she get AIDS". At the OASIS office one day, a young man walked in because he had always been interested in the activities of the office. A female PLWHA and I started talking with him about his status, and getting tested, etc. Finally, the PLWHA asked if he would consider getting into, or staying in, a relationship with a PLWHA. He stated emphatically "no" and that he would know if a woman had AIDS, and would not get into a relationship with her. We then asked how he would know, and then proceeded to disclose the HIV positive status of the PLWHA. He was completely shocked. He sat back in his chair in silence for approximately five minutes. After he "recovered" he started shaking his head and proceeded to ask her about how she got infected and how she was living with HIV, etc. In the end, he stated that he had never actually met anyone living with HIV, and that he wouldn't have known. We reiterated that that was the point, and therefore was the reason for him using condoms, getting tested, and ensuring that his partners are tested.

A community member talked about a conversation with a girl the night before. She had shown him her HIV test result, it was negative, and she expected him to produce his. He wanted to know

whether that means she really does not have HIV. I told him that what the test shows is that at least six months before she did the test she did not have HIV. That does not mean that she didn't have sex with someone a couple of days or weeks ago and contracted the virus, hence the need to continue using condoms. Following the thought about what an HIV test means, another community member told me that he was hesitant to eat foods from the vendors within the local market place. To sell at the market and other institutions in Tobago, a food badge must be obtained. The process includes presenting a document from a doctor stating that you are indeed healthy, and attending a lecture about food safety, etc. The community member believed that an HIV test was also required for the food badge. He firmly believes that individuals could "fake the blood test", so they could be HIV positive, and "contaminate the food."

Finally, a belief that kept repeating itself was the belief that God could prevent someone from getting HIV or could treat someone who was HIV positive. Whenever I asked this question, the community member would pause to think about the answer. In some cases they would start to laugh nervously, and most seemed torn about the issue. On the one hand, they have been taught that God is all mighty and could do all things; therefore it would be blasphemous of them to think that he can't prevent or cure HIV. On the other hand, the medical community and the media keep saying that there is no cure for HIV. Many after thinking about this, stated that yes, because of their faith, they believed that God could prevent or cure HIV. A health professional working within the HIV field also discussed the philosophy held by locals about destiny. He expressed frustration because on several occasions, while trying to counsel individuals, they have told him that "if it supposed to happen, it will happen", therefore there was no need for them to protect themselves because "what is for them is for them."

6.3.3 Fear of Association

Several community members and leaders talked about wanting to be part of the fight against HIV, however they were afraid that individuals would believe that they were infected, or closely affected by HIV if they did so. One community leader, who is now associated with an HIV-related organization, stated that she had to fight several rumors about herself or her children being HIV positive. Another community leader stated that his name has been a part of the gossip circuit for some time now, so he was a little hesitant to use his voice for HIV prevention. In fact, on several occasions when I spoke with community members about talking with that community leader, they would state that "he must know, because he have it," or "everybody know that he have it. He get it since [year], when he was [profession] and he sleep with that girl who died from it."

This fear of association also prevents individuals from getting tested for HIV. Again, the belief that only certain types of people (prostitutes, homosexuals, drug users, etc) get HIV drives this fear. The thought process follows: since only certain types of people get HIV, then the only people who should be testing for HIV are the ones who are associated with those types of behaviors, or types of people. Therefore even if you suspect that you may have been exposed to the virus, you would be indirectly

admitting "wrong" by going to be tested. According to one community leader, if other individuals see a client going to get tested, they automatically begin to question that person's integrity because they want to know "if she ent do nothing, what she going there [HIV testing facility] for?"

6.3.4 Individual To Institutional Denial

The denial about HIV does not only exist in the PLWHA population, but also in the general population. In Tobago there is a general denial about the level of risk in the general population. Individuals generally are in denial that they are at risk for HIV. For World AIDS Day, I placed a few homemade posters with very basic information about HIV at a local business place. According to several of the people working at the business place, the posters were up for a few days when three young men walked into the business place. All three of them read the posters; however, one of them started reacting very badly. He started telling them to take down the posters, because "nobody ent want to know about AIDS." They responded by saying that it was good information, and that he should be concerned about his status. He stated that he knew that he "didn't have it". The owner then told him that if he has ever had sex, then he is at risk, and should be aware of it. He again stated emphatically that he "know that [he] ent get no AIDS", then he walked out. This individual is an example of the people Janice speaks about when she says that people do not want to be associated with HIV, not even to confirm their negative status:

> "They [people generally] ent want to go nowhere near there [places dealing with HIV], because they don't want to know. Most people don't want to know they HIV positive. They don't even want to know if they negative."

Melissa gave another example of this type of denial. Though she knows about her status and is dealing with it, the person who she feels transmitted the virus to her has never actually been tested. He prefers not to know. While in Tobago, a young lady had died of suspected HIV related illnesses. It was rumored she was HIV positive, although she had never actually disclosed this fact. One PLWHA stated that she was told on several occasions that she was HIV positive. Apparently the young lady dreamed that a frog had bitten her, which means that someone was "working obeah on she", so she refused HIV-related medication. Instead she decided to go to Trinidad to see an "obeah man." He prescribed that she take a "bush bath", which she did using very cold water. She died shortly after.

In addition to the denial experienced by the PLWHAs and the community members, several community leaders also expressed denial about the rates of HIV infection in Tobago. One community leader stated that she didn't believe that the rates were as high as everyone was trying to state. This is in direct contrast to observations within the PLWHA community, particularly those who receive treatment in Trinidad. As Janice highlighted, the officials in Tobago have no idea how many people are living with

HIV in Tobago, since "half of the people in Tobago who are HIV positive don't go to Tobago for treatment, they prefer to go somewhere else, whether is New York or Trinidad or other places in the Caribbean."

Similarly, when talking about the connection between HIV and tourism, another community leader stated that he didn't believe that there was such a direct link anymore. He believes that initially HIV was closely linked with tourism, but he no longer sees that direct connection. The specific observations about the current links between HIV and tourism are discussed later in this chapter. I spoke with one health professional working in the HIV arena, who is very upset about the state of affairs on the island. He stated that denial is a major contributor to the increasing infections on the island. He identified several levels of denial, ranging from individual denial about individual risk levels, to the institutional denial that prevents appropriate prevention and treatment programs from being implemented. He gave several examples of prevention programs that were suggested, but were not allowed because they targeted groups like commercial sex workers, drugs addicts, homosexuals and beach boys. He stated that these projects were dismissed because these groups of people (commercial sex workers, etc) "did not exist on the island" in the eyes of the politicians and administrators responsible for overseeing the affairs of the island.

6.4 RELATIONSHIPS, SEX AND SEXUALITY

Since HIV is transmitted mainly via sexual intercourse in Tobago, I thought it important to understand the dynamics involved within sex and sexual relationships in Tobago.

6.4.1 Talking About The "S" Word

One concept that continued to emerge in the interviews was the fact that no one openly talks about sex. Sexual partners do not discuss sex with each other and parents do not discuss sex with their children. According to Janice, "people don't want to talk about sex. Sex is taboo." One female health professional tried to explain why discussion of sex is still taboo. She believes that adults do not understand their own sexuality; therefore it is difficult for them to communicate with other adults or with their children:

> "Many adults do not understand their own sexuality, so what do we expect them to tell their children? Most teachers in schools are uncomfortable with their own sexuality, so what do we expect them to teach the school children… So the young kids get to learn about it and deal with it on their own, and you see where that getting we [referring to the cell phone sex videos of school children having sex, that were being circulated]?"

One community member remembers getting a gift for her 10th birthday. It was a book, "What a Young Woman Should Know About Sex." This is important, because she was one of only a handful of individuals at that age with correct information about sex. As a result, when her friends had their menstrual cycles for the first time, they would go to her. She knew exactly what it was and told them exactly what to do. She believes that her mother used that approach because she did not want to repeat her grandmother's approach. When her mother's menstrual cycle started, her grandmother simply stated "don't talk or play with boys. You go breed[35]!" Her mother did not understand anything about sex, and she became afraid of even looking at boys because she "didn't want to breed."

Similar to other cultures, a method of talking about sex that reduces the taboo surrounding it is the use of other words and phrases to describe either the sexual acts or the sex organs. In Tobago, there are many words or phrases that signify sex – *bull, bunta, taste ah piece, touch skin, skin, piece ah ass, a chuck, wife*, and the list goes on. In many instances, these words are used to allow young people to discuss sex among themselves without alerting the adults in earshot. There is a general belief, also, that although there isn't communication between adults and younger people, youths are very willing to discuss sex among themselves.

6.4.2 Sex Education In Schools

While looking at a secondary school-aged community member's social studies book, I noticed a section on sexuality. I asked the community member if this was actually talked about and she stated that indeed it was discussed but only for a short period. She also mentioned the fact that while she was in Standard 5 there was a Social Worker who came to school and spoke with them about sex. From talking with her, students in different classes and different schools, I noticed that she was in the minority; that only a few of them have had any form of sex education. I interviewed a health professional who is working in the school system, and she stated that she is in the process of reviewing what is indeed taught in schools, with the plan of presenting a more comprehensive "Family Health" program. This program would include sex education, violence, nutrition, etc.

While attending meetings for the World AIDS Day planning committee, I met several young people who were official representatives of an abstinence-based program that is being presented in secondary schools. It is based on the idea of "building character", with the premise that individuals with character do not have pre-marital or extra-marital sex. Facilitators, young people who state that they have maintained or "regained" their virginity, teach these classes. These classes are taught as part of the regular school curriculum.

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[35] To "breed" refers to getting pregnant or having a baby.

6.4.3 Youth Sexuality

Statistics show that HIV is the leading cause of death in the 15 – 44 age group in the Caribbean. As a result, I thought that it was important to explore the sexual beliefs, expectations, norms and experiences of young people in Tobago. Conversations with community members and PLWHAs indicate that sexual activity starts at relatively early ages in Tobago. The average age suggested was approximately 14 years old. When I asked about whether starting sexual activities at young ages increases HIV risk, several community leaders and health professional suggest that the problem lies in the fact that young girls have sex with older men. Since these older men have had several sexual partners, many are HIV positive, and transmit the virus to the young girls. The young girls then have sex with young boys their age, transmitting the virus to them. According to a male health professional, HIV infections would decrease if "14 – 19 year old girls [only] had sex with 14 – 19 year old boys."

Another health professional related the expectation of young women to prove that they can have children at relatively young ages. As a result, condom use hinders this need. I remember turning 22 and having a panicked feeling because it was time for me to have children. My mother had me at 21 and my grandmother started having children in her teens, so I was running woefully behind. Moreover, all but three of the other females in my secondary school class were either pregnant or already mothers. In addition, while collecting the data for this study, several men asked why I did not already have children. One male community member asked "What happen? You sick?" I stated that I was not sick, but I wanted to finish my schooling first. He then nodded and stated, "well, that's okay, but don't wait too long. You go get too old."

A third phenomenon that became very apparent in the course of my research was the willingness of parents to condone sexual relationships between their daughters and older boyfriends because of the financial support provided to the family as a whole. I personally know of at least five situations where young women (ages 16 to 21) are having sexual relationships with older men (ages 19 – 30), and these relationships are condoned or at least tolerated because the males provide financially for the whole family.

6.4.3.1 Cell Phone School Sex Scandal

At the time of my interviews, the scandal rocking the island was the presence of several cell phone sex tapings. Almost everyone that I met had seen or knew someone who had seen the videos of young girls in school uniform[36] having sex. These sexual encounters included either boys in school uniforms or older men. In these tapes, the faces of the females were always shown, while none of the tapes that I saw had the faces of the males. One scene is set in a classroom on the top of a desk. Another is set in a bedroom.

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[36] School uniforms are required for all preschools, primary and secondary schools in Trinidad and Tobago.

Another scene is set next to a waterfall, where the young girl is being coerced to perform fellatio on an older male. The background scene of the fourth isn't clear, however, the young girl is masturbating for the camera. Condoms were not used in any of the videos that I viewed. Eric highlights the fact that in situations like these, young men and women are not likely to use condoms:

> "… because there are situations which I have seen, where young school boys and school girls thieving[37] a moment after school in some corner in the bush to have sex. You feel, lets be honest, you feel that them going and practice safe sex? No."

To prevent the taping and transmission of this type of information and behavior, the Secretary for Education banned the use of cell phones in schools.

6.4.3.2 The PH Phenomenon

In the legal system in Trinidad and Tobago, cars fall within one of two main categories – "P" for private cars, and "H" for cars for hire (taxis). It is relatively easy to get a corresponding "P" drivers license compared to getting an "H" license. In addition, the services of individuals with "H" drivers licenses are relatively expensive and mainly tourists use those services. To deal with the need for transportation, individuals with "P" cars use them for hire (the equivalent of a jitney in Pittsburgh, or a dollar van in New York). These are locally known as "PH cars". In many instances, relatively wealthy individuals purchase private cars and give them to young men to drive. The usual arrangement involves the young man taking care of the car, providing for its general maintenance, hustling[38] the car, and giving the owners a predetermined sum of money every week.

Since the young men maintain these cars, they usually make them very flashy with big rims, tinted windows, and loud audio and DVD systems[39]. These cars and young drivers are therefore seen as very attractive to young girls, particularly schoolgirls. It is very prestigious to be picked up from school in a very nice looking car, with a very nice looking young man at the wheels. As a result, sexual relationships are developed between the schoolgirls and these young men. As one male community member who "hustles" explains, "dem[40] school girls would give you a bull[41] for a $6[TTD] ride and a box of KFC[42]. Who ent go take it when they give it up?" As usual, condom use isn't very common in these relationships.

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[37] "Thieving" is synonymous with "stealing" - so the school girls are stealing a moment to have sex.

[38] "Hustle" is the term used to describe the process of traversing the roads looking for passengers.

[39] On a personal note, I was truly surprised to see the degree to which these vehicles are customized. All most every car (old or new, expensive or cheap) has elaborate music and DVD systems.

[40] "Dem" is equivalent to the word "them".

[41] "Bull" is a term used to describe sexual intercourse.

6.4.4 Serial Monogamous Sexual Relationships

From discussions with community members, interviews with PLWHAs and my own experience living in Tobago, the various patterns of relationships on the island were revealed. One such pattern is the presence of serial, monogamous relationships. From early teen years, individuals engage in long or short-term relationships. When these end, another relationship is started relatively quickly. In many instances, one relationship is ended so that a new relationship could be started "without sleeping with two men at the same time." It is not a norm to casually date someone. In other words, you are either together, or you are not together. These relationships usually include sex. As one community member who has spent a considerable time in the United States stated, "I don't know how to date. That is not something that we do in Tobago – you either have a man or you don't have a man, it ent have no in-between." This can be problematic, because as Eric stated, relationships usually end because of infidelity, and the thought of getting tested for HIV is usually not considered. The hurt partner usually starts another (sexual) relationship without getting tested:

> "You just finish with a relationship with somebody, because you find the person was involved with somebody else. You ent telling yourself anything. All you telling yourself is 'me and he done, he cheated on me with another woman, or she was with another man' and you leave it at that… You ent thinking at that time that look 'supposed that person was HIV positive'. And you move on to another relationship. You may have contracted the virus then, who knows."

The other issue pertaining to relationship types is the fact that if you are from a very religious family, being seen with someone of the opposite sex frequently is considered courtship, which usually results in marriage at very young ages. Since these individuals did not really spend time learning about each other, shortly after the marriage it is discovered that they are not compatible. In religious communities, divorce is considered a sin; therefore individuals tend to stay married, but engage in sexual relationships outside of the marriage. Again, because of the stigma associated with condoms and condom use, these "married" individuals will not buy condoms, because their intentions will be questioned. The issues concerning condoms are discussed further below.

6.4.5 Multiple Sexual partners

Having multiple sex partners, particularly when condoms are not always used, is a major contributing factor to the epidemic in Tobago. Though I knew about this, I was somewhat surprised by the extent it is accepted in Tobago. One day I went on a site-seeing tour of Tobago. A large number of my friends and family went on this trip and as a result we needed several vehicles to transport the group. One male who

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[42] KFC refers to Kentucky Fried Chicken, the fast food franchise.

is a very good friend of the family accompanied us. I've known his family (wife and kids) for years, and therefore I was very surprised when he came on the excursion with his "other woman". I didn't know who she was, so I asked another friend. She was not as surprised, because as she stated "that is his madam, she does be with him almost everywhere we go… you feel the wife ent know about she?"

I also know a second female who is in the process of having her fourth child. The father of the youngest child, and the baby she is carrying, is married with children. On several occasions he takes the child to spend time at his house (with his wife and other kids). Another friend of the family has a child with a man who is living in a common-law marriage. He has three other children in that household. When I expressed surprise for the level of openness with which these extra-marital relationships occur, everyone kept telling me, "that is the way it's done in Tobago." As a final example, an older female community leader explained that her husband (who is now deceased) once told her that he had to have extra-marital affairs. He said "what would everybody think if I only had one woman? What kinda man you think I is?" As a result, this community leader as part of her role as "good wife," took care of at least four of her husband's "outside children." Other individuals expressed the idea that historically having multiple partners was acceptable. And the acceptance of the resulting children was a normal part of the process. Eric and Robert talked about how many children their fathers have. Eric's father has "me with one [woman], he have two with a next one, and he have five with a next one, plus them where we must be ent know about." Similarly, Robert's father has "five children with five separate women."

Though it seems obvious, I asked individuals to discuss whether they believed the sexual patterns in Tobago resulted, or could result, in HIV infections. They all agreed that it was an important factor. As an example, Robert described a known situation of a couple in Tobago, where the man recently discovered that he was HIV positive. His primary partner left him because she discovered that he was being unfaithful; however, by "the end of the story, this man used to deal[43] with three different women. Each ah them woman had they own man." As a result, from this man, at least six possible infections could have occurred. Camille, who is continually propositioned by men for sex, used herself as an example of how accepted having multiple sexual partners is, and how it could result in HIV infections:

> "… because, a lot of men that I come across, they are interested or they want to know me, I would say that I have a man, and they say that they don't care, that have nothing to do with them. And most of them are in relationships, most of them are married. And they want to get a piece of the action."

[43] To "deal" is another term referring to having sex.

6.4.5.1 Le Chatelier's Principle and Multiple Sex Partners

A male health professional in Tobago likens sexual situations in Tobago to Le Chatelier's principle of thermodynamics. According to him, Tobago has a small physical space, which represents the fixed volume container filled with gases. Sexual contact represents the gases colliding with each other. Heating the gases is equivalent to decreasing the age of first sexual contact, and increasing the number of sexual partners due to having multiple sexual partners, or even serial monogamous relationships. Due to the size of the population, it is very likely that sexual partners are shared – either at the same time, or in serial relationships. As a result, if one individual within the circle becomes infected, it is likely that several other individuals may be infected because of contact with that initial partner.

6.4.6 Sex In Exchange For Goods And Services

Similar to the situations reported by PLWHAs, individuals within the general population have exchanged, or continue to exchange sex for goods or other resources. As usually, when placed in situations where this is necessary, condom use is not common, and therefore the risk for HIV infection is increased. Only one PLWHA talked about having sex for the sole purpose of getting money. However, women commonly discussed having sex with their partners because they provided needed resources in Tobago. As Sharon states, she was still with her children's father "because he there and he giving me the money." Several other community members discussed the expectation of receiving money from their boyfriends, because "he can't expect to get it [sex] for free."

6.4.6.1 Sex Tourism

The connection between sex tourism and HIV infections exists in Tobago. As stated previously, the initial awareness of this phenomenon occurred when Simonetta, a Swiss tourist, announced on television that she was HIV positive, and had unprotected sex with local males on the island in the early 1990s. When asked about whether this still occurs, most health professionals, community leaders, and community members agreed that the exchange of sex for foreign currency, trips or other goods was a common phenomenon. On several occasions, health professionals and community leaders commented on the length of the lines in the banks on the Southwestern end of the island. They claim that locals go to the banks to exchange the foreign currency sent to them by their foreign sex partners. Apparently, the common scenario includes the tourist coming to Tobago and having sexual relationships with local residents. After they have returned to their homes, they continue sending money to Tobago to "maintain" the relationship while they are gone.

The sexual relationships with tourists occur in both heterosexual and homosexual relationships. One community member who is homosexual and works in the hotel industry stated that he has been sponsored several trips to Germany and other European countries by the men he met in the hotels. When

I spoke with other members of the gay community, they all agreed that this phenomenon was very common, and several of them were indeed being "maintained" by their foreign boyfriends. These relationships are important in the HIV infection scheme because many of the young men and women who engage in sexual relationships with tourists have local men and women with whom they are also sexually involved. During the off peak seasons, and when the tourists have returned home, the locals return to having relationships with other locals. Andy angrily explains how this affects the women on the island, because they are then forced to live with the men, because they are "trying hard to hold on to their young men." Other reports include the observation that several commercial sex workers from Guyana frequent Tobago and engage in unprotected sexual intercourse with both foreigners and locals.

Though it is obvious that sex tourism is a contributing factor to the HIV epidemic in Tobago, there are currently no prevention programs aimed at this sector. In fact, one community leader working within the tourism sector stated that he did not believe that there was a direct link between HIV and tourism any more. He agrees that there was an issue a few years ago, particularly during the period of Simonetta, however the current situation is very different. In addition to this denial about the connection between HIV and tourism in Tobago, one health professional stated that he had created a prevention program targeting this population. This project was not approved because it was believed that it would cause the island to be viewed negatively, which would ultimately affect tourism.

6.4.6.2 Sex In Exchange For Jobs

Health professionals, community leaders and community members all discussed the practice of politicians and other leaders requesting sex in exchange for better paying jobs. According to one community member, one prominent community leader talks about HIV very openly and always includes the fact that he is STD free. This is usually followed up with a proposition to have sex, since he is "safe." As a result, it was suggested by one community leader, that the politicians and other leaders must first "make strong political statements and act on them, " implying that they must publicly state that having multiple sexual partners is dangerous, and they must also maintain that stance in their own lives by not "screwing with all of the girls before giving them jobs in their offices." According to another community member, "no one has a moral high ground, so no one can openly talk about HIV."

6.4.7 Homosexuality

In Tobago homosexuality is not widely accepted. In fact, due to the religious influences on the island, homosexuality is seen as a sin. I've had several experiences with friends and family that highlight the negative views of homosexuals in Tobago. For example, I was invited to a celebration hosted at the home of a homosexual community member. Another community member, who was not invited, warned me to be careful because she was concerned that they might rape me. I told her that I am positive that none of

the guys there would want to have sex with me because they are gay, and they are not interested in having sex with girls. She said, "just be careful with those people." Another conversation occurred between another community member and myself. He emphatically stated that he "didn't want none ah dem fags in [his] house, car or anywhere near [him]." I asked him what his concerns about being next to homosexuals were, since he could not "catch gayness", and his response was that he "just didn't want no battyman[44] round [him]." I continued the conversation by asking about some of the fears surrounding gay men, and he stated that he knew that gay men rape little boys and "they would be kissing and touching and having sex in public". Andy angrily identified the media and religious leaders for these negative views about homosexuality. He related a television show that blamed homosexuals for the HIV epidemic. The preacher stated that "man having sex with man, that is where you going to get HIV".

On my last day at OASIS, a community member, in my honor, came to my going-away party in drag. This caused the biggest uproar throughout the capital city. People would literally run out of their businesses to see him. One Rastafarian lady became so enraged that she threatened to "burn down OASIS." She happened to be a customer in one of the stores on the first floor of the building, so she saw the community member walking into the building. She loudly stated that she was always in support of the OASIS group, but not if "they bringing dem type ah people" there. According to her, everyone in the OASIS building was "going to hell." On another occasion, I was walking through the capital city accompanied by this same community member. He was dressed like a man. As we walked past a construction site several of the men working shouted very offensive comments towards him. Apparently the rumor had begun circulating that he was gay, and the men at the construction site were "offended" by his homosexuality and therefore threatened to beat him up, among other things.

Due to these negative views, homosexuality is not openly talked about, and there are several reports of "down-low[45]" sexual behaviors. Several gay male community members talked about having "boyfriends who married or have girlfriends… that they can't talk to in public." While at a party, the majority of males present were homosexual men. One young man present seemed very uncomfortable. He stayed on the outskirts of the party, outside of the limelight, and at the end when a group picture was taken; it was obvious that he was hiding to prevent being photographed. During the party, another young man entered the party. He backtracked when he recognized one of the females at the party. At the end of the night he jokingly stated that he did not want his picture "on the internet anywhere." I noticed that he seemed uncomfortable, so I asked the lady that he saw why he was that uncomfortable. She stated that she knew him, his wife and his two children; therefore he was surprised to see her at this "gay party".

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[44] The derogatory term used to describe male homosexuals. It was coined within the reggae/Jamaican culture, and has since been adopted throughout the Caribbean.

[45] "Down low" is a termed originating in the African American community. It describes men who are married or otherwise sexually engaged with women. They also have sex with men; however they do not admit such.

According to this community member, "he definitely one ah the down-lowers." Another male community leader talked about personally knowing "several very respectable men, who hop the plane and go to Trinidad, have their sex [with men], and then come back and infect their wives."

6.4.8 Incest

Throughout my research, the issue of incest kept coming up. All of the research participants knew someone or knew a situation where incest was involved. One female PLWHA disclosed the fact that she was a victim of incest. Her father was responsible for taking her virginity, and as a result she has never been able to trust men, particularly around her female children. She also suggests the history of slavery as possibly being responsible for the level of incest in Tobago today:

> "you telling me about incest? Me know about incest, me grow up in an incestuous home. You hear me? I am one of them that could tell you that Tobago man, daddy like to bull[46] their daughter. Incest rampant. I grow up in a home, remember me ent have no man now, and people does keep it underneath, but I know that Tobago fathers dirty. If you get a father that don't trouble the daughter, thank god. Plenty Tobagonian man incestuous. I know that for a fact. You does watch them and see it in them. Like that was an in-thing you know? I think that that come from slavery you know? That is a thing that pass on through the generations. Remember that in slavery days they used to take some men to breed. They does even take the men and put them on farms like studs, and sometimes they bring a young girl and give you and that your own child, you know?
>
> … Girl I never know about virginity you know? I never knew what it is to be a virgin. Which is one thing that I would have liked, to have a sweet man, a boyfriend, and say that this is my first time. I never knew that. I know about man calling you, big man in the house tell you (whispering) 'don't tell mammy nothing you know', and bulling you. Poor you, when you see break[47] on you, you don't know, and you frightening every fucking night because this man go come down and bull you, you understand?"

Each of the other PLWHAs interviewed discussed either knowing a family or situation where incest occurred, or knew stories about incest. Rebecca stated that while she was traveling the day before the interview she had a conversation with a grandfather who was on his way to court. His four year-old granddaughter was being molested by another family member. Eric talked about another case where the father, uncles and an older brother were sexually assaulting a 12 year old. In this case, the daughter tried telling her mother about the abuse; however, she did not or did not want to believe her. To explain this phenomenon, Robert described a situation where a woman claimed that she "alone can't take all the [sexual] heat", so she was happy that her daughter was deflecting the sexual heat from her. Because it is believed that incest is so rampant, Janice suggests teaching young children about condoms and condom

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[46] To "bull" is a term used to describe having sex.

[47] "Break" is a term used for ejaculate.

use at very early ages to help protect them from HIV. She knows several young girls who are HIV positive, who "don't have breast, [and] they don't have nothing to attract a man, but they HIV positive". After further investigation it was discovered that they became infected from their fathers, uncles or brothers. A PLWHA related a story about a young woman who was sexually abused by her father and her uncle. She later discovered that she was HIV positive. To avenge the abuse, she continued sleeping with her father and uncle with hopes of infecting them.

I am also aware of several incidences of incest throughout the island. There is one prominent family where it is well known that the father has fathered several of the grandchildren in the household. At one point a couple of years ago, one of the daughters tried to bring a criminal case against him, and several of the young girls were removed from the family; however, the mother pleaded with the girls not to testify against him, because "if [he] goes to jail, who go feed the rest a children them?" The case was dismissed, and the young girls returned home.

These young girls now have several other children, and it is normal for them to continually bring different men into the house to live with them for short periods. One evening a several community members and I were speaking about the situation in that household. One community member wondered why the grandfather did not put a stop to it and prevent these young men from living in his house. I said "he can't stop that, he is the one that start them out, so he can't tell them nothing now". Everyone else looked at me with utter dismay. They could not believe that I had actually said those words out loud. This situation solidified in my mind the degree to which incest occurs, and the degree to which everyone knows about it, but refuses to talk about the issue. As one health professional stated "we try to help with the situation, but what are we supposed to do when we can't find nobody to talk about it? The mothers deny that it is happening, the fathers do not admit it, and after a while the daughters stop talking."

6.5 CONDOM USE

Since correct and consistent condom use has been listed as an effective method of HIV prevention, I decided to ask my interviewees about condoms. I wanted to know what people thought about condoms, who frequently uses condoms, and whether the PLWHAs currently use condoms.

6.5.1 Lack of Information, Misinformation and Myths About Condoms

In addition to the misinformation and myths about HIV, there are also misconceptions pertaining to condom use and their ability to prevent HIV infections. I've heard several male community members state that in an effort to protect themselves, they have or would use more than one condom at a time.

They believed that since HIV was small enough to pass through the pores of the condom, they needed more than one condom at a time to fully protect themselves. As the discussion progressed I would correct this misinformation. I also talked about the type of lubricant needed to prevent bursting, and ways of keeping the condom safe (not keeping it in the wallet, checking the expiration date, etc.). Most of the male participants stated that they did not know about the proper ways to care for condoms.

I also volunteered at the annual youth day in Tobago, by being at an information table hosted by the Tobago OASIS Foundation. In addition to having information about HIV and other STDs, a male and a female model was available to demonstrate the correct method of putting on condoms (both the male and female condom). Most individuals had never seen a female condom; therefore they were very intrigued when that was demonstrated. They were all very familiar with the male condom, and in an effort to examine their techniques, I asked some of the young men present to demonstrate. None of the young men demonstrated the correct way to open the condom package, place the condom on the model, or remove the condom from the model.

6.5.2 Condom Use Among PLWHAs

Condom use by PLWHAs is extremely important in HIV prevention. There were mixed views within the PLWHA community interviewed about consistent condom use. Some individuals stated emphatically that they use condoms each and every time they have sexual intercourse. Melissa uses condoms with her HIV positive partner because she does not want to re-infect him, nor does she want to be re-infected with another strain of HIV. Janice's motto is "no condom, no sex, no compromise". Andy states, "since I found that I am HIV positive, I always use condoms."

Other individuals were not as consistent. Frank explains that he did not negotiate condom use as well as he should have with his most recent sexual partner, therefore he uses condoms, but not consistently. Rebecca, on the other hand, has sex without condoms with her primary sexual partner, because he is also HIV positive; however whenever she has sex with other people she uses condoms, because she does not want to "give anybody else." Like Rebecca, Donna does not use condoms with her primary partner. Her partner has never been tested for HIV, so he does not know his status. When she asks him why he doesn't want to use condoms, he states that he wants her to "feel the hardness[48]."

6.5.3 Only "Bad" People Use Condoms

There is an idea that only certain types of people use condoms. These include prostitutes, people who are cheating, people with multiple sexual partners, and people who are sick. For example, Sharon explains

[48] Referring to the firmness of his penis.

that she "wasn't running around" before she became infected, hence she did not see the need to use condoms. According to her, if she "was making ah fairs[49], [she] would have had to slip on the bag[50]." On the flip side of that coin, Sharon stated that some women might feel offended if condom use is suggested, because the woman may feel like the man is treating her like a prostitute or is just using her. Other participants mentioned the societal philosophy that women who have or buy condoms are seen as being "bad" or as prostitutes. Robert discussed a prostitute who was known as "Condom Specialist" because she always had condoms while she "worked":

> **"…** I know it had[51] one of them they used to call Condom Specialist, she always had condoms. Any man who want she and she knows she have to open up she self for a twenty dollars to buy she thing to smoke, she always have she condom, and that name just come and stick on she."

6.5.4 Condoms Imply Infidelity or Lack Of Trust

A community leader, who is a little suspicious about the fidelity of her husband, confided in me that she does not use condoms because they irritate her skin. One morning she stated that she tried using it the night before, but discontinued use because of the irritation. After discussing the experience, she stated generally that "if you have to be in a relationship where condoms are worn, then that means you ent trust the man", and it may be better "to just be by yourself if you so worried."

6.5.5 Buying A Condom In Tobago

Condoms are usually given out at health centers, family planning clinics, HIV related offices and other related events. However in most cases condoms must be purchased. Due to the social stigma that surrounds condoms and condom use, women in particular see buying a condom in Tobago as a very difficult task. In the first place, in drug stores and other stores, condoms can only be found behind the cashier. Therefore individuals must ask the cashier to give them condoms. Janice talks about this process feeling like "begging them [the cashier]." Due to the process for purchasing condoms, Robert explained that most people don't "want to face the store to buy condoms, so they does send people to buy the condoms."

There is also a belief that the cashiers and the other people in line would scrutinize you and therefore make you feel uncomfortable when asking for condoms. As several participants stated, they

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[49] The term "making fairs" refers to prostitution or exchanging sex for money.

[50] To "slip on the bag" is a phrase used to describe condoms, or condom use.

[51] "It had" in this context can be translated as "there was."

look at you in a very questioning way, wondering "who you going to use it on, because they know that you have a wife." Camille describes a situation when she bought condoms. The cashier started laughing, while other customers looked at her scrutinizing:

> **"**The last time I was there, I bought two packs of Rough Riders[52], I said 'can I have two packs of Rough Riders please?' The cashier start to laugh, and this man in the line watching me funny."

To experience this process, on several occasions I went to drugstores to ask for condoms. On one occasion I noticed that the female condom "Femidom" was available for sale. I asked the cashier "how much for the femidom?" She said "the what? What is that?" I said "the femidom" She continued looking at me because she did not understand what I was saying. I finally said "the femidon, the female condom?" She then stuepped[53], reached up for the package and in a very annoyed tone she said "its $25[TTD]. You want it?" I said "no thank you", paid for my other items, then left.

On a second occasion, I went to another drug store with the sole aim of asking for condoms. Janice (one of the well known PLWHAs in Tobago), and another health professional (lets call him Jason) accompanied me. The situation follows:

Janice: Hi Ms. what kind of condoms you all have?

Cashier 1: (Stueps) I don't know. Look them behind there (pointing to the wall behind her where the condoms were hanging).

Jason (talking to Janice): I wonder what flavours they carry?

Jason: Ms. what flavours of condoms it have up there? I can't see that far.

Cashier 1: I don't know. What flavours it have up there? (She asks the other cashier)

Cashier 2: Look them right behind you.

Cashier 1: Look, I don't know what kinda condoms it have (as she gets more and more agitated)

Me: (When I finished paying for the other items, I said) Actually, I would like to know what kind of condoms you all have, and how much they cost?

Cashier 1: (Stueps), look them up there? I don't know what kind it have!

Janice, Jason and I then looked past the cashier and started talking among us about the types of condoms available, the flavors and the price. The first cashier stuepped again and then walked away.

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[52] "Rough rider" is a brand of condoms sold in Trinidad and Tobago.

[53] To "stueps" is to make a hissing noise with your mouth/teeth. It usually implies anger, frustration and/or disgust

These two personal examples indicate the level of discomfort that is experienced when individuals try to purchase condoms. On the other hand, however, a male community member stated that condoms can be purchased at some rum shops throughout the island. The situation there is a little different, and the individual, who is relatively young, stated that he did not feel as uncomfortable purchasing condoms at these venues, compared to purchasing them at drug stores and grocery stores.

6.5.6 Other Reasons For Not Using Condoms

I specially asked community members about whether they currently use condoms, and whether some of the factors discussed earlier affect their condom use. During one of my ethnographic interviews, while testing the in-depth interview guide, I asked a community member about whether she used a condom during her last sexual encounter. She said that she did and we continued the interview. A few days later, she met me and confessed that she had lied about her answer. We had become very good friends, and she was feeling very guilty that she had lied to me. In addition, after listening to some of the other questions, she was more and more concerned about her HIV status and wanted to talk more about it. Her new boyfriend states that he is allergic to latex, hence the reason for not using condoms. Though they have both been tested in the past, neither of them had been tested within the last two or three years, as a result she was concerned. She, however, didn't want to disappoint him, and she didn't want to be seen in a negative light. So although she knows about the dangers of unprotected sex, and warns her younger sisters about the dangers, she still engaged in unprotected sex. A couple weeks later the community member reported that due to her continued nagging about the issue, they got tested for HIV.

Several other reasons for not using condoms were given. Camille and her boyfriend, who was HIV negative, wanted to have a child. Other guys stated that the "condom too small" or "the condoms does squeeze" or they "doesn't get hard." Though the female condom is available in Tobago, it is not very popular. Sharon talks about its appearance as deterrence to using female condoms:

> "I see female condoms come in, I pick it up and say 'I go try it', when I watch it I said, 'oh God look at this thing, who I go use this with?'"

6.6 ABORTION

Abortions normally occur to end an unplanned or unwanted pregnancy. These usually occur via unprotected sex; therefore abortions are indirectly related to HIV. The issue of abortions came up by accident while doing this research in Tobago. While helping out at one of the HIV related organizations,

an invitation to a workshop sponsored by Advocates for Safe Parenthood: Improving Reproductive Equity (ASPIRE), came into the office. I was invited to attend the workshop, so I did. ASPIRE is an organization that is working on changing the criminal abortion law to a civil abortion law. After being at this workshop, I decided to talk with community members about their views about abortions. Several community members stated that they had indeed had abortions, or at least knew of someone who had an abortion. One mother-to-be interviewed at the maternity ward stated that she had had six abortions. She was about to have her 4th child. Another community member while discussing her marriage history talked about having at least three abortions because she could not "have any more children", at least not in the financial situation that she and her husband were in.

6.7 PRE- AND POST-TEST COUNSELING, AND TESTING

One of the issues that I wanted to explore was the degree to which individuals are counseled before and after receiving an HIV test. From participant observations and ethnographic interviews with health professionals at the Tobago Health Promotion Clinic, I believe that individuals who are tested at that facility are adequately counseled. However there was no information available about the private clinics or the other facilities where testing is done.

6.7.1 Private Labs

There are three private biomedical labs in Tobago (all located in Scarborough, the capital city of Tobago). For the price of $100 TTD[54], any individual can be tested for HIV at these clinics. As part of my participant observations, I got tested at two of these clinics:

Testing Lab 1

At approximately 4.30pm one Monday evening in November, I walked into the waiting room of Lab 1. There were two people sitting in the waiting room. They pointed me to a door, and one lady suggested that I knock on the door. I did and a lady came out. I told her that I was interested in getting an HIV test. She said ok, and asked me to come inside that door. I sat at her desk. She proceeded to fill

[54] The average currency exchange rate between United States dollars and Trinidad and Tobago dollars is $6.25TTD = $1USD. Therefore $100TTD is approximately $16USD.

out an information form (name, date of birth, address, etc). She then told me that the test costs $100TTD. I gave her the money and she wrote me a receipt. She then asked me to extend my arm for her to take the blood. After she took the blood, she told me that I should come back the following day after 11am for my results.

At approximately 11.30am the following day, the lab called me on my cell phone and told me that my results were ready. I went to the lab shortly after. As I walked into the room, the technician who took my blood the previous day said hello to me and proceeded to look for a white envelope in a box sitting on another table in the lab. She found my results and handed the envelope to me. I stood at the doorway and opened the envelope. The result was 'HIV negative". I then asked her what would have happened if I had tested positive. She said that if it were positive she would have had to talk to me some more. She said that they would have had to take additional blood and send it to CAREC for confirmation. I responded by saying 'ok', but I didn't walk away. I guess that she sensed that I wanted to talk some more, so she asked if this was my first HIV test. I said that it wasn't, and asked why she asked. She said 'because you would have had to come back in a couple months. And you know that you need to stay clean and stuff. Ok?" I said 'ok, thank you', and I left.

Testing Lab 2

About a week after visiting the first lab, I visited the second testing lab. I went in approximately 11am. After waiting in the empty lobby and finally knocking on a closed door, a young man came to my assistance. I told him that I was interested in getting an HIV test. He said 'ok', and asked me to follow him into the back room. After sitting down, he asked why I wanted a test, whether a doctor sent me or whether I was doing this on my own. I said that I was doing this on my own, and I followed by asking what difference that made. He said that if a doctor sent me, then the doctor would have given me a piece of paper with all the tests needed. He then explained that it was possible that the doctor also ordered other tests, but HIV was the only one that I remembered. I said 'ok', then he proceeded to take basic information from me (name, address, phone number, etc).

After taking my information he stated, "the test would give [me] a clear indication of how [I] was six months ago, and a not so clear indication of how [I] was three months ago. It ent go show up any recent activity like last night or last week." He continued, "once I do the test and it come back negative, you could come back today after 5 o'clock and collect the results. If by chance I do it and it come back positive, what happen I will explain that to you then. What happen is that I have to send it Trinidad for a confirmation test. Once I send it for the confirmation test, it go take at least a month to come back up. But once it negative you could come back for it this evening." I said "ok" and asked him how much the test costs. He said $100TTD, I gave him the money and he wrote me a receipt. He then asked me to extend my arm for him to take the blood.

I went the following day for my results. After waiting in the lobby again, then knocking on the closed door, the same young man came out. He said "you ent come for that yesterday? I said "no." He then riffles though a box with brown envelopes, looking for my results. After looking for a while, he said that he couldn't find them, so he would print another set of results for me. As he was walking towards a room further back to print the results, he says "let me print it, but you negative!" He finally comes back with my results and he hands them to me. I then ask him what would have happened if I were positive. He said that "I woulda just tell you that the screening test shows positive, and we have to send more blood to Trinidad to confirm the results. And then we would put you on to the rest of clinics and places in Tobago." We continued with a little chitchat about whether the tests are done right here in this clinic. He said yes everything is done right there. I said 'thank you' and left.

The lack of counseling at these private labs was apparent by these two experiences. I also asked a friend who was recently tested at the third lab to describe her experience. She stated that she went in, they took her information, took her money, took her blood, then told her to return at a later date for the results. She did not receive any pre- or post-test counseling. She actually asked the technician why he did not counsel her and he stated that he was not trained to counsel people. She asked what would have happened if she was positive, and he told her that the person in charge would have to give those results, and therefore she would have to return another day.

Another issue that arose was testing without consent. For example, one community leader stated that once while he was very sick he went to the hospital. They ran several tests but could not diagnose him – he still has no idea what was wrong. Anyway, during one conversation with a doctor, the doctor accidentally told him that at least he does not have HIV. When the community leader questioned him further about the HIV test, the doctor changed the topic.

6.7.2 Antenatal Testing

Recently, free, voluntary HIV testing was introduced in the pre- and post-natal clinics and the maternity wards in Trinidad and Tobago. In an effort to evaluate this project, health professionals on the island developed a questionnaire. This questionnaire, for the women already offered the HIV test, was a 55-item instrument, which evaluated their knowledge about HIV, information about their experiences with getting tested, their history of getting tested, their parity history, and their current HIV/STD risk level. I was asked to help administer approximately 25 of these questionnaires, so I include some of the information gathered during those interviews in this dissertation.

The vast majority of the women interviewed were offered the HIV test during their pregnancy. Each of them accepted the offer and was tested. When I asked about the degree of counseling given, none

indicated that they were adequately counseled. In many cases, the nurses told the mothers-to-be that the doctor said that they needed to do an HIV test, and they needed to sign the consent form. They all simply signed the form. Very few were given information about HIV, the HIV test or ways of reducing their risk of infection. According to most of the women, they did not know that the test was voluntary until I asked them the question about whether they accepted the test or not.

Several women were upset because they had never been given their results. In some instances, when they asked about their results, they were told that their specimen was lost, so they gave additional blood to be tested. At least four of the women that I interviewed did not receive their results. Of the others who knew their results, they all reported a negative HIV result.

6.8 ALCOHOL USE

Alcohol use has been associated with increased HIV risk since it reduces inhibition, and subsequently prevents individuals from protecting themselves during sexual intercourse. Alcohol consumption in Tobago is very common. It is a part of everyday life. On the field trip around Tobago previously described, I explained the need for several vehicles to accommodate the large number of travelers. On the tray of one van was a cooler filled with beers and rums. At every other village, the vehicles would stop and the drivers would each take a drink. From my rough calculations, each driver had approximately 15 cans of beer throughout the course of the day, while driving. This type of drinking, particularly when on field trips or other similar get-togethers, is normal. While in Tobago, I noticed a couple of public service announcements warning people about the dangers of drinking and driving. I believe that there are laws against drinking and driving, however they are never enforced. As one community member stated, “if they have to lock up people for drinking and driving, then the whole police force go be in jail,” implying that everyone, including police and other protective servicemen, also drink heavily and drive. The legal age limit for purchasing and consuming alcohol is 18 years old. This is also never enforced. I remember buying alcohol on the compounds of my high school Christmas concert and dance. Anyone can go to the bar to buy alcohol, and no one is ever asked for identification before being allowed to purchase alcohol.

6.9 HIV AND POWER IN THE PROTECTIVE SERVICES

An issue that was not directly asked about but came to my attention was the influence of the protective services on HIV infections in Tobago. The protective services in Trinidad and Tobago include the Police Service, the Fire Service, the Army, and the Coast Guard. Like in other countries, these men and now

women are trained and then deployed to areas that may not be their home regions. As a result, the issue of having sexual relationships with women in the village where they happened to be deployed is common. One community leader shared a hypothetical situation about a policeman being stationed in different villages in Tobago and therefore having several children with different women - a situation that is very common in Tobago:

> "The policeman living all the way in Charlotteville[55] – whet he supposed to do? So he sleep with one woman in the village and she get pregnant. A year later they move him to Castara and he find another woman to live with and she get pregnant. Then they move him to another village. You could see how he have five children with five different women, in five years. And that is how the thing does go."

A real life example of the influence of the protective services on the possible infection rates of HIV was explained to me. On the HIV awareness walk, soldiers from the Trinidad and Tobago army services who were stationed in Tobago were asked to accompany the walkers, and provide protection and guidance if needed. I met one soldier on the way and we walked for a couple hours together. At first he did not know what the walk was about, because they were simply given an order to accompany the walkers the night before. When I told him it was for HIV awareness he related a story about the previous weekend. This solder, and the others stationed with him, are all from Trinidad. Some have wives or are in committed relationships in Trinidad. Last weekend, they went out to a popular party spot. One of the soldiers met a young lady at the party. Apparently the lady propositioned the soldier and he accepted. As they were about to leave the party with the sole aim of having sex, a local told another soldier to "tell that soldier to leave she alone, she have the virus." The second soldier warned his friend, so he did not have sex with the young lady that night.

6.10 SEX IN THE MEDIA AND POPULAR CULTURE

6.10.1 Sex In The Media

While in Tobago, I was pleasantly surprised by the availability of cable and satellite programming on the television. It is relatively cheap to obtain cable or satellite programming, therefore almost every house that I visited had these services. In addition to having the basic network channels, the packages included stations like HBO, Showtime, Encore and Cinemax. Unlike in the United States, these channels were intermingled between the other "children friendly" channels like Disney and Cartoon Network. One

[55] Charlotteville and Castara are remote fishing villages in Tobago

Friday night approximately 10pm after everyone else had separated into their respective corners, I started perusing the channels looking for something worth watching. As I moved from ABC (channel 20) up one level, I was surprised to see two women having sex. This was channel 21, HBO, and apparently a major part of the weekend line-up includes several soft pornographic movies and other x-rated shows. The following day I asked my mother about whether she was aware of the types of programming on television, and whether she knew about options for blocking this type of programming. Of course the response was "no" for both questions. I continued looking at the other movie channels, particularly late nights on weekends, to see if this was a common occurrence. Yes, it was a normal part of the weekend line-up to have soft pornographic movies and other x-rated shows.

At a workshop one weekend in Tobago, the topic of the level of sexual activities occurring in the schools and other places relating to youth was raised. One facilitator stated that she did not know where the young people were learning about sex at such early ages, and she proceeded to blame the parents because they "should have control of their children." Another participant asked her if she had cable, and whether her 15-year-old daughter watches cable late at nights on the weekend. She stated that yes she did have cable, and that she did not know what her daughter was watching because she was usually in bed sleeping by that time. The second participant continued by explaining the types of programming available at that time of the night. The facilitator was not aware of the types of programming available on her television. They continued to discuss the impact of young children viewing these sexually explicit programs, particularly because the appropriate sexual health conversations needed to help youth deal with these images are not engaged in.

6.10.2 Our Music – Soca and Reggae

While preparing to collect my data, I spent a great deal of time listening to the music commonly played in Trinidad and Tobago – soca and reggae. As a result, I started noticing the sexually explicit lyrics of some of these songs. I wanted to know if individuals in Tobago listen to words of these songs, whether they believe that they are influenced by them, and finally whether they could be used as part of prevention programs. Most individuals believed that most people do not really listen to the lyrics of the songs: instead individuals only listen to the rhythm and the commands to "jump and wine." Some participants stated that even the positive lyrics are ignored. Most of the participants believed, however, that the music (rhythm and lyrics) indirectly influences sexual behavior. Eric believes that the type of dancing that these types of music promote is very sexual. He gives the example of the "dutty wine", which was the newest reggae song and accompanying dance in the Caribbean:

> "… the soca and the Jamaicans with their 'dutty wine'. It's a sexual thing. It promotes this heightened sexual feeling, so I think the music has something to do with it."

Similarly, Camille believes that "during carnival is plenty winin'[56] and thing and once a man seeing that movement you know one time what on his mind [sex]. When you drinking and you head nice[57], you might get carried away." Melissa explains that most of the songs tell people to "'cock up this or that', [so] what do you expect them to do?" Andy also noted that these songs, particularly the reggae that promotes violence against homosexuals, do in-fact influence human behavior, and that they should be censored. A new song talks about getting burned by "Jah Jah fire[58]" if you "were born a man and wearing woman dress", which represents the type of discrimination in music against homosexuals.

Some participants believed that soca and reggae can be used in HIV prevention. In fact, there are several songs with prevention messages, however these are usually not widely played. It so happens that the National AIDS Coordinating Committee (NACC) has launched a major HIV prevention campaign in which they utilize famous reggae and soca artists[59]. It is ironic, however, that there is a debate about whether these reggae and soca artists are ideal role models for this type of promotion. Melissa believes that we should use these artists because they are role models and people would listen to them:

> "Yeah, because I think this guy is doing a great job, Maximus[60]. And they using people that the public is accustomed to. They used Shurwayne Winchester[61] and all these people. Because they would listen to these artists."

Janice disagrees with Melissa, however, because she believes that the individuals being used are not role models. According to her, she would not want her sons to be like those guys since they portray one persona on stage, and then they try to tell individuals to abstain:

> "And I think that the people that they using to make the promotion is downright ridiculous… . I want my son to look like Bunji, with all them things in his face? I ent discriminating, but I think they use the wrong choice. And take for instance Destra. Destra going up on the stage with no clothes. Is that how I want my daughter to see the future calypsonian? … Why couldn't they use somebody who living with HIV? I mean Shurwayne kinda decent, and I not being biased, but it's the way he put out himself. Now I would look at Shurwayne and say yeah 'I would like mi son to look like that.' … But them they now trying to tell me that because Bunji now start to scale down he music,

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[56] To "wine" or "winin'" is a sexually suggestive dance that involves gyration of the waist, hips, and/or bottom.

[57] "Head nice" is a term used to describe being intoxicated.

[58] "Jah Jah fire" refers to the punishment of fire expressed in the King James version of the Bible. This is also known as "hell's fire."

[59] This is discussed in detail in the following chapter.

[60] Maximus Dan is the name of a popular soca/reggae artist from Trinidad and Tobago. He has done several HIV prevention ads for NACC.

[61] Shurwayne Winchester is another soca artist who is from Tobago. He has also done several NACC HIV awareness ads.

because people ask him to do that. That he is going to make a good role model. My children go remember the first time he come out with a song it was about violence, and people don't change overnight."

Several other community leaders echoed Janice's sentiments, and suggested that the NACC think carefully about the people it chooses to do the PSAs. According to one community leader "we have to look at the images of these people. One image is of them telling you to abstain, while the next image of them includes them behaving badly on stage."

6.11 ANALYSIS – FACTORS THAT INFLUENCE HIV INFECTIONS

The actual HIV prevalence or incidence rates in Tobago are unknown. The Health Promotion Clinic reports 206 PLWHAs (0.4% of the population) being treated at that clinic, while UNAIDS estimates a prevalence rate of 2.6% for Trinidad and Tobago. If it is believed that the true prevalence rate for the island of Tobago is 5%, then there are 2492 PLWHAs in Tobago who know about their status and are treated elsewhere, know about their status and do not get treated at all, or do not know about their status. I believe that a large portion of that "missing population" falls into the third category, i.e. they do not know their status. This is very important and highlights the possibly explosive nature of HIV in Tobago. If HIV is not prevented, and those already infected not treated, Tobago can quickly experience the disastrous effects of HIV as seen in some African countries.

In Tobago, HIV is still synonymous with death, which implies that the 25 year-old messages about HIV/AIDS have not evolved. HIV continues to be marketed as a "killer". This may be intentional, since there is a belief that informing individuals about how they can live with HIV may increase their risky behavior. Farmer argues against this concept, since studies in Haiti have shown that a predictor of getting treatment (when available) is HIV status knowledge. In resource poor communities, increased HIV testing occurs when the availability of HIV medication is publicized. By learning about the availability of HIV medication, individuals at risk understand that HIV is no longer a death sentence, which encourages them to get tested [147, 148]. This philosophy reigns true in Tobago, since community members or leaders who personally knew someone with HIV, or those who were exposed to detailed HIV educational programs, were the ones who understood HIV as a chronic disease and not a death sentence. These individuals were also willing to learn about their HIV status.

Given the high visibility of HIV prevention programs on the television, radio, t-shirts and other forms of media, the level of misinformation and myths about HIV is surprisingly high. The questions that

individuals asked me and some of the responses to interview questions indicate that the information contained in the PSAs is not being understood. This implies that either the information is not present within the PSAs, or the method of dissemination is inadequate. I believe that in some situations both of these factors are culprits. The specific discussion about the HIV prevention programs is included in the following chapter; however, the lack of basic information about HIV is a factor that influences the rates of HIV infections in Tobago. For example, if individuals do not know the methods of HIV transmission, they will not be able to make adequate decisions about preventing infections. Similarly, if information about testing (where to get tested, accuracy of the test, what the test result means) is not given, then individuals may not be tested, or they may not understand what their results mean.

Similar to African and other Caribbean countries, there is still denial about HIV in Tobago. This denial ranges from individual to institutional denial. Individuals do not believe that they are at risk for HIV, particularly since they do not belong to the traditionally "high risk" groups. The data in the Caribbean shows that these traditional high-risk groups are no longer the groups at greatest risk. Women and youths are the ones most at risk, and according to Hirsch, marital infidelity is increasing the risk levels for women in Latin America and the Caribbean [149]. This fact corroborates the stories of the PLWHAs interviewed who were in "monogamous" relationships when they became infected. This implies that the traditional messages of prevention have not, and will not work in this setting. In fact, in the Caribbean, the messages of "abstain, be faithful, or use a condom" may be placing women in seemingly monogamous relationships at risk. These women have abstained, been faithful, and have used condoms when they are not in monogamous relationships, but the virus continues to "come home to them."

Though it is argued that the entire sexually active population is at risk, it is a fact that harder to reach populations (drug users, commercial sex workers, and beach boys for example) must be met on their terms, since the programs targeting the general population may not reach these individuals. In addition, the messages given to the different segments of the population must be tailored to their specific situation and circumstance. The reluctance of politicians and other administrators to undertake HIV prevention programs geared to the high risk groups also presents an issue for HIV prevention in Tobago. Due to the size of the population, these "high-risk" individuals are not isolated; therefore their increased risk indirectly increases the risk of the general population. As one health professional stated, a community like Tobago is as weak as its weakest link, so we are all at risk. Therefore high risk groups must be targeted.

Sexual relationships in Tobago are not talked about, yet sex seems to be happening everywhere. Two main types of relationships occur in Tobago: serial monogamy and concurrent partnerships. Serial monogamy refers to an individual having only one sexual partner at a time. When this relationship ends, a subsequent sexual partner is taken. Concurrent partnerships refers to having more than one sexual partner at a time [150]. In Tobago, both of these phenomena are engaged in without the correct and consistent use of condoms. The viral load is relatively high during the initial stages of infections, but it

decreases after some time and possibly decreases the probability of infection. As a result, studies have shown that serial monogamy is protective against HIV since the virus is "trapped" within that relationship for months and sometimes years, and it does not have an opportunity to move outside of the relationship. In concurrent relationships, however, other sexual partners are at risk for infection during the initial infection stage [151]. In Tobago both of these phenomena occur, therefore the protective properties of serial monogamy are outweighed by the increased risk of concurrent relationships. In addition, according to the reports from the Health Promotion Clinic, over 90% of the clients who present at the clinic present with AIDS, which implies that they may have been infected for five or more years, during which they have been sexually active, potentially infecting several others.

Several participants raised the issue about women having less sexual health control due to financial, social or cultural constraints. In many instances women engaged in unprotected sexual intercourse because they needed money or other resources from their husband, boyfriends or other male counterparts. Though none of the study participants identified physical, emotional or verbal abuse as reasons for them engaging in unsafe sex, many knew of situations where that was the case. As a result, there are gender-specific issues that increase women's risk for HIV due to financial need or threat of abuse in Tobago. The example of the female community member who did not insist on condom use because her partner was allergic to latex must be highlighted. Due to her continued "nagging", her partner did get tested for HIV, which implies that the women in Tobago may have more control over sexual issues than previously assumed. It would be interesting to investigate further the factors that would influence a woman's ability to insist on condom use or on HIV testing in Tobago.

The fact that HIV-related disease is the leading cause of death of youth in the Caribbean warrants that there be a focus on the youth in HIV prevention programs in Tobago. As the school cell phone sex tapes now prove, the youth of Tobago are engaging in unsafe sexual activities. Therefore special attention must be paid to that section of the population. Currently, sex education in schools is not comprehensive, and in many cases is based on the abstinence only philosophy. Abstinence is an important aspect of HIV prevention, however in situations where the youth are already engaged in sexual activity, it may not be the most appropriate method of HIV prevention. This is particularly the case since the young girls seem to be having sex with older men because of the money and other resources that these men provide. In addition, in other communities, condom use at first sexual contact seemed to predict future condom use [152]. Therefore targeting youth before they initiate sexual activity in Tobago may increase the probability of them using condoms at their first sexual contact and subsequent sexual experiences.

Homosexuality is not accepted within the larger Tobago population. As a result, similar to what has been reported in Jamaica, the concept of "coming out" isn't very common [153]. Since many of the homosexuals interviewed talked about the "down-low" community, this is something that can potentially influence HIV rates in Tobago. Though there is no direct information about whether men who have sex with men in Tobago frequently used condoms, it can be extrapolated that similar to the general

population, condom use is not common. Since unprotected anal sexual intercourse (insertive or receptive) has higher risk levels for contracting HIV [154, 155, 156], then it can be seen where the down-low population may be at risk for contracting HIV and then infecting their female sexual partners.

As has been discussed, incest is a problem in Tobago. Though there are no specific studies that have measured the rates of incest, the fact that community members, community leaders, health professionals and PLWHAs all know about specific cases, indicates a relatively high rate. In a culture where "normal", "acceptable" sex isn't discussed, it is very difficult to discuss incest, and therefore it is not openly discussed. Due to the social, economic, religious and other complications relating to incest, it is very difficult to deal with incest in Tobago. It increases the risk of HIV infection in Tobago, since children who are victims of incest are usually very young, and therefore they begin sexual contact at early ages. Additionally, forced sexual contact is usually followed by continued unsafe sexual behavior. Therefore young men and women who are sexually assaulted are at higher risks for contracting HIV.

Given that correct and consistent condom use is important in HIV prevention, the misinformation, myths, lack of information, resistance to use, and social meanings carried by buying, requesting and using condoms in Tobago is disturbing. Most of the sexually active PLWHAs stated that they used condoms consistently. However it is likely that those individuals who have not disclosed their HIV status may not consistently use condoms because of the infidelity and illness associations of condom use. In addition, it seems likely that very few community members consistently used condoms, particularly with their primary sexual partner. Again this relates to the idea that only "bad people" or people who are sick or cheating use condoms.

Accessing condoms in Tobago also seems to be a difficult feat, particularly for married individuals, women and young people. If condoms must be bought, individuals are usually scrutinized and their sexual "intentions" judged by the cashier or the other people in line. This prevents individuals from buying condoms, and according to Moore *et al* (2006), purchasing condoms produces the highest level of embarrassment and stress relating to condom use [157]. As a result, although individuals may be aware of the protective capabilities of condom use, the social harm of being seen purchasing a condom is much greater and thereby prevents individuals from using condoms. The lack of availability of different types of condoms also seems to be a factor in Tobago. Community members discussed the fact that they or their partners were allergic to latex; therefore they did not use condoms during sexual intercourse. Recent studies have shown that the risk of semen exposure is similar for the male latex condom and the female polyurethane condom (3.5% and 4.5% respectively) [158], therefore the issue of latex allergies can be alleviated if polyurethane condoms are available and are advertised as being effective. Though the female polyurethane condom is available, I am unsure about whether the male polyurethane condom is available in Tobago.

The issue of abortions is important when dealing with HIV because a large percentage of the individuals who resort to abortions in developing countries do so because of unintended pregnancies

resulting from unsafe or unwanted sexual intercourse [159]. As a result the fact that these women have become pregnant means that they are at risk for contracting HIV. According to research done by ASPIRE, approximately 3000 cases of abortion-related complications are reported to the public hospitals of Trinidad and Tobago yearly [160]. This indicates a relatively large proportion of unwanted pregnancies, which can be extrapolated to indicate a large portion of unplanned pregnancies due to unprotected or unwanted sexual intercourse.

The limited or no pre- or post-test counseling currently available in Tobago is definitely a problem when dealing with HIV prevention. According to the 2001 Center for Disease Control's (CDC's) recommendations for HIV testing, effective pre and post test HIV prevention counseling is "effective at reducing high-risk sexual behaviors and new STDs, [is] feasible to use even in busy publicly funded clinics, [is] acceptable to clients, counselors, and health-care providers, and [is] cost-effective at preventing STDs in persons at increased risk for HIV" [161]. As a result, a great opportunity to help reduce the risk of HIV and other STDs is being missed when individuals are not adequately counseled when tested for HIV in Tobago. This issue of lack of counseling is also seen in the antenatal, maternity and postnatal wards where testing is done in Tobago. This also represents missed opportunities.

According to the UNAIDS 1998 report on HIV and the military, the military and other protective services tend to have higher rates of HIV and other STDs compared to other sectors of the general population [162]. Though there are no specific published studies about Trinidad and Tobago, the factors that increase the risk of protective service men in other countries are also present in Trinidad and Tobago. Therefore it can be extrapolated that this population warrants special attention when dealing with HIV prevention in Tobago.

Our culture in Trinidad and Tobago has always included sexual images, connotations, and insinuations. As a result, from a very early age individuals are exposed to what may be seen as relatively sexually explicit materials, music lyrics and actions. This exposure, coupled with the reluctance to talk about sex and sexuality, has created a recipe for disaster. Individuals, particularly young people receive mixed messages because the "powers that be" state that sex should be between a married man and woman, while these young people continue to see images of sex on television, during carnival and other such situations.

In the end, many factors directly or indirectly increase the risk of contracting HIV for the Tobago population. This includes the different types of sexual relationships engaged in, coupled with the limited use of condoms. Lack of information about HIV/AIDS, testing and treatment options, in addition to lack of information about condoms increases the risk of HIV in Tobago. Additionally, gender related issues influence women's abilities to adequately protect themselves. In the end, Tobago presents a special situation, where if HIV isn't dealt with effectively, the social, economic and cultural fabric is in jeopardy.

7.0 HIV/AIDS PREVENTION IN TOBAGO

7.1 WHY IS THIS IMPORTANT?

In an effort to understand the current situation pertaining to HIV/AIDS prevention in Tobago, and ultimately make recommendations, it is very important to identify what is already being done. If there are programs already being implemented, it may be necessary to simply tweak them for improvements to be seen, or it is possible that they are working but have not been given enough time to demonstrate their positive effect. This section therefore identifies the current HIV prevention programs operating in Tobago, and highlights some of their strengths and weaknesses.

7.2 PREVENTION STRATEGIES IN THE CARIBBEAN

HIV prevention in the Caribbean focuses on preventing transmission via sexual (primarily heterosexual) contact, and preventing MTCT [163]. Since most of these initiatives are done on the grassroots level, it difficult to find detailed descriptions of HIV prevention programs in the Caribbean. For example, the Behavior Change Intervention manual was created by CAREC in 2004 [164], however the specifics about this manual are not publicized. In addition, the CAREC website reports on partnerships with the different media outlets to disseminate information about HIV/AIDS, but again, the specifics about how this is done, and what type of information is disseminated is unavailable. CAREC has also reported on educational sessions, and condom promotion programs implemented during carnival seasons in Trinidad and Tobago [164]. Before looking specifically at HIV prevention programs in Tobago, four prevention programs carried out in other Caribbean countries and described in detail in the literature are discussed below.

7.2.1 Apwe plezi – St. Lucia

The "Entertainment-Education Radio Soap Opera" aired in St. Lucia from February 1996 to May 1997 [165]. This program was named *Apwe plezi,* which is the shortened version of a French Creole saying "*Apwe*

plezi cest la pain", which means, "After the pleasure comes the pain." *Apwe plezi* was based on Bandura's social cognitive theory (SCT), and was designed to address 37 educational issues including "knowledge, attitudes, and behavior relating to family planning, HIV prevention gender equality, relationship fidelity and domestic violence." The characters of the soap opera were developed to follow one of three "behavior patterns": positive (embodies positive values and are rewarded), negative (embodies negative values and are punished), and transitional (are usually torn between positive and negative values, who then typically chose positive values and were rewarded in the end) [165].

About 12% of the adult population were regular listeners of *Apwe plezi*, making it the second most popular program on that particular station and the fourth most population radio show in St. Lucia. Most listeners identified correctly the "behavior patterns" of the positive and negative characters, and generally followed the negative-to-positive transition of the transitional characters. There was a mixture of characterizations of one negative character (he was accused of date rape, had irresponsible sex and contracted HIV) however: females were more likely to state that he was "morally good". Eighty-four percent of the regular listeners reported learning something from the program, while 80% of those reported attitudinal changes. Of those who reported attitudinal change, 46% reported actual behavioral changes [165].

The results of the study were mixed, probably due to deficiencies in the design of the program, which neglected to consider important characteristics of Caribbean cultures. It may be important to understand the concepts of individualism and collectivism described by Hofstede's "cultural dimensions measures." According to Hofstede, communities that exhibit individualistic characteristics reinforce individual achievements, individual rights are highly valued, and less rigid relationships are formed. Collectivist communities on the other hand, tend to reinforce extended families, and each member is responsible for the wellbeing of others within that community (often at the expense of his/her personal achievements). On the scale created by Hofstede, Caribbean countries tend to be very collectivist in nature [166]. Due to this collective nature, behavior change in the Caribbean is also very communal, which includes collective changes in the culture, social, economic and other factors that influence sexual behavior.

In addition to the individualistic and purely knowledge-based critique of this program, one other aspect must be critiqued. The program uses punishments and rewards for "good" and "bad" behaviors respectively. As a result, this program reinforces the moral distinctions that contribute to the stigma associated with HIV/AIDS in the Caribbean, where the "bad"/"immoral" people got the disease, and the "good"/"moral" people stayed healthy [165]. Even though this program is successful in increasing knowledge and showing individuals that they too can make individual changes, it alienates the individuals who seem to fit the characteristics of the "bad" characters, which may reduce their willingness to get tested and be treated.

7.2.2 Preventing Mother-To-Child-Transmission – Dominican Republic

In the Dominican Republic, a comprehensive program was implemented to prevent MTCT in 2000. Though the report of the program did not explicitly state a formal health promotion theory, the Ministry of Health used an "integrated package of interventions" [167]. This program included voluntary HIV counseling and testing in antenatal and postnatal clinics for mothers, the administration of nevirapine (an antiretroviral drug) at the onset of labor or eight hours before a cesarean section to reduce transmission during childbirth, administration of medication to the neonate 8-72 hours postpartum, and an elective option of cesarean sections and formula feeding [167].

Fifty four percent (n = 23,067) of the women attending the clinics were tested for HIV, however only 28% of those women participated in pretest counseling, and 15% of those tested participated in posttest counseling. Eighty-nine percent of the HIV positive women accepted the nevirapine treatment, while antiretroviral drugs were administered to 98% of the children born to HIV positive women. Cesarean sections were performed for 67% of the births. Perez-Then *et al* (2003) highlighted the feasibility of implementing a large-scale MTCT prevention program. The authors credit several factors for its relative success, including the involvement of a broad coalition (Ministry of Health, hospitals, military services, HIV related NGOs, among others). In addition, though a specific formal theory was not explicitly stated in the report, it can be deduced that the program utilized the influence of the *familismo* culture by focusing on the family and specifically, the need to produce healthy babies, to increase the acceptance of the program. This shift in focus from the HIV infected mother to the need to protect the family, removed the stigma and "morality" concerns usually associated with HIV, and placed it on the importance of having healthy children [167].

The MTCT prevention program is relatively successful because it involved a large proportion of the medical facilities in the country, it shifted the focus from individuals to universal access for all expectant mothers, and it involved policy level changes. While the percentage of women who accepted the HIV tests and treatment were relatively high, the small number of pretest and posttest counseling is one area that needs to be improved, since these counseling sessions are important in preparing the clients for possible HIV positive results [167]. More importantly however, pre- and post-test counseling sessions present a perfect opportunity to provide basic information about HIV/AIDS, and methods of prevention and care. These sessions are usually done using a one-to-one format, which gives the client the opportunity to have a meaningful conversation with the medical practitioner, which would increase the clients' knowledge and reduce HIV related stigma. Unfortunately, this lack of counseling has also been observed in Tobago, where surveys of mothers in the maternity wards highlighted the fact that the majority of the women who agreed to be tested, were never accurately counseled [168].

7.2.3 100% Condom Program – Dominican Republic

One final prevention program reported in the literature was an "Environmental-Structural" (E-S) intervention that was implemented in the sex-work industry in the Dominican Republic in 1999 and 2000 [169]. This intervention was modeled after the Thai *100% condom* program [170], with the aim of decreasing STDs and HIV in female sex workers [169]. The E-S has five main components: solidarity and collective commitment (regular workshops and meetings with sex worker, establishment owners, policy makers, etc.), environmental cues (establishment owners placed *100% condom* posters, in addition to bowls with free condoms within their establishments, information mechanisms geared to the male clients were also implemented), clinical services (the Ministry of Health implemented a policy requiring all sex workers to be tested monthly, monitoring of this requirement was also implemented), monitoring and encouraging adherence (establishment owner were notified monthly of their adherence status, with intense educational sessions being targeted at establishments not in compliance) and policy and regulation (regional regulations requiring condom use between sex workers and clients were publicized) [169].

The rate of consistent condom use increased from 75.3% to 93.8% in one region, and from 96.5% to 98.6% in another region with new clients, while the rate of consistent condom use increased from 13% to 28.8% with regular paying or non-paying partners. The percentage of sex workers who refused unsafe sex increased from 50.0% to 79.4%, while the STI prevalence decreased from 25.5% to 15.9% [169].

When asked about the advantages and disadvantages of having a *100% condom* use national policy for the sex industry, the sex workers were supportive since it increased the knowledge about STDS, which then reinforced condom use. In addition, the sex workers appreciated the fact that they could use the law as a method of coercing the clients to use condoms. In fact, several of them stated that they specifically told their clients that it was illegal to have sex without a condom, which made condom use a legal issue, not an individual issue. This increased the sex workers' control over condom use. In addition, the sex work establishment owners also welcomed the suggestions because they believed that having such a policy would improve their establishment (being STD free) and as a result increase the number of clients [169].

7.2.4 CHAMP – Trinidad and Tobago

In Trinidad and Tobago, the Collaborative HIV/AIDS Prevention and Adolescent Mental Health Project (CHAMP), a program developed at the University of Illinois, Chicago, was implemented [171, 172]. This program involves both youth and their parents/caregivers. It targets youth before and during the adolescent stage, and it includes "education and skill-building activities to strengthen family-level characteristics that relate to sexual risk taking" (parental monitoring, discipline effectiveness, conflict resolution and parent/youth communication frequency and comfort when dealing with sensitive issues). Finally, the program aims to improve youth social problem-solving abilities (risk-refusal and

assertiveness). A community participation framework was used in the development and implementation of the program. This framework included linking collaborators from outside and within the setting to design the program, creating a stakeholders' advisory board to oversee the program activities, integrating scholarly and indigenous knowledge to shape prevention messages, and using credible messengers [171].

CHAMP resulted in significant increases in knowledge and awareness about HIV/AIDS from pre-intervention to post-intervention. In addition, both parents and youths reported an increase in discussions about HIV/AIDS, however there was no increase in the comfort level of having these discussions. There was also no significant increase in parental monitoring, in fact, some the responses from the youth suggested decreased parental monitoring. There were no measurements of actual behavioral change within this intervention [171].

The use of the "community participation" framework, which is used to increase cultural appropriateness and local owning and acceptance of the program, was utilized in the development and implementation of this program. This proved successful, since the interest to participate, participant retention and session attendance rates of the participants were very high (78%, 100% and 91% respectively) [171]. Though community participation is very important, the fact that actual behavior change (parental monitoring, comfort in discussing sensitive subjects, for example) was minimal, indicating the need for the program to focus on broader social and cultural factors (in addition to education and skill building activities).

For example, the data from the condom self-efficacy scale, which measures parents and youth confidence in securing and using condoms, indicates that there was an increase in the self-efficacy of both the parents and the youth. Though this is promising, the fact that the majority of the youth population were female posses a threat to this "self-efficacy" being translated to actual condom use. According to Allen, while reporting on the sexual behavior of youth in Tobago, fewer girls felt that they had the access to and control over condom use, since their male partners were usually older and had greater control of the relationship [71]. As a result, it is unlikely that increased individual self-efficacy would actually increase condom use. To include the wider cultural and social context of youth sexuality in Tobago, the program needed to ensure that both males and females were represented in the study population, due to the gendered dynamics of the country.

7.3 HIV PREVENTION POLICY IN TRINIDAD & TOBAGO

In an effort to develop a comprehensive response to the high rates of HIV in Trinidad and Tobago, the Office of the Prime Minister, in conjunction with several other stakeholders in 2003 outlined the "2004 to 2008 HIV strategic plan" for the country. The two main goals of the five-year plan were to (1) "reduce the incidence of HIV infections in Trinidad and Tobago", and (2) "mitigate the negative impact of HIV/AIDS on persons infected and affected in Trinidad and Tobago" [173]. The strategic plan was founded on the principles of inclusion, sustainability, accountability and respect for human rights. The strategic plan was based on a Situational and Response Analysis (SARA), conducted in Tobago in 1999 and Trinidad in 2001, in conjunction with continued dialogue among HIV-related stakeholders through out the country. This continued dialogue included consultations with the ministry of heath, youth groups, PLWHAs, trade unions and the business community from September 2001 to December 2001.

The SARA and subsequent consultations highlighted seven factors that influence HIV in Tobago, and nine factors in Trinidad. The factors in Tobago include youth unemployment, substance abuse, stigma and discrimination against PLWHAs, powerlessness among women, increasing expatriate population, and abstinence of a coordinated response. The nine factors in Trinidad include multiple sexual partnering, alcohol and drug abuse, violence (intimate partner and other types), inconsistent condom use, gender inequalities, migration, illegality of men having sex with men, commercial sex practices and stigma and discrimination of PLWHAs. The strategic plan proposed an organization structure. This included the development of the National AIDS Coordinating Committee (NACC), with the foci on "policy formulation, programme management, coordination, monitoring and evaluation and finance". The NACC is supported by a Secretariat. The strategic plan also recognized Tobago's autonomy, therefore it recommended that the Tobago House of Assembly have a representative on the NACC, and create a coordinating body to guide the Tobago response. In addition, a Tobago Secretariat was also recommended to ensure effective implementation of the Tobago response [173].

The national strategic plan outlined five "priority areas", each with its own objectives and strategies for accomplishing those objectives.

- The first priority area is *prevention*. The objectives include promoting safe and healthy sexual behavior throughout the general population (via increasing education and awareness, improving access to and availability of condoms, and increase government and civil society response); promoting healthy sexual behavior among high-risk and vulnerable communities (via providing behavior change interventions for young women, youths, MSM, and commercial sex workers, providing support for prisoners and prison workers, and reducing the impact of drug use on HIV transmission); reducing mother-to-child-transmission (via implementing a national MTCT program); increasing the general populations serostatus knowledge (via implementing a national voluntary counseling and testing program (VCT) and provide VCT services); reducing the

probability of post exposure infections (via providing post exposure prophylaxis (PEP)); and improving the management of sexually transmitted infections (STI) (via increasing knowledge about STIs, effectively managing STIs, and providing "youth friendly" sexual health services).

- The second priority area is *treatment, care and support*. The objectives include providing treatment and care for HIV/AIDS (via implementing a national management and treatment system, and improving access to medication and treatment for opportunistic infection); reducing the incidence of HIV-Tuberculosis (TB) co-infections (via improving the surveillance, treatment and care of HIV-TB co-infections); and creating an environment that supports PLWHAs (via providing economic and social support for PLWHAs).

- The third priority area is *advocacy and human rights*. The objectives include reducing stigma and discrimination (via encouraging openness and acceptance of PLWHAS in the workplace and wider community); and ensuring human rights for PLWHAs and other affected by HIV/AIDS (creation of "a legal framework" that protects PLWHAs and others affected by HIV/AIDS, monitoring human rights abuses and creating avenues for redress, and mobilizing community leaders on HIV/AIDS human rights concerns).

- The forth priority area is *surveillance and research*. The objectives include strengthening the surveillance of HIV/STIs (via improving existing surveillance systems and strengthening national laboratory systems); and undertaking and participating in clinical and behavioral research about HIV/AIDS (via researching link between psychosocial issues and HIV infections and conduct epidemiological research and clinical trials).

- The fifth priority area is *programme management, coordination and evaluation*. The objectives include achieving national commitment, support and ownership of the strategic response (via developing a management structure for the national response, gaining support for the plan, and mobilizing adequate and sustained sources of support); monitoring the implementation of the strategic plan; and building capacity among the stakeholders of the national response (via strengthening the constituents of the NACC and strengthening the support of PLWHAs).

7.4 HIV PREVENTION STRATEGIES IN TOBAGO

HIV programs in Tobago are predominantly focused on information dissemination. Information about HIV/AIDS is distributed via lectures and talks, television and radio advertisements (public service announcements – PSAs), and t-shirts and other memorabilia distribution. This includes limited

information about what HIV is, how it can be transmitted and how to protect yourself from becoming infected (use a condom).

7.4.1 Television or Radio Advertisements

The theme of the PSAs thus far has been "What's Your Position?", which focuses on the ABCs of HIV/AIDS prevention: A - abstain, B -be faithful to one partner, C – correct and consistent condom use (condomize as it is referred to by Tobagonians), D – do get tested, E – educate yourself, and F – free yourself from drugs and alcohol. These PSAs utilize local popular culture celebrities (soca and reggae artists) who ask you "what's your position?" Then proceed to tell you the different positions that you could take to prevent HIV infections. The PSAs all start with music that was created for the NACC. As the music continues to play, the refrain is sung:

> "Position yourself, make a choice
> Position yourself, win the fight
> Position yourself against HIV. What's your position?"

The artist then gives the message about HIV. I am not sure who developed the messages within the advertisements (the artists or the NACC). The PSAs usually end with a repeat of the refrain. Following are transcripts of three radio and television advertisements:

> <u>Theme: HIV-Prevention</u>
> (1)
> Me? Have sex without a condom? No way
> I protect myself from HIV, sexually transmitted diseases and unplanned pregnancies
> I have to protect myself, and I have to protect my partner too
> So if you are sexually active, do what I do
> Use a condom, each and every time
>
> (2)
> "You can't get it the first time"
> "Go with a virgin"
> "I don't study that, what is for you is for you"
> "Wash off right after"
> "Use bleach"
>
> Everybody talking about HIV and AIDS,
> But don't be fooled by idle chatter
> Don't get confused, get educated
> You have to protect yourself
> With HIV and AIDS you can't say you didn't know
> One slip is all it takes
> It's time to get the facts, educate yourself to win the fight against HIV
> What's Your Position?

Theme: Anti-Discrimination

(3)
What is your position?
Position yourself, make a choice
Position yourself, win the fight
Position yourself against HIV. What's your position?

Stigma and discrimination destroys the nation
And adds to the spread of HIV
Fight stigma and discrimination
Not people infected with HIV

Position yourself, make a choice
Position yourself, win the fight
Position yourself against HIV. What's your position?

7.4.2 Lectures and Talks

As stated before, the Health Promotion Clinic, the Tobago Youth Council, members of the PLWHA communities and other individuals frequently give talks or lectures about HIV/AIDS. I viewed several of these sessions throughout the island. In most cases, the method of instruction included one or several instructors providing information about HIV/AIDS and other STDs. The instructors usually sat at the front of the room, while the participants sat in chairs facing the lecturer, or the board. Visual aid instruments like power point or projectors were often used. Though the lecturers stressed that the process would be interactive, very few questions were ever asked during the sessions that I witnessed. At the end of the lectures, a few individuals would ask questions, usually the outspoken person asking the questions that everyone else wanted to ask but was afraid to. Approximately 40 individuals attended each of the four sessions that I witnessed.

7.4.3 Booths and Information Tables

On several occasions I either observed or participated at booths or information tables with information about HIV/AIDS. On these tables were brochures and booklets about HIV/AIDS. In addition, condoms were usually distributed. At one session, there were models where the techniques for putting on both male and female condoms were demonstrated, and individuals were invited to learn the correct techniques.

(a) (b)

Figure 4: HIV prevention booth in Tobago
(a) Picture of an HIV information booth in Tobago. Booth has pamphlets, different type of condoms, etc. (b) Penis model used to demonstrate the correct way of putting on and taking off the male condom.

7.4.4 Posters and Banners

Posters and banners with information about HIV/AIDS created by the National AIDS Coordinating Committee (NACC), the Caribbean Epidemiology Center (CAREC), the International HIV/AIDS Alliance in the Caribbean (the Alliance), Friends for Life and/or the Pan American Health Organization (PAHO) were available. Apart from displays in the offices that specifically dealt with HIV/AIDS, there were very few banners or posters about HIV/AIDS in offices or other public spaces. Of course, more information was seen in the banks and other businesses in the capital city for World AIDS Day. Examples of the messages in these posters are:

"What message does your workplace send? AIDS does not discriminate…why do we?"

"How can we treat poeople like this? AIDS does not discriminate…why do we?"

"She is my mother… She is my sister… She is my girl… She is my wife… She is my daughter… She is my friend… She is my woman… She is to be respected."

7.4.5 T-Shirts and Other Memorabilia

Since most of the HIV related t-shirts and other memorabilia were produced by the NACC, they presented the same message of "What's Your Position?" Usually these asked the "What's Your Position" question

followed by the ABCs of HIV prevention. A new campaign done by CAREC is the "Ouch" campaign. It is an antidiscrimination campaign with the message that "discrimination does not stop HIV. Ouch, it hurts". Very few individuals who had recently returned from regional conferences and workshops wore these types of t-shirts.

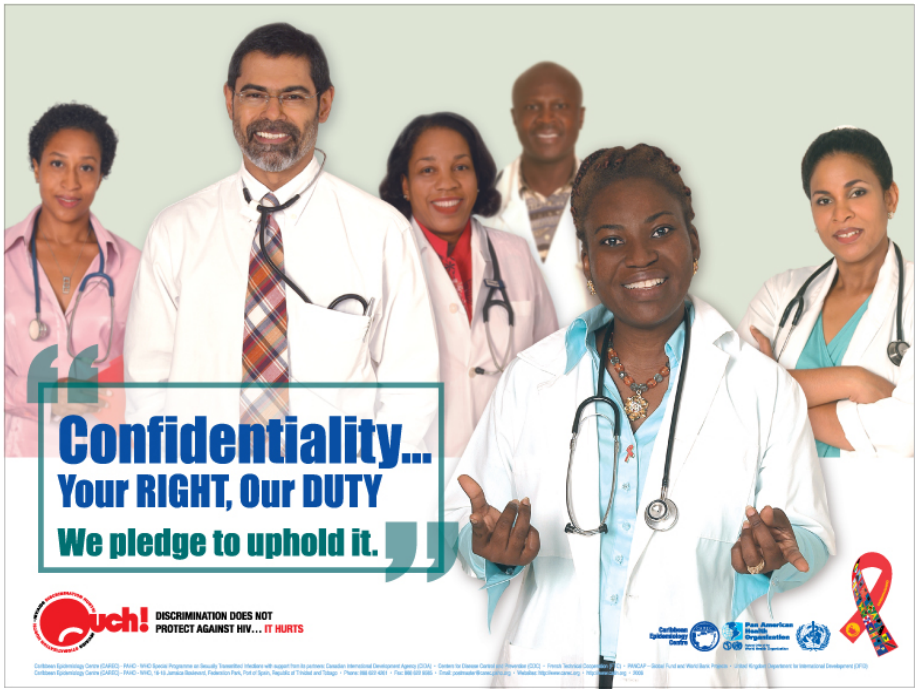
(a) (b)

Figure 5: HIV prevention memorabilia
(a) Pictures of the t-shirts featuring the NACC "What's Your Position?" campaign. The front shows the NACC logo, and follows the World AIDS Day theme. The back of the jersey highlights the A, B, C, D, and E of HIV prevention. (b) The new CAREC anti-discrimination poster.

7.4.6 Other Prevention Strategies

At least two of the health professionals interviewed were frequently featured in the newspapers. They both wrote articles about HIV, family and relationships, which were published in various newspapers. Several community leaders and health professionals talked about using the concept of "guarding your negative status" as a means of getting people tested. They believe that HIV prevention programs should encourage people to get tested to "make sure that they are negative", with the hopes that this would change their sexual behavior to stay negative. This is known in this circle as the "thumbs up" approach. They personally state that this method is used in their speeches when addressing HIV.

(a)



(b)

Figure 6: Other HIV related posters and symbols
(a) An anti-discrimination advertisement created by CAREC and PAHO. It talks about the confidentiality rights of all individuals attending health facilities.
(b) The "What's Your Position?" logo, used on most HIV related material created by the NACC.

7.5 VIEWS ABOUT HIV PREVENTION IN TOBAGO

The success of HIV prevention programs depends heavily on the information that is given; whether the programs are seen or heard, whether the messages are accepted, and finally whether they are utilized. To answer some of these questions, I asked several individuals about whether they have seen or heard the ads available, and whether they understood what was being presented and finally whether these messages influenced their behaviors in any way.

The study participants who were HIV positive and actively involved in HIV related programs were aware of the HIV-related prevention and care programs in Tobago. In many instances they had volunteered to speak at lectures, and represented their respective organizations at information booths in the past. As a result, they were aware of the HIV programs and knew exactly what was meant by "What's Your Position?" and the other campaign messages. These PLWHAs, however, believed that these programs are not enough, and they were doubtful about whether individuals really listen to the messages within these advertisements. As Eric explained:

> "The way we try to get that information out is by t-shirts and stuff like that, but the thing is, you may have it on television, you may have it in papers, in the media, but I wouldn't say that it is being done on any large scale. I am not seeing it on any large scale, because you could walk from here to downtown and if you lucky you may find 2 or 3 business with a sticker. Other than that you may see people walking around with their jerseys saying 'what's your position', half of them don't even know what 'what's your position' means. As far as they are concerned, they get a free jersey to wear."

Camille commented about the monotony in the information that is available. According to her, all of the pamphlets carry the same message, and she is interested in learning something new about HIV/AIDS:

> "I does get some information, but I don't feel like it is enough. I have some pamphlets from when they had the CARIFESTA[62] thing, and all of them saying the same thing. I had about 10 of them, and all of them saying the same thing in different words."

It must be noted that one community member did state that he had noticed a significant increase in the number of HIV-related advertisements on the television and radio within a couple of months prior to the interviews.

To gauge the level of understanding about the messages in the PSAs, I asked the PLWHAs and some community members to explain what was meant by "What's your position?" The PLWHAs all gave similar answers, which included "where do you stand?", "are you protecting yourself?" "decide whether you will abstain, use a condom, educate yourself", "are you promiscuous?", "are you protecting your loved ones?", and "what's your stand on HIV and AIDS? where do you stand? how would you conduct yourself?" among other responses. The community members, however, did not provide these types of answers. In many instances they remembered seeing or hearing the ads, but could not explain what they thought, "what's your position?" meant. Those who attempted to explain the ads stated that it referred to your HIV status. One community member stated that they wanted to know "if you have AIDS or not", another stated "what's your position? healthy or unhealthy?", yet another stated "negative, positive, dead, alive."

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[62] CARIFESTA is the Caribbean Festival of Creative Arts. It showcases the arts and culture of Caribbean and Latin American countries. In 2006 the opening ceremony was held in Trinidad and Tobago.

7.6 ANALYSIS - CURRENT STATE OF HIV PREVENTION

I believe that because Trinidad and Tobago, and specifically Tobago, started its fight against HIV relatively recently, the theories used in the development and implementation of these programs are simplistic and therefore ineffective. Though it has not been explicitly stated, these programs are based on the Knowledge, Attitudes, Perceptions and Behavior (KAPB) model used in other communities. In fact, the NACC recently announced that it has embarked on gathering KAPB baseline information for future use in the evaluation of its programs. Since HIV is a very complicated disease, I believe that the use of these simplistic models is not effective in HIV prevention. This section outlines some aspects of the current state of HIV prevention in Tobago that are adequate in addition to those that may be improved upon.

The national strategic plan outlined by the Office of the Prime Minister is very comprehensive. The priority areas are very important, and it provides a general guideline for combating the effects of HIV on the country. As the strategic plan outlines, the situation in Tobago is different from the situation in Trinidad and therefore Tobago must take responsibility for creating its own strategic plan. While doing this research, this process was being undertaken. It must be noted that the factors outlined as influencing HIV in Tobago by the SARA and subsequent consultations include some of the factors addressed in chapter six of this document. However, there are several factors important to the Tobago context not included in the SARA. For example, factors like multiple sexual partners and inconsistent condom use are listed for Trinidad but not for Tobago. These factors are equality or possibly more important in the Tobago context. In addition, the issue of early sexual contact and primarily the influence of incest were not discussed. As a final example, the influence of the nomadic nature of the protective services was not included in the SARA. These exclusions reinforce the recommendation of the strategic plan for Tobago to create its own strategy for dealing with HIV/AIDS.

I have noticed, and several individuals I interviewed stated, that the information about HIV that is currently given in the HIV prevention materials is simply not enough. In most cases the materials state that “HIV” stands for “Human Immunodeficiency Virus”, and that “AIDS” stands for “Acquired Immunodeficiency Syndrome”. In addition, they state that HIV can be contracted via sexual contact, needles, mother to child transmission, and blood transfusions. Given that the majority of cases in Trinidad and Tobago are via sexual contact, the method of protection highlighted is abstinence, condom use and faithfulness. No information about the fact that HIV and AIDS are distinctly different, or that with appropriate treatment one can be HIV positive and never progress to AIDS, or the fact that testing and treatment is available and free to all citizens, is ever discussed.

This additional information is necessary because it helps to change the views about HIV in Tobago. As I have stated, there is still a widely accepted view that getting HIV is equivalent to getting a death sentence. This is perpetuated by the fact that most individuals do not actually know someone who

has HIV and is living with HIV. They only know people who have died from AIDS, and they have heard the horror stories about how bad the person's life was, and how horribly they died. In addition, there are still images of people dying of HIV (versus living with HIV) in the media. Given these negative stimuli, it is necessary to combat that type of information with facts about the possibilities of living with HIV. Particularly, the resources that are available to Tobagonians must be highlighted. This would encourage individuals to get tested because they know that if they are HIV positive it isn't a death sentence, but it can be treated like a chronic disease.

In addition to not giving adequate information in the advertisements, some of the advertisements still use the "scare tactics" methods that were initially used in HIV prevention. Several of the advertisements talk about one night of pleasure "ending your life", or one mistake "ending your life". These ideas again perpetuate the idea that HIV is a killer. In fact, one advertisement explicitly stated that "AIDS is a killer." In the minds of the general population, this is translated to HIV being a killer that is to be feared, not faced. Again, this results in individuals not wanting to talk about HIV, which means that they will not be informed, will not be tested, and will not be treated if they are HIV positive.

A third aspect of these advertisements that is counterproductive is the use of moral judgments to compel individuals to protect themselves. Several ads talk about the need to act or "live right". One advertisement aimed at preventing teenage pregnancy is an example of this. In this advertisement, two young girls are talking. One is excited about going out to a party or something with her friends, and she has invited the second girl to come along. The girl laments and states that she is unable to go because she has a young baby at home "to see about" – she has to feed the baby and bath the baby, etc. Her mother helps her a lot, but the main responsibility is hers. She finally laments that she got pregnant way too young and should have waited before having children. The narrator then reaffirms that sentiment, and ends with "just live right!"

Though this advertisement is not an HIV-specific advertisement, the ideas conveyed in it are conveyed in other HIV ads. This technique is somewhat counterproductive, because it continues to identify individuals living with HIV as bad people – people who did not "live right". This is unfortunate because from the interviews that I've done with PLWHAs, the majority of them were "living right". These individuals were in relationships where their partner was either unfaithful, or they had contracted the virus in a previous relationship. This use of moral judgment is also counterproductive because it perpetuates the need for individuals to not want to know their status, using the rational that if they don't know that they are HIV positive, then they do not have to deal with the label of being immoral. In addition, it prevents individuals from disclosing their status for fear of being labeled as "bad" because of their status.

Primarily individuals in the music industry are seen giving the messages in the current advertisements. As part of their on-stage image, these individuals usually perform with very sexually suggestive lyrics and accompanying dances. As a result, they may not be seen as the most appropriate

individuals to carry the messages of abstinence, etc. In addition, the advertisements tend to be filled with music and other distractions. In fact, one individual stated that she never really listened to what the ads were saying, but she liked the music and the beats used.

There are a few noteworthy advertisements that I believe must be highlighted. Following are the words of two of the advertisements that I believe provide the appropriate information without using scare tactics or moral judgment. The first is an advertisement targeting pregnant women or women who are thinking of becoming pregnant. It encourages them to get tested because they can transmit the virus to their baby, however if treated this risk is reduced:

"If you are pregnant or planning on having a baby
It is in your interest to get tested for HIV
A pregnant mother can pass on HIV to her baby during pregnancy, labour, delivery or breast-feeding
Our health facilities provide testing, advice and medication
So, even if you are HIV positive, your baby can be born completely free of HIV
The National AIDS Coordinating Committee invites you to call the AIDS hotline now at 625-AIDS, or 800-4HIV for more information."

All of the advertisements that were previously described air on local radio or television stations. There are, however, a few advertisements that are aired on a regional television station. This station is relatively new, and is therefore not widely viewed. There are three advertisements that I have seen on this channel that I think have "hit the nail on the head" and would be very appropriate for showing on Trinidad and Tobago television, or have replicated using the Tobago context.

The first advertisement addresses the issue of condom use. This advertisement is set to music by reggae artists who talk about the need to protect yourself. The ad shows the progression of a sexual relationship. It depicts young men and women at a *fete*. After a while a couple pair off and it is obvious that they are interested in having a sexual relationship. They leave the party and head to the young man's house. At the door of the house, just as they are about to enter, they both hesitate and look at each other. You can sense that they are thinking and are concerned about the reaction they are about to get. After a while they finally show what is on their minds – both have condoms in their hands, indicating that they were informing the other partner that they needed to use condoms. They both laugh since they were both thinking the same thing, then they proceed to go into the house.

In my view, this advertisement is ideal in reducing the stigma associated with condom use. It shows that it is normal for young men and women to be attracted to each other sexually, and to pursue sexual relationships. It does not use scare tactics, nor does it use moral judgments. Finally, it shows that it is okay to insist on condom use, and particularly it is okay for females to carry condoms and insist on condom use.

The second advertisement addresses the issue of buying condoms and the fear and shame associated with buying condoms. It is situated in a drug store where a young man is paying for several

items. There are other individuals purchasing items at the store. Like the situation described in Tobago, in this community individuals must ask for condoms at the cashier. The young man pays for his product, however he pays too much money. The cashier tries to give him his change, however he insists that she keep the extra money. He leaves the store, goes outside and writes that he wants a pack of condoms on a piece of paper. He returns to the store and gives the cashier the paper. She reads it, realizes that he wants the condoms but is afraid to openly state that. She discreetly puts a pack of condoms into a brown paper bag and gives it to him. He leaves with the condoms.

Given my personal experiences with buying condoms in Tobago, this provides several lessons. First it shows that there are several different ways to ask for condoms. Even if the young man couldn't state what he wanted, he knew that it was important for him to have them, so he decided to write what he needed. The second, and possibly more important, lesson is the reaction of the store cashier. She showed tact, discretion, and respect for the young man's privacy. The negative reaction from cashiers and pharmacists is something that prevents individuals, particularly young individuals, from purchasing condoms in Tobago.

A third very interesting advertisement is aimed at younger children. In cartoon form, it tells the story of Corey, who is seven years old and HIV positive. He states that he got HIV from his mother when he was a baby. He stresses though that he is like any normal boy. He loves to play and go to school and do all the normal things that other kids do. He also states that it is okay to play with him, share his toys and food, and sit next to him, etc. He says that he is sad when people shun him or don't want to play with him because he is HIV positive, but he also stresses that they only do this because they do not know enough about HIV. He then tells you in very age appropriate language, ways of getting HIV and ways you will not get HIV. He stresses that if he or anyone else at school gets injured, they should call the teacher to deal with it, especially if the person is bleeding. In the end, he states that he is living a normal life with HIV.

In a very simplistic way, this advertisement gives very detailed information about living with HIV. It addresses the issues of acceptance and discrimination, and it advises adults to get tested for HIV, because it's better to know and deal with it. Finally, since Corey is seven years old, it helps remove the stigma associated with HIV, because obviously this little boy is not "bad".

In the end, the HIV prevention programs in Tobago have both positive and negative reviews in my opinion. The fact that these ads are being produced means that individuals are aware of the need, and therefore represent a push in the right direction. The content of the ads, however, continue to perpetuate some of the negative views relating to HIV/AIDS, including the idea that AIDS is a killer, and that people who do not "live right" contract HIV. Finally, the ads give basic information about HIV, and in my view additional information and options are needed to truly deal with the HIV epidemic in Tobago. My recommendations are included in the following section.

8.0 RECOMMENDATIONS FOR HIV PREVENTION STRATEGIES

Research Questions Answered In This Chapter

(d) What methods might be used to incorporate relevant social and cultural factors into HIV/AIDS prevention programs?

(e) What are the most appropriate models/methods for improving HIV prevention in Tobago, including but not limited to the type of information needed and the most appropriate methods of dissemination?

8.1 WHY IS THIS IMPORTANT?

The realization that HIV/AIDS prevention is complex, and the fact that HIV infection rates have been increasing in Tobago, warrants that new approaches in HIV prevention be explored. This section therefore examines HIV prevention using non-conventional theories, and focuses on the factors that are important to and for the Tobago population. It must be noted, however, that these recommendations are based on in-depth work with a small number of research participants. Work with different populations or in different settings within Tobago might generate alternative understandings.

8.2 RETHINKING HIV PREVENTION IN TOBAGO

A shift in approaches includes moving away from the knowledge, attitudes, perceptions and behavior model to looking at more comprehensive theories - theories that have not been previously used in HIV prevention. The data collection and subsequent analysis in this study incorporated two models (PEN-3 and the Theory of Gender and Power). The third construct of PEN-3, the *cultural appropriateness of health behaviors* was used to identify the social and cultural aspects of health behaviors in Tobago that are either **P**ositive, **E**xistential, or **N**egative as they relate to HV infections risks. The **P**ositive and **E**xistential health behaviors may be rewarded or encouraged; however the ***N***egative behaviors were identified and are the focus of HIV prevention strategies as outlined below. In addition to these **N**egative

behaviors, other factors were analyzed to determine whether they perpetuate the gender imbalances that directly and indirectly influence HIV infection risks according to the Theory of Gender and Power.

8.2.1 Harm Reduction Model

Due to the specific social and cultural factors that influence sexual decision-making in Tobago, and specifically the complexities that the interactions of these social and cultural factors create, I recommend that a client-centered harm reduction model of HIV prevention be used. Hirsch et al, looking at rural Mexican populations makes the same recommendations "given the complex and intertwined types of support for such [high risk] behavior [174]." The traditional "abstain, be faithful or use a condom" message does not provide enough viable options, given the circumstances in Tobago. As a result, many Tobagonians simply do nothing to reduce their risk. In the traditional sense, "harm reduction" has been associated with HIV in the form of needle exchange programs or other methods of reducing drug intake, thereby reducing HIV risk [175]. In this setting, however, the definition given by Mattson is used. Harm reduction refers specifically to accepting the "inevitability of unhealthy behavior, positing an emphasis on reducing the harms associated with risky behaviors rather than eliminating risky behavior" [176 pg (334 - 335)]. In other words, it stems from the understanding that individuals, for whatever reason, will continue engaging in risky behavior, and therefore the goal of professionals is to incrementally decrease the risk by incrementally changing human behavior. The recommendations therefore take into consideration the "dynamic needs of individuals and communities" [176].

Several tenets of the harm reduction model apply directly to HIV/AIDS prevention, and to the Tobago population. In this chapter, I highlight those most applicable to the Tobago population, with slight modifications:

- All individuals deserve to be treated with respect, dignity, and compassion.
- Most people will practice unsafe sex at some point in their lives.
- Unsafe sex is not necessarily the problem but is a symptom or coping strategy used to deal with other more complex aspects of life.
- Unsafe sex can increase risk for HIV/AIDS, and is therefore potentially harmful to the individual, family, community and country.
- This "harm" may result in personal, social, economic, and cultural hardship to the individual, family, community and country.
- Most individuals, when given the right tools and situations, can make the choices and take subsequent action to reduce their risk.

- HIV/AIDS health professionals, due to their upbringing and religious affiliation, for example, bring certain biases about sex, safer sex, and monogamy. These biases must be acknowledged and understood, and their impact must be minimized because the goal of the process is risk reduction that is client-centered (versus health professional centered).

- Highlighted or recommended risk reduction strategies must be relevant to and practical for the client. These strategies must belong to the individual, not forced upon the individual by the health professional.

- The strategies must be "attainable, short-term, [and] personalized", not idealistic, long-term and impractical given the individual circumstances.

- A hierarchy of choices must be offered (abstinence, reduced number of sexual partners, sex with condoms, oral sex only, sex without condoms with monogamous partner, etc).

8.3 RECOMMENDED SEXUALLY-RELATED HIV PREVENTION STRATEGIES

The Socio-Cultural Theory of Learning is the other theory recommended for use in HIV preventions in Tobago. There have been no reported uses of this theory in HIV prevention in the literature. This theory is described in detail in chapter three, therefore only a brief summary is repeated in this section. There are six (6) main components of learning according to the SCTL. Learning is said to occur within (1) the Zone of Proximal Development (ZPD), which on a macro level refers to where the person lives, and therefore all factors of the environment. It can also be viewed on a micro level to describe the specific situation where learning occurs. In this case it may refer to a specific training program, or a health center. When a person moves from having (2) knowledge-in-waiting (basic knowledge about a topic or health issue), to doing (3) knowledge-in-use (actually doing the recommended action via specific skills), true learning is said to have occurred. Simply having knowledge-in-waiting does not constitute true learning according to the SCTL. Learning is facilitated by (4) agents of change or instructors, who are individuals within the community with high "cultural capital". In other words, these are highly respected individuals within the community. They are seen as having the character, knowledge and ability to "instruct" others on learning. The (5) available resources include the financial, infrastructural, and other resources that may be needed to facilitate learning. Finally, the (6) social environment represents the other social and cultural factors that directly or indirectly influence learning. Though a specific HIV prevention program is not outlined below, I argue that prevention programs should entail one or more of the examples given below for each of the six components.

8.3.1 The Zone of Proximal Development (ZPD)

The fact that Tobago is only 116 square miles provides a special setting in that the entire island can be identified as the ZPD. Specifically, HIV prevention learning can take place in public settings where general information about HIV, messages about what HIV means, or messages about what condoms mean can be given. This includes television or radio PSAs, newsprint, banners, and posters. Additional ZPDs are identified below:

- In Tobago there is a need for places where youth can feel comfortable accessing information, condoms, HIV counseling and testing. This place should represent a non-judgmental space where young people do not feel like they need to give moral explanations for why they are having sex, or why they need information, or why they need condoms. Yes, youths should be counseled when they come to this facility, and abstinence should be included in this counsel, but it should be client-centered and comfortable.

- Other community businesses like rum shops, bakeries, barber/beauty shops and mechanic garages are ideal places where information about HIV/AIDS, community norms about condoms and skills needed to reduce risk can be transferred. In Tobago a substantial amount of time is spent at these settings, which normally include very heated conversations about politics, religion and other similar topics. As a result, having one HIV poster is likely to spark conversations in a setting where a captive audience is already present; therefore these are ideal settings to subtly insert information about HIV/AIDS. HIV testing drives can also take place in these settings.

- There are weekly fetes, harvest dances, concerts and other social venues that continually attract Tobagonians. Information booths, with free condoms at the entrance or in the bathrooms would be ideal. Demonstrations on putting on condoms and other such skills can also be done at these venues. The information packets may be very small with information about places to get tested for example. The DJ or artist performing may remind the patrons about the need to protect themselves, and encourage them to visit the booths and take the free condoms.

- Sports venues are also ideal settings for HIV prevention programs. Throughout the year, several small- and large-scale football, netball, basketball and cricket tournaments occur at village fields and other similar venues. The same individuals usually frequent these games each week; therefore a thematic approach may be used where a different type of information is available each week (HIV basics one week, HIV risk reduction strategies demonstrated another week, HIV testing and treatment options given a third week, for example). This may culminate with a testing drive after a couple weeks of information and skills building sessions.

- Schools present a unique possibility for HIV prevention for both the student and their parents. Obvious in health classes or biology classes, age appropriate information about human sexuality

and therefore HIV can be presented. School is also a place where teachers, social workers or other similar professionals can inform children about incest, rape and other forms of sexual assault, giving them the opportunity to report to the health professional if they feel that they have been inappropriately touched. This type of information can also be presented to parents during PTA meetings and other similar settings, since it is apparent that parents are unable to discuss HIV and other issues relating to sexuality with their children or their spouses because they are not equipped with the appropriate information.

- Churches and other religious organizations are interesting places for HIV prevention programs. A large percentage of Tobagonians are frequent churchgoers, therefore having the religious community embody HIV prevention, and be an integral part of the process would increase the probability of the general community embracing the messages. Though religious leaders may be reluctant to talk about HIV from the pulpit, churches may sponsor HIV prevention programs in the church at other days/times.

- Going into individual home and talking about HIV is a model that would work in Tobago. This gives individuals the opportunity to ask questions in a relatively safe setting. In addition, even if an individual may be uncomfortable in the home, they become aware of the individuals with the pertinent information, and therefore they may be prompted to ask questions at later times. This also encourages discussion about sex and sexual health in the homes (between parents and children or between spouses).

- Targeted venues: A recent article by Hirsch (2007), discusses the importance of defining "sexual geography", which are "geographic spaces" where individuals are more likely to engage in high-risk sexual behavior. The goal is to target those spaces with HIV prevention programs [174]. In Tobago there are several "spaces" that must be the focus of HIV intervention: (a) Beaches, hotels and other similar surrounding venues where sex tourism is likely to occur are also places for targeted HIV prevention messages. Posters, information booths with counselors, and possibly HIV testing facilities may be present at these settings. This information should cater to both heterosexual and homosexual needs. (b) The "ants nest" is a place where drug addicts congregate; therefore having health professionals visit these places with information about HIV/AIDS may be needed. Many of these individuals exchange sex for money or other resources, so information about HIV, general risk reduction, testing and treatment would be ideal for this setting. (c) Though no specific research has been done with HIV and the protective services in Tobago, this section of the population is at increased risk. As a result, the training required for new recruits (and continuing service men) should include HIV risk reduction information.

8.3.2 Knowledge-In-Waiting

Although the traditional knowledge, attitude, and belief model isn't effective in HIV prevention, specific pieces of information are necessary for effective HIV prevention. Following is a recommended list of the types of information that should be included in HIV prevention programs in Tobago:

- What is HIV and what is AIDS: The fact that HIV is the virus, while AIDS is the syndrome that occurs if HIV is not treated, should be included. It must be emphasized that HIV and AIDS are two separate entities, and that one could be HIV positive and never progress to AIDS. Information about what HIV "looks like", or in this case, the fact that HIV positive individuals no longer "look sick" must be reiterated. The importance of CD4 counts and viral loads should be available for individuals interested in more in-depth information.

- The methods of HIV transmission: The two main methods of transmission in Tobago (sexual transmission and mother to child transmission) must be included. The different degrees of risk from each method, or from variations of the methods, should also be discussed. For example, the fact that vaginal sexual intercourse presents a higher risk of infections compared to oral sex should be discussed. Other methods of transmission should also be highlighted.

- The fact that ANYONE who has ever had unprotected sex within the last 25 years is at risk for HIV should be discussed. This would remove the idea that only certain types of people (homosexuals, drug users, prostitutes, etc) are at risk for HIV, and increase the perception of risk within the entire sexually active population.

- HIV tests: The types of tests and what the test means should be discussed. The possibility of false negatives or false positives should be discussed, since several individuals do not trust the HIV test. In addition, information about what the test measures (HIV antibodies), and the fact that there is a lapse in time between infection and detection should be discussed. Where, when and the cost of HIV tests should be discussed. In addition, information about the length of time between getting tested and getting a result should be included.

- HIV medication: The availability of HIV medication should also be discussed. This includes the fact that all Trinidad and Tobago citizens are entitled to free medication and the rates of success for the medications. How HIV medications work (decrease viral load, increase CD4 count), and the possibility of side effects should be discussed.

- Condoms and condom use: Information about how condoms work, the different types of condoms (latex, polyurethane, and lambskin, male or female), and the risk reduction rates of each type of condom. Additionally, the safe methods of storing, opening, putting on (using fun methods like using your mouth, or putting them on in the dark) and disposing of a condom should be included. The difference between water-based, and oil-based lubricants and their effect

on condoms, and the effect of nonoxynol-9 should be included. Finally, redefining what condoms mean, and therefore altering the social norms surrounding condoms should be a focus [79].

- Secondary prevention: In addition to uninfected individuals reducing their risk, HIV positive individuals should also be counseled in secondary prevention. The goals of secondary prevention includes preventing infection of new individuals, maintaining health living of PLWHA (via medicine adherence, healthy eating, exercising, etc), and preventing re-infection of new strains of HIV and other STDs. Therefore, when HIV positive individuals take care of themselves and their partners, the HIV risk of the general population decreases.

- Other STDs: The fact that the presence of other STDs increases the risk of HIV should be highlighted; therefore the importance of testing for and treating other STDs must be reinforced.

- Other social norms: Social and cultural norms in Tobago have influenced risk for contracting HIV on the island. Culture evolves as communities evolve, therefore although it may be difficult to change some of these factors; highlighting their presence and outlining how they increase risk are important first steps in the direction of changing these norms. (a) Gender relationships – information targeting the gendered norms in Tobago should be given. This includes rejecting the *macho* expectations of males and submissive expectations of females, and showing that females who carry condoms are not "bad." In addition, the prevalence of domestic violence, and its effect on HIV, and family and community structures should be highlighted. (b) Relationship issues – having multiple sexual partners puts you at increased risk; encourage and recommend that everyone who is sexually active should have conversations with their sexual partners about safe sex, birth control, STDs, etc. (c) Incest – acknowledging the degree of incest on the island, and the negative influences of incest on HIV risk, sexual health, and mental health should be highlighted. (d) Alcohol use – information about the excessive use of alcohol and its influence on HIV risk along with other risk should also be highlighted.

8.3.3 Knowledge-In-Use

Knowledge-in-use refers to the specific skills needed to reduce the risk of HIV infection. This encompasses all of the steps that enhance an individual's ability to move from simply having knowledge-in-waiting to putting that knowledge to use. These include communication skills, negotiation skills, and correct condom-use skills. These skills should be client centered, and specific for the different "high risk groups" in Tobago - young men, young women, older men, older women, married/common law/visiting individuals, individuals in casual sexual relationships, commercial sex workers, homosexuals, drug addicts, etc. For example, communication skills including when, where, and how to raise issues about sex, sexuality, safe sex, and pregnancy should be a focus when dealing with young male and female clients. Negotiation skills can be taught via role-playing, and other methods that engage individuals and allow

them to "practice" appropriate responses to resistance. Skills relating to condom use may include practicing the correct way to open a condom, or fun ways of putting them on (using the mouth, in the dark, etc).

8.3.4 Agents Of Change

Using the SCTL, the agents of change in HIV prevention can be members of the community with greater social and cultural capital. In other words, these instructors are members of the community considered community leaders, role models, and pack leaders, by other members of the community. In addition, because these agents of change are members of the community, they should have knowledge of and experience with the different "risk groups." The CDC has outlined several characteristics or qualities of good HIV prevention counselors, and I believe that these qualities can also be transferred, with modifications, to agents of change in Tobago. Some of these characteristics include active listening, "ability to use open-ended rather than closed-ended questions, ability and comfort with an interactive negotiating style rather than a persuasive approach, ability to engender a supportive atmosphere and build trust, interest in learning new counseling and skills-building techniques, being informed regarding specific HIV transmission risks, comfort in discussing specific HIV risk behaviors (i.e., explicit sex or drug behaviors), [and] ability to remain focused on risk-reduction goals" [161].

Possible agents of change include politicians and other people of power. These men should publicly speak about the situation where men in power use sex in exchange for jobs, and they should state that this is undermining the fight against HIV. Other similar men should publicly speak about the level of infidelity that occurs on the island, and how these increase the risk for HIV. In many instances in Tobago, simply speaking with me about HIV, encouraged women to speak with their husbands or sexual partners, therefore the presence of strong role-models, both men and women, who can transfer information and teach skill is important in HIV prevention in Tobago. As a result, I argue that Tobago would benefit from a system similar to peer education [177, 178, 179], where individuals within particular clichés could be trained and dispersed into the local rum shops, mechanic shops, corner stores, corner limes[63], homes, etc. Both men and women should be trained, giving each the information and specific skills needed for different sectors of the community. For example male agents of change should be trained to address the influence of male infidelity on HIV infections, and encourage condom use generally, or when engaged in sex outside of the marriage as a method if risk reduction. Female agents of change should be trained to address the issues of assertiveness and insistence of condom use, HIV testing or other risk reduction methods. These

[63] A "lime" is an informal gathering. It usually starts with a couple people casually (possibly accidentally) meeting, who have decided to stop and talk with each other. After a while the crowd expands, and very regularly food, drinks and music are introduced. A "lime" can occur in homes, on the street corner, on beaches, or anywhere else where individuals can congregate. "Limes" can also be planned events. For example a back yard barbecue or a house party can also be classified as a "lime."

agents of change can also encourage their friends and colleagues to get tested together (for example yearly on a particular date), etc.

People Living With HIV/AIDS (PLWHAs) are also important agents of change in Tobago. PLWHAs can publicly discuss their HIV status, highlighting how they became infected, and how they are LIVING with HIV and not dying from AIDS. They can discuss the importance of preventing infection, getting tested, and getting treated if an HIV positive diagnosis is made. They are also very important in secondary prevention, since they can provide support for other PLWHAs to seek medical help, adhere to medication, and practice safer sex.

8.3.5 Available Resources

Available resources refer to the resources that increase an individual's ability to reduce their risk, get tested or get treatment if a positive diagnosis is made. Tobago has a great deal of resources already available, compared to other countries. This section therefore highlights a few more that would improve the possibility of HIV prevention success:

- Make condoms more accessible: Condoms are considered over the counter products in Tobago, however they must be acquired from behind the cashier/pharmacist. This prevents individuals from buying condoms, due to the stigma associated with condom use. In addition, allergy to latex is frequently used as an excuse to not use condoms; therefore providing more options combats that argument. I recommend that all types of condoms (latex, polyurethane, and lambskin, male and female) be available free of charge or at low cost. Even though lambskin condoms are not as effective as latex or polyurethane condoms, individuals allergic to both latex and polyurethane can use those because some protection is better than no protection whatsoever using the harm reduction model. I also recommend that condoms be removed from behind the counter in Tobago ensuring that all types of condoms are available for sale and free distribution.

- HIV medication: Although HIV medications are available free of charge to citizens of Tobago, their availability is not being publicized. Since available resources also includes the perceived availability of resources, knowledge about free HIV medications would help change the view of HIV from a death sentence to a chronic disease. This knowledge may increase the willingness of individuals to know their status and therefore get tested.

8.3.6 Social Environment

The social environment includes social relationships, cultural ideas and ideals, economic situations, and other external factors that influence human behavior and in this instance learning. I

therefore propose policies and actions that would immediately, or over time, alter the social environment in Tobago, indirectly reducing the risk of HIV infections on the island.

- Provider initiated testing: The WHO and UNAIDS recently published a report that strongly encourages health providers to initiate HIV testing. This report suggests that all individuals attending a health facility should be offered voluntary HIV counseling and testing as part of the "normal standard of care provided to the patient, regardless of whether the patient shows signs and symptoms of underlying HIV infection" [180 (p. 7)]. According to the women interviewed in the antenatal clinics in Tobago, they would all accept an HIV test at the time of the interview if it was offered, therefore suggesting that other members of the general population would accept the test if offered to them. This method of universal testing would eventually reduce the stigma associated with getting tested for HIV because everyone is offered the test (not just the "bad" individuals who believe that they are at risk). I recommend that provider initiated HIV counseling and testing be implemented in Tobago. Finally, to ensure appropriate services, all health professionals should be briefly trained in HIV counseling, testing and treatment. Health professionals interested in additional information should be trained, however, a reference manual (algorithm) should be available for all health care professionals.

- Church initiated HIV testing before getting marriage: In several African nations, the churches have taken it upon themselves to help reduce the rate of HIV transmission by requiring an HIV test prior to marriage. Though a negative result is not required for marriage, it provides an opportunity for individuals to learn about their status. I recommend that churches in Tobago institute this policy, and strongly encourage HIV testing as part of their pre-marital counseling.

- Mandatory pre- and post-test counseling: According to the guidelines provided by the CDC, pre- and post-test counseling has been effective in reducing risky behavior and thereby reducing HIV and other STDs [161]. When a client-centered harm reduction model is used in these sessions, information about HIV and other STDs is given, and the client can identify specific, achievable, risk reduction strategies. This process increases the likelihood that the client would undertake the identified risk reduction strategies, and therefore reduce their risk for HIV infections. In addition, in the event that the HIV test result is positive, this counseling prepares the client for such a result and helps in the process of dealing with this chronic disease. I recommend that client centered, risk reduction pre- and post-test counseling be mandatory in all settings where HIV tests are conducted, including hospitals, clinics and private laboratories.

- Anti-hate and anti-discrimination laws: The PLWHAs and community members interviewed all identified some degree of hate or discrimination occurring in Tobago due to HIV status or sexual orientation. This stigma and discrimination seems to play an important role in determining whether individuals disclose their status or whether they get tested. As a result it is necessary for

the general population to know that it is illegal to discriminate against someone because of their sexual orientation and HIV status, and that there are specific consequences of this discrimination.

- Workplace policy on HIV/AIDS: The International Labour Office (ILO) strongly encourages that all employers develop a comprehensive workplace policy on HIV. This is for several reasons: (1) it aids in preventing HIV/AIDS by providing information and opportunity for testing, (b) it manages and in some cases mitigates the impact of HIV/AIDS in the workplace by aiding in early detection, treatment and care, (c) it provides, in some form or other, care and support for individuals infected and affected by HIV, and (d) it eliminates stigma and discrimination on the basis of "real or perceived HIV status" [181] These are all factors that are important within the Tobago setting, since HIV has the potential to negatively affect the social and economic standing of the island if not dealt with effectively. I recommended that the Tobago House of Assembly, the largest employer in Tobago, institute its own comprehensive workplace policy on HIV and mandate and facilitate other employers to implement comprehensive HIV workplace policies.

- Anonymous partner notification system: At the Health Promotion Clinic individuals who test positive for HIV are encouraged to notify their sexual partners; however there is no systematic system of anonymous or named partner notification. I recommend that a system of partner notification be implemented. This may include providing support and encouraging individuals to notify their partners themselves, or doing contact tracing and notifying sexual partners that "someone that [they] have been in contact with has been diagnosed with HIV," giving them the opportunity to be tested. According to the officials at the Health Promotion Clinic, the vast majority of clients present with AIDS, implying that they have been infected for several years before getting tested. Anonymous partner notification would at least give individuals the opportunity to get tested and treated for HIV before progressing to AIDS if they are infected.

- Sexual assault laws and punishments: Sexual assault, including incest, increases HIV risk in Tobago. Though there are laws against sexual assault, it has been reported that these laws are not enforced. Increasing the enforceability of these laws could be obtained via training for police, social workers, teachers, among others. This training should include the knowledge and skills needed to (a) identify victims, (b) to work with victims encouraging them to report the cases, (c) to help the family and others affected by the abuse, and (d) to work with perpetrators. Although I am unaware of the punishments for these types of crimes, I recommend that they be reviewed to ensure that the punishment fits the crime, and that counseling and other rehabilitative techniques be included in the punishment.

- Social and economic development programs: These final recommendations include factors that indirectly influence HIV risk in Tobago. (a) Half-way homes or shelters for abuse victims. Since

domestic and other types of abuse increase a woman's risk for HIV, having shelters and other means of support would provide a safe-haven and ultimately reduce risk. (b) Economic development. The THA and the Central Government have continually provided development opportunities for the citizens of Trinidad and Tobago. I recommend that additional opportunities be provided to increase the financial stability of females, which also decreases their dependence on males, ultimately decreasing their risk for HIV infection.

9.0 CONCLUSION, LIMITATIONS & FUTURE STUDIES

9.1 SUMMARY OF FINDINGS

HIV infections in Tobago are influenced by a host of social and cultural factors. In this final chapter, I review some of these factors, followed by a discussion of the benefits and limitations of qualitative research methods. A list of new or refined research questions or topics is also presented. Finally, I end by emphasizing some of the positive characteristics of Tobago, and discuss how these positive characteristics can be used to bring about the desired changes, and ultimately positively affect HIV in Tobago.

9.1.1 People Living With HIV/AIDS in Tobago

The demographics of the interviewed PLWHAs highlight the fact that HIV does not discriminate in Tobago. In fact, the traditional "high-risk groups" (drug users, prostitutes, and homosexuals) are not the ones at most risk on this island. A large percentage of the PLWHAs were in seemingly monogamous relationships, where their partners had other sexual partners, or were infected in previous relationships. As is common in this community, condom use was non-existent, inconsistent, or discontinued as the relationships were solidified. Many PLWHAs continue to have sexual relationships, either with other PLWHAs or with non-PLWHAs. Some indicate consistent condom use, while some indicate inconsistent or no condom use.

Most PLWHAs interviewed discovered their seropositive status because of unexplained illnesses (either theirs or their sexual partner's), where an HIV test was conducted as a diagnostic tool. The majority of these PLWHAs were not counseled pre- or post-test. As a result many were not prepared for the HIV positive diagnosis, which resulted in denial and therefore continued "high-risk" behavior. The economic situation of the PLWHAs also indirectly influenced their "high-risk" behavior. Generally the male PLWHAs had better jobs, with higher salaries compared to the female PLWHAs interviewed, both at the time of infection and at the time of the interviews. The male PLWHAs continued to work, however several female PLWHAs depend on social service support, which influences the frequency with which they currently (or in the recent past) exchange sex for resources, or demand condom use. Both of these behaviors increase the risk of the general population.

The availability of anti-retroviral medicines was very surprising to me. The government of Trinidad and Tobago, and therefore the Tobago House of Assembly, has ensured that HIV-related medication is available free of charge to all HIV positive citizens. The Health Promotion Clinic was created with the treatment of HIV/AIDS as one of its main purpose. As the name suggests, the clinic treats other chronic diseases, however it is widely known as the "AIDS Clinic." This local branding of the clinic prevents individuals from seeking medical care there. Confidentiality or lack thereof, is an issue in Tobago. There are complaints that health professionals, and other community members directly or indirectly disclose the seropositive status of PLWHAs. As a result, many PLWHAs opt to travel to Trinidad to receive HIV-related treatment.

There is still immense stigma and discrimination against PLWHAs in Tobago. Several have lost jobs, been scorned, and been abused in other formats because of their HIV status. Many PLWHAs indicate that they discriminate against other PLWHAs. As a result, the majority of the PLWHAs interviewed expressed reluctance in disclosing their seropositive status. In instances where they chose to disclose, the PLWHAs interviewed expressed having support from friends and family. Incidences of stigma and discrimination were revealed however (either personal experience or experiences of other PLWHAs). Many are extremely religious and therefore churches form an integral part of their support systems.

There are two main HIV-related organizations in Tobago - the Tobago AIDS Society, and the Tobago OASIS Foundation. A third organization, the Friends of the Tobago AIDS Society, helps by financially supporting the two main organizations. These organizations provide emotional, social and economic support to the PLWHAs and their families. They provide moral support by providing a space where PLWHAs can feel safe, express their fears and concerns, and relate good news. In addition, the organizations provide important information about prevention, treatment and care by hosting health professionals to have discussions with their members, or by sponsoring PLWHAs to attend conferences and workshops nationally and internationally. Finally, the HIV-related organizations in Tobago provide financial support to PLWHAs, and they have begun increasing their role as advocates for PLWHAs.

9.1.2 Factors That Influence HIV Infections

Tobago's official HIV infection rate is 40.12 per 10,000, which represents approximately 200 PLWHAs. These statistics rank Tobago as the sector (compared to other counties on Trinidad) with the highest HIV rate in Trinidad and Tobago. If the estimated HIV prevalence rate of about five percent is correct, then there are close to 2500 PLWHAs in Tobago who either do not know they are infected, know and are not treated, or are treated in Trinidad or other countries. I believe that most of these individuals fall into the first category – they are unaware of their seropositive status. This increases the HIV risk of the general population because these "unknowns" are husbands, wives, girlfriends, boyfriends, fiancés, and extramarital partners who are conceivably having unprotected sex.

There is lack of information, misinformation and myths about the causes, prevention and treatment of HIV within the community. There is also the idea that "HIV equals death", which prevents individuals from wanting to know their HIV status. In addition, in Tobago there is both individual and institutional denial about the rates of infection and how HIV is transmitted; therefore there is increased risk for infection because the proper precautions are not taken to reduce that risk. This denial surfaces in HIV prevention programs, where the ideas of "abstain, be faithful, and use a condom" continue to be the focus. These programs do not take into consideration the realities of the community members and in some cases give false security to married individuals or individuals in long-term relationships, who believe that they are adhering to these rules. In fact the risk level of these individuals may be increasing because of infidelity, multiple sexual partnering, and serial monogamous partnering.

In Tobago, sex is something that happens, but is not openly spoken about. Comprehensive sex education is not a staple in schools, while "abstinence based" programs are part of the curriculum. Young people, who represent the largest group of new infections in the Caribbean, are having unprotected sex in Tobago. The "cell phone school sex" scandal highlighted this fact. In addition, the relationship between schoolgirls and "private cars for hire" drivers is also a major issue in Tobago. Serial monogamy, without confirming the HIV status of the new partner is a common practice. This, coupled with high levels of multiple sexual partnering, again without confirming the HIV status, and without the consistent use of condoms, increases the risk level of the general population. Sex tourism is still a budding trade, and there are reports of the exchange of sex for jobs. Homosexuality is part of the sexual lifestyle on the island. However, since it is illegal (sodomy is illegal), and very stigmatized, many men are bisexual and on the "down low." Incest is also very common in Tobago, and this increases HIV risk by decreasing the age of first sexual intercourse, and perpetuating unhealthy sexual practices as the victims age.

Condom use is not common in Tobago. Many PLWHAs do not consistently use condoms, and community members do not consistently use condoms. It is believed that only "bad" people carry and insist on condom use, and it is seen as an insult to one partner when the other partner requests that condoms be used. In addition, it is difficult to purchase condoms. Condoms are kept behind the counter, which requires individuals asking the cashier to retrieve condoms for purchase. There is a belief that individuals are scrutinized and judged when condoms are requested for purchase (particularly if the buyer is married, female, a PLWHA or young). Women are also disadvantaged because social and cultural norms insinuate that women do not talk about sex, or buy and/or request condoms. The economic situation of many females, coupled with abuse at the hands of their partners, and the importance of the family structure, also prevent females from being assertive and making safer sex choices in Tobago.

HIV testing is not common. Individuals can be tested free of charge at the Health Promotion Clinic, health centers and the hospital. There are also clinical laboratories where HIV testing can be done for a fee of $100TTD (approximately $17USD). Voluntary HIV testing is also offered free of charge at the pre- and post-natal clinics. Except at the Health Promotion Clinic, appropriate pre- and post-test

counseling does not occur, therefore individuals are not given information on how to reduce their risk, nor are they psychologically prepared for a positive HIV result.

It is believed that the popular culture in Trinidad and Tobago influences sexual health. Cable television is widely available, and sexually explicit programs can be seen on specific channels. Most adults are unaware of these shows, however the youth who are awake late at night are able to view such shows. The music in Trinidad and Tobago, soca and reggae, are also sexually explicit, where references to sexual acts are commons, and listeners are encouraged to dance very provocatively. Violence, particularly violence against homosexuals, is also prevalent in reggae and this has influenced the continued stigmatization and discrimination against homosexuals in Trinidad and Tobago.

9.1.3 Recommendations

Given the complexity of sexual health, a client-centered risk reduction model is recommended for HIV prevention strategies in Tobago. This model addresses the risk of the client, and allows recommendations that are incremental and achievable to be made (which increase the likelihood that the recommendations are heeded to). The Socio-Cultural Theory of Learning is another model recommended for HIV prevention strategies in Tobago. It highlights six key elements of learning, which is defined as the process of moving from having knowledge to actually using that knowledge. The six key elements include:

- The zone of proximal development: the environment or physical space where learning occurs. In this context of HIV prevention, the ZPD includes homes, churches, local businesses, parties and other social gatherings.
- Knowledge-in-waiting: the actual information needed for learning, which includes accurate information about HIV, HIV prevention, and treatment of HIV.
- Knowledge-in-use: the skills and techniques needed for learning to occur (negotiation skills for example). This includes the specific skills needed for different sectors of the community – young men and women, married men and women, homosexuals, drug users, beach boys.
- Agents of change: the individuals with social capacity who facilitate learning by providing the information, teaching the skills, and being examples of the learning process. These include community leaders, teachers, and community members.
- Available resources: the resources needed to facilitate learning, including condoms and HIV medications.
- Social environment: the external factors like social structure, cultural norms, and policies that indirectly influence peoples' ability to reduce their risk. This includes implementing

comprehensive work policy and anti-discrimination laws, in addition to working towards changing views about infidelity, women's roles, and condom use.

9.2 IMPORTANCE OF STUDY METHODOLOGY

HIV/AIDS is a very taboo topic in Tobago. PLWHAs are stigmatized and discriminated against; therefore PLWHAs do not frequently disclose their seropositive status. This presents a problem of access to this population. The use of qualitative methods however, created an invaluable opening into this community. One technique used was participant observation. I spent a great deal of time at HIV-related organizations, observing and chatting with the clients. After a long while, I developed friendships with the clients. Although I spent six months in the field, the process of earning their trust was very lengthy, and as a result I did not conduct interviews with many of the PLWHAs until four or five months after I had been there. Other non-qualitative methods would not have allowed me the luxury of spending such a long time, doing participant observation (and indirectly gaining trust) without actually conducting in-depth interviews.

Another community that I assumed would be very difficult to reach was the homosexual community in Tobago. Again, as I spent time at the HIV-related organizations, I had many discussions with clients from the homosexual population. After a while, I also formed friendships with them. They were all aware of my research focus, and many volunteered to be interviewed. In addition, several encouraged other homosexuals to be interviewed, and in three instances, one homosexual male interviewed three others on my behalf. These three men had not disclosed their HIV status, and therefore were uncomfortable being interviewed by me. I firmly believe that my presence in the office doing participant observation gave the members of this community an opportunity to get to know and trust me, therefore allowing me to be intimately involved in their lives.

In addition to gaining entry into these special populations, qualitative methods allowed me to observe individual and collective behavior, which provided insights into many factors that may not have been considered before entering the field. For example my trip around Tobago, and the subsequent observation of the driver and his "outside woman" caused me to think more about the influence of extramarital affairs and its influence on HIV infections. My indirect discussions with members of the community who quickly disclosed the status (or suspected status) of individuals highlighted the significance of confidentiality and the negative feelings towards PLWHAs or people suspected to be living with HIV/AIDS. As a final example, my observation of the type of sexually explicit programs that are uncensored and available to young people highlighted the type of information that the youth are exposed to. This coupled with the lack of communication about sex presented a very important factor that

influences HIV infections in Tobago. Qualitative data acquisition and the subsequent analysis allows for this type of information to be considered and included, although they were not initially part of the "interview guide" for example.

Finally, qualitative methods allowed relatively broad, open-ended questions to be asked. As time was spent in the field, and observations and conversations occurred, these questions became more focused. Since the population being studied directly influenced the direction with which the research questions took, the factors most important to the community being studied was unearthed. As a result, the *emic* and *etic* perspectives of the people of Tobago were fully incorporated and intertwined into the research questions, the data acquisition, data analysis and subsequent recommendations of this study.

9.3 LIMITATIONS OF THE STUDY

I believe that the research questions and problems were suited to qualitative methods. There are however a few limitations to doing this type of research. One such limitation is researcher's bias. Since the researcher is intimately involved in all aspects of the study, his/her biases, real or perceived, could influence the direction of the study. This is possible in quantitative research also. However in qualitative research, one method of dealing with these biases is to be open about them. I believe that in this study, my biases may have helped instead of hindered the process. My bias was the belief that current methods of HIV prevention have not been successful; therefore more comprehensive strategies are needed. This bias forced me to "think outside the box" and utilize models and theories not conventionally used in HIV prevention.

A second limitation refers to the applicability of the recommendations to the general population. This study was conducted with a limited number of participants who were selected because of their expertise in the field of "living in Tobago." These individuals were not picked because they represent outliers, therefore the understandings and subsequent recommendations based on their data should/would fit cases other than those interviewed. Of course, the inclusion of other individuals may unearth alternative understandings of the social and cultural factors surrounding HIV infection in Tobago, which warrants that research and evaluations continue.

9.4 FUTURE STUDIES

Although this study answers many questions about what social and cultural factors influence HIV infections in Tobago, it leaves many questions unanswered and raises new questions. As a result, several future studies are suggested.

- This study highlights the fact that economics play an integral part in determining whether female or feminine individuals can reduce their HIV risk. As a result, I recommend that a more in-depth study of the economic situation of women, and how that influences their ability to make better choices in Tobago, be the focus of future research studies. In addition, this study should include recommendations for improving the economic situation of women in Tobago.

- There is a belief that the majority of Tobagonians treated for HIV do so in Trinidad or other countries (versus being treated in Tobago). Though this study highlighted some of the factors that influence this choice, a more in-depth understanding of their rationale is needed. This would ultimately improve the HIV related services in Tobago.

- If the statistical estimations about HIV are correct, there are thousands of PLWHAs who are unaware of their HIV status in Tobago. While a community testing drive is recommended in the previous section, a comprehensive monitoring and surveillance system is needed to track these individuals. Given the confidentiality issues in Tobago, studies on the best method for collecting this information, while assuring the privacy of PLWHAs are needed.

- In the United States and other places partner notification and mandatory premarital HIV testing are controversial topics. The situation in Tobago warrants that more routine HIV testing is needed, therefore studies on how the "mandatory" testing requirements would be accepted in Tobago is needed. This study should also include recommendations for ensuring that these tests are communicated in culturally appropriate language/methods.

- Stigma and discrimination are catch phrases frequently used in HIV. In this study PLWHAs initially stated that they did not experience stigma and discrimination, then they described what I would view as stigma and discrimination. Is this a method of coping in this population? Studies on how PLWHAs view stigma and discrimination and how they deal with these are also needed in Tobago.

- An evaluation of the HIV prevention programs currently being implemented in Tobago is needed.

- In the United States, condom use at first sexual contact predicts future condom use. The influence of condom use at first sexual contact on future condom use needs to be studied in Tobago.

- The term "men who sleep with men" has been adopted because many of these men do not self identify as "homosexuals." A study on how men who sleep with men view their sexuality in Tobago is needed to clear up this concept. In addition, the presence of the relatively large MSM community in Tobago warrants that research on the special needs of this community is needed in Tobago

- A clinical study about the use of herbal medication or remedies and their interaction with anti-retroviral medication is needed in Tobago, since many PLWHAs interviewed stated that they use these natural remedies in conjunction with their HIV medication.

9.5 REVISITING THE POSITIVES IN PEN-3

According to the PEN-3 theory, the *cultural appropriateness of health behavior* has three main components – ***P***ositive, ***E***xistential and ***N***egative health behaviors. I have spent a great deal of time highlighting the social and cultural factors that have ***N***egative consequences for HIV prevention. However I would like to use this opportunity to reinforce some of the ***P***ositive social and cultural factors that I believe are important in the fight against HIV in Tobago.

First and possibly most important is the fact that Tobago is a **community**. The citizens of Tobago are individuals who proudly see themselves as "Tobagonians." The fact that "everyone knows everyone" and the belief that "I am my brother's keeper" exist in this community. As a result, the human rights, or more accurately, the *collective human rights* argument for preventing HIV has weight in this community and this may be the marketing strategy needed as the catalyst for effective HIV prevention and care. The idea that Tobago's communities are special and must be preserved, and that HIV works against preserving these communities, reinforces the need for preventing HIV-related illnesses or taking care of individuals already infected with HIV.

A second positive attribute of Tobago is the importance of family, and the need to maintain the family structure. This is important for two main reasons. First, HIV prevention can be marketed as a method of maintaining the family structure. If individuals and therefore families protect their HIV negative status, the negative social effects of HIV could be avoided and the family structure could be protected. Secondly, the maintenance of the family structure and the close-ties within nuclear and extended families could be used as a method to reduce stigma and discrimination against individuals already infected with HIV. As part of the counseling of newly diagnosed individuals, the family (or at least those individuals that the PLWHA plans to disclose to) should be counseled about the importance of their support in improving the health and wellbeing of the PLWHA. This would ultimately improve the wellbeing of the family unit.

Each year during the months of July and August, Tobago celebrates its oral, dance, and drama African traditions. Although this festival, the "heritage festival," is geared primarily for tourists; the talent that resonates demonstrates the wonders of Tobago's people. Drama, dance and oral traditions have been instrumental in HIV prevention in other communities, and I think that the same could be done in Tobago. The talent is there, the message simply needs to be injected into the production.

Let me end this dissertation where I began – "This is Tobago." On many occasions while in Tobago, I discussed my ideas, frustrations, and concerns about some of the negative aspects of the community. The response would frequently begin or end with "you can't change that because this is Tobago." Though this has been used to describe negative phenomena, I want to challenge the people of Tobago to use that phrase positively. "This is Tobago" and we have the ability to use all of our strengths to make the small changes needed to improve this little island. "This is Tobago" the "Capital of Paradise."

APPENDIX A: In-depth Interview Guide

In-depth Interview Guide
People Living With HIV/AIDS

1. Study Number

2. Date of Interview (day/month/year)

DEMOGRAPHIC DATA

First, I would like to get a little background information about you -

3. Age (years)

4. Sex (1) Male ☐ (2) Female ☐

5. Ethnic group
   (1) African ☐ (2) East Indian ☐ (3) Chinese ☐
   (4) Caucasian ☐ (5) Mixed (Please specify) ☐ (6) Other (Please specify) ☐

6. Marital status
   (1) Single ☐ (2) Married ☐ (3) Common law ☐ (4) Separated ☐ (5) Visiting ☐
   (6) Divorced ☐ (7) Other (Please specify) ☐

7. Which of the following best describes your housing situation
   (1) Shelter ☐ (2) Room in someone else's house ☐ (3) Renting an apartment ☐
   (4) House ☐ (5) Other (Please specify) ☐

8. How would you describe your current sexual orientation?
   (1) Heterosexual ☐ (2) Gay ☐ (3) Lesbian ☐ (4) Bi-sexual ☐ (5) MSM ☐
   (6) Other (please specify) ☐

9. Highest level of education reached
   (1) No school ☐ (2) Primary ☐ (3) Secondary ☐ (4) University ☐ (5) Trade school ☐
   (6) Other (please specify) ☐

10. What is your religion
    (1) None ☐ (2) Christian (please specify) ☐
    (3) Muslim ☐ (4) Other (please specify) ☐

11. Do you currently work outside the home? (1) Yes ☐ (2) No ☐
    What type of job do you do?
    What's your income?

12. What stage of HIV are you at?
    (1) HIV+ ☐ (2) AIDS ☐ (3) Don't Know ☐ (4) Does not want to disclose ☐

HIV/AIDS IN TOBAGO

Ok, now I'd like to talk with you about HIV and AIDS specifically -

13. Can you tell me what is HIV?

14. Please tell me what is AIDS?

15. How can a person get HIV?

16. How can a person successfully prevent getting HIV/AIDS or any other sexually transmitted diseases?

Ok, now we are going to talk about your experience being HIV positive and living in Tobago -

17. First, would you mind telling me your story about when you found out that you were HIV positive?

    - How did you find out?
    - How did you feel when you found out?
    - What were the circumstances surrounding your infection? (prompt for who, when, where, why, etc)

18. Where you employed during the time that you got infected? Doing what, etc?

19. You know, we always look back and think about what we could have done differently, is there anything that you think could have prevented you from contracting the virus?

20. What is your view on life right now?

21. Are you currently being treated for HIV or any other HIV related illnesses?

22. When did you start taking the ARTs?

23. Have you ever taken any herbs or bush medicine or anything like for HIV related symptoms?

24. Where are you being treated? Tobago, Trinidad, Health Promotion Clinic, Medical Research Foundation, etc

25. What are the treatment facilities like here in Tobago?

26. When you go to the clinic, who do you see there? The doctor, counselor, nutritionist, social worker, etc?

27. Do you feel comfortable being treated in Tobago? Why or why not?

28. Do your family and friends know about your HIV status? Why or why not?

29. Have you been treated differently because of your status? Explain?

30. Is there anything that you can do, or an HIV organization can do to help reduce the level of discrimination and stigma?

31. Would you be willing to meet and interact with other people who are HIV positive? Why or why not?

32. Do you use the services of OASIS, TAS, or any other organizations in Tobago?

33. When talking about HIV, health care, confidentiality or anything else, people always tell me "this is Tobago", what does this mean?

34. What do you thing is responsible for the high HIV rates in Tobago?

Okay, so lets talk about condoms -

35. When you visit your doctor, do they talk about ways to prevent getting reinfected or infecting other?

36. Generally, is condom use common in Tobago?

37. Have you ever tried buying a condom in Tobago? What was that experience like?

38. Who do you think should have condoms? Men, women or both? Why?

39. Did you use condoms during your last sexual intercourse? Why or why not?

Ok, lets talk about relationships in Tobago -

40. How would you describe a typical male/female relationship in Tobago?

41. What about people cheating in Tobago, is that common?

42. Do you think the types of relationships that are common in Tobago affect the HIV rates? Why or how?

43. Should married people or people in long term relationships still use condoms?

44. Ok, what about incest, is this common in Tobago? Have you heard about cases on the island?

Ok, now I will like to talk with you about programs pertaining to HIV/AIDS in Tobago -

45. Have you ever seen any information about HIV/AIDS in Tobago?

46. What type of information have you seen?

47. Do you know about any programs that try to prevent AIDS or that offer for support for persons living with HIV? Could you tell me about these programs?
Have you participated in any of them? Why or why not?

48. I've heard and seen advertisements asking "what's your position?", have you ever seen or heard about these advertisements?

49. What does that mean to you?

50. Ok, what about the letters A, B, C, D, E? Have you ever seen or heard about these letters relating to HIV/AIDS?

51. What do these letter stand for?

52. What do you think should be done to reduce the level of infections in Tobago?

53. Ok, lets say that you were creating a program to teach people about HIV/AIDS, what type of information would you like to see in that program?

54. How do you think that information should be given? (One on one, private setting, community program, workshop, etc)

Okay, now lets talk about something a little differently

55. Do you really listen to the lyrics of soca and dancehall? (do you only listen to the beat of the song?)

56. Have you heard songs that have positive messages pertaining to HIV prevention? Which songs, and what do they say?

57. Have you heard songs that have negative messages pertaining to sexuality? Which songs, and what do they say?

58. Do you think that these types of songs influence people? Have you been influenced by the words of these songs? If so, under what conditions?

59. Do you think that soca and dancehall can be used in HIV prevention programs? Why, why not?

Well those are all of my questions –

60. Is there anything else about HIV/AIDS in Tobago that you would like to talk about?

APPENDIX B: Acronyms and Abbreviations

ACRONYM	MEANING
3TC	Lamivudine or Epivir (HIV medication)
AIDS	Acquired Immune Deficiency Syndrome
ARV	Anti-retroviral medication
AZT	Zidovudine or Retrovir (HIV medication)
CARe	Community Action Resource
CAREC	Caribbean Epidemiology Centre
CARICOM	Caribbean Community and Common Market
CD4	Cluster of Differentiation 4
CRN+	Caribbean Regional Network of People Living With HIV/AIDS
CSW	Commercial Sex Worker
FOTAS	Friends of the Tobago AIDS Society
GDP	Gross Domestic Product
GNP+	Global Network of People Living With HIV/AIDS
HIV	Human Immunodeficiency Virus
HPC	Tobago Health Promotion Clinic
IVDU	IntraVenous Drug Use
KFC	Kentucky Fried Chicken
MRF	Medical Research Foundation
MSM	Men who Sleep with Men
MTCT	Mother-To-Child Transmission
NACC	National AIDS Coordinating Committee
NAP	National AIDS Programs

ACRONYM	MEANING
OASIS	Tobago Oasis Foundation
PAHO	Pan American Health Organization
PEP	Post Exposure Prophylaxis
PLWHA (PLWHAs)	Person Living With HIV/AIDS (People Living With HIV/AIDS)
PSA	Public Service Announcement
PTC	Peer Treatment Counselor
SARA	Situational and Response Analysis
SCTL	Socio-Cultural Theory of Learning
STD (STI)	Sexually Transmitted Diseases (Sexually Transmitted Infection)
TAS	Tobago AIDS Society
TB	Tuberculosis
TGP	Theory of Gender and Power
THA	Tobago House of Assembly
THACC	Tobago HIV/AIDS Coordinating Committee
TTD	Trinidad and Tobago Dollar
UNAIDS	Joint United Nations Programme on HIV/AIDS
USD	United States Dollar
UWI	University of the West Indies
VCT	Voluntary Counseling and Testing
WHO	World Health Organization
ZPD	Zone of Proximal Development

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