

**STIGMA AND DISCRIMINATION: INVESTIGATING FINAL YEAR  
STUDENT NURSES ATTITUDES AND PERCEPTIONS OF PEOPLE  
LIVING WITH HIV IN GUYANA**

**A Thesis**

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## ABSTRACT

Stigma and Discrimination: Investigating final year student nurses attitudes and perceptions of People Living with HIV in Guyana

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This study explored the issue or claim that stigma and discrimination exist among health care professionals in Guyana. The study was conducted using qualitative (focus group discussions) and quantitative (questionnaires) methods of data collection. Data was collected from the four nursing schools in Guyana: St Joseph Mercy Hospital (located in Georgetown), Georgetown School of Nursing (located in Georgetown), Charles Rosa School of Nursing (located in Linden) and New Amsterdam School of Nursing (located in New Amsterdam, Berbice).

The study design was based on symbolic interaction theory and positivism. The researcher explored some of the reasons why persons stigmatize and discriminate which include fear of contagion, myths about modes of transmission, values, norms and moral judgments and lack of knowledge. The data revealed that student nurses were comfortable providing service for People Living with HIV but they were fearful of contagion. These findings can be used by the Ministry of Health and other stakeholders to understand HIV-related stigma and discrimination and implement programmes to reduce these negative behaviours towards People Living with HIV. Stigma and discrimination goes beyond the student nurses and demonstrated by persons in the wider society. As a result, persons who are HIV positive will experience stigma and discrimination which can result in them refusing to access treatment at the health facilities.

Keywords: stigma and discrimination; attitudes and perceptions; People Living with HIV

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## ACRONYMS

HIV	-	Human Immunodeficiency Virus
AIDS	-	Acquired Immunodeficiency Syndrome
NAC	-	National AIDS Committee
PLHIV	-	People Living with HIV
UNAIDS	-	Joint United Nations Programme on HIV/AIDS
PAHO	-	Pan American Health Organisation
MSM	-	Men who have sex with men
CSW	-	Commercial Sex Workers
ICRW	-	International Center for Research on Women
FPDs	-	Former Plasma Donors
STI	-	Sexually Transmitted Infections
TB	-	Tuberculosis
KAP	-	Knowledge, Attitudes and Practice
CAREC	-	Caribbean Epidemiology Centre
PMTCT	-	Prevention of Mother-to-child transmission
VCT	-	Voluntary Counselling and Testing

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## CHAPTER 1

### INTRODUCTION

#### 1.1 Background

We are now twenty-five years into the epidemic and the Human Immuno-deficiency Virus (HIV) remains a complex and incurable disease which continues to devastate the lives of millions of individuals worldwide, and affect communities and nations. HIV can be deemed as one of the greatest threats to human development.

The issue of HIV-related stigma and discrimination remains a serious obstacle to the HIV response. The message consistently reported in the body of literature reviewed indicates, HIV-related stigma and discrimination are substantive impediments to successful responses to the epidemic (Rao 2001; UNAIDS, 2005a.) According to Peter Piot, UNAIDS Executive Director, since the beginning of the epidemic, stigma, discrimination, and gender inequality have been identified as major obstacles to effective responses to HIV” (UNAIDS, 2007, p, 1). These “obstacles” have undermined the success of HIV-related interventions in many countries throughout the world and Guyana is no exception.

The UNAIDS 2008 Report on the Global AIDS Epidemic has revealed, an estimated 33 million people were living with HIV at the end

of 2007. There were 2.7 million new infections and 2 million AIDS-related deaths. In the Caribbean, an estimated 230,000 people were living with HIV. There were an estimated 20,000 new infections and an estimated 14,000 AIDS-related deaths. The Caribbean has the highest prevalence of HIV in the Americas and the epidemic is driven by high levels of poverty, unemployment, gender and other inequalities and stigma and discrimination (UNAIDS, 2008).

Guyana recorded its first HIV case in 1987. According to the UNAIDS (2008) report, Guyana has an adult prevalence of HIV infection rate of 2.4% with HIV being the leading cause of death among the 15-44 age group. At the end of 2007, it was estimated that there were approximately 12,000 People Living with HIV. Research has also shown that while the epidemic earlier affected more men than women, there is an increasing feminization of the epidemic in Guyana. More women are recorded with HIV today than men, especially in the 15-24 age groups (Ministry of Health, 2006). Guyana like many other countries in the world has been faced with various social ills which include poverty, substance use and abuse, violence, rising cost of living, cultural and religious taboos, migration and displacement both internal and external and a limited legal and ethical framework to protect People Living with HIV (PLHIV).

The issue of stigma and discrimination has been reported through numerous forums and is one of the more serious issues facing People Living with HIV in Guyana. Stigma and discrimination play a significant role in driving the HIV epidemic underground in certain marginalized sub-groups such as men who have sex with men (MSM), prison inmates and Commercial Sex Workers (CSWs). Due to stigma and discrimination, the Government of Guyana as part of its National HIV/AIDS Strategy 2007-2011 has committed to promote legislation to prevent stigma and discrimination based on HIV status (Ministry of Health, 2006). According to the HIV/AIDS Behaviour Change Communication Strategy for Guyana 2006-2010, stigma and discrimination act as major barriers to behaviour change and the maintenance of positive behaviour in Guyana. Stigma and discrimination prevent People Living with HIV from seeking information; disclosing their HIV status among partners, family members and others and inhibit testing for HIV and other Sexually Transmitted Infections (STIs) (Ministry of Health, 2006). Stigma, or non-acceptance of People Living with HIV (PLHIV), is the single biggest obstacle to developing an effective response to the virus in Guyana (National AIDS Committee, 2008).

In an effort to combat the epidemic in Guyana, the Ministry of Health along with national and international partners has embarked on a

number of health care delivery services for HIV in Guyana. These services include:

- **Care and Treatment**, approximately 1,701 persons are on treatment;
- **Counseling and Testing**, approximately 40 sites (including 2 mobile sites);
- **Home-based and palliative care**, approximately 1,026 persons received home based care in 2006;
- **Prevention of mother-to-child transmission of HIV**, approximately 94 service outlets in eight regions
- **Orphans and Vulnerable Children**, approximately 7000 orphans and vulnerable children.

Most of these services are provided by health care workers. However, it was found through studies, program assessments and anecdotal information that health care providers often fail to provide confidential services and exhibit stigmatization and discriminatory attitudes/behaviours towards People Living with HIV (Ministry of Health, 2006; Walton, et al. 2005; Cummings, et al. 2005; National AIDS Committee, 2008). The findings of these studies coupled with my eight (8) years experience working in the HIV/AIDS field have driven my interest on the issue of stigma and discrimination as it relates to health care workers, specifically those who are new to the profession since they may

have biases and prejudices towards People Living with HIV. The study sought to determine whether these biases and prejudices lead to stigma and discrimination and to ascertain the contributing factors. It also examined the influence of individual's attitude and perception on their behaviour and treatment of people with HIV. Factors such as ethnicity, sex, age, religion and individual social background were taken into consideration since these can influence health care provider behaviours toward People Living with HIV.

Guyana is a multi-ethnic, multi-cultural society and stigma and discrimination can result due to people's socialization and value-system. Many persons in Guyana associate HIV with 'bad or immoral behaviours' and it is felt by many that HIV is a 'homosexual disease'. This perception is stereotypical among the major ethnic groups in Guyana (Africans, East Indians and Amerindians). Very religious people tend see HIV as a punishment from God for living a 'loose life' or breaking the commandment of God. This stereotypical perception is not limited to Guyana. According to a study done by Lawson et al, (2006), the participants mentioned, religious belief and norms, homophobia or the denial of homosexuality within communities, and silence about health and sexuality are issues affecting responses to HIV within African and Caribbean communities. Studies on stigma and discrimination have found that people who have minimal education or misperceptions regarding HIV

transmission are more likely to hold discriminatory attitudes (Shulman, & Mantell, 1988; Siminoff, Erlen & Lidz, 1991). Moreover, when health care providers are unfamiliar with appropriate procedures, such as universal precautions, incidences of unintentional discrimination are likely to be higher (Li et al, 2007).

Professional student nurses in Guyana are products of an educational system that places little emphasis on health education and health promotion which helps to foster numerous misconceptions as it relates to health and sexuality. After obtaining passes in the required subjects at the Caribbean Examination Council (CXC), students can enroll at the four (4) nursing schools in Guyana. The professional nursing programme is conducted over a three year period. Upon successful completion, nurses are certified and registered for practice. The nursing curriculum focuses mainly on clinical nursing and while HIV and AIDS are taught, it relates more to the disease and not to the social and other determinants of the infection. HIV and AIDS are taught as part of subjects such as Pediatrics, Gynecology, Personal and Community Health, Anatomy and Physiology, Clinical Nursing, Nutrition, Health and Safety and management of the client. In recent years, the intake of student nurses has grown. The most recent batch saw over 400 students enrolling for the professional nursing and nursing assistant training programme (Stabroek News, July 26, 2008). The students are often young, between the ages of

16 – 25 and the main composition is Afro-Guyanese with a few Indo-Guyanese, Amerindian and persons of mixed ethnicity.

Li et al, (2007) posited that HIV-related stigma and discrimination in health care settings have multiple sources and take on many different forms. Persons stigmatize and discriminate for many reasons, often, it relates to fear and shame. Fear because HIV is perceived as devastating and deadly. Shame because HIV is transmitted by sex which is deemed taboo in the Guyanese society. Sex is deemed taboo because although persons are involved in sexual activities, they do not discuss it openly and often when the topic of sex is raised, they shy away from the discussion. The fear and shame are often derived from lack of knowledge and understanding of people living with the HIV situation. Often the HIV positive persons rights are disregarded, for example, *from a report received, late 2007, June Ann (not her real name) who is HIV positive gave premature birth to a six month old baby. Because her status was know to the nurse on duty at the time, she was not attended to. Other patients in the ward had to render assistance. She was told by the nurse “why you having sex and getting pregnant when you are HIV+”* (Reported by a Person Living with HIV). This case is not isolated from other anecdotal reports. These and other incidents have led to People Living with HIV calling for a Human Rights Desk to report when they are discriminated against and their rights were not upheld.

According to Pan American Health Organisation, (2005), health professionals have a tremendous influence on the physical and emotional welfare of People Living with HIV or who are vulnerable to infection since they could grant or deny access to life-saving treatments. In a study done in Nigeria, it was found that health professionals refused to care for patients with AIDS and also refused to admit HIV positive patients in hospitals (Letamo, 2005). These negative behaviours can affect the HIV positive person's view of health care professionals and may discourage them from accessing medical care which can prolong their lives.

## **1.2 Statement of the Problem**

Health care providers need to be equipped with the correct knowledge, and have the right attitudes to cope not only with the bio-medical aspect of the disease but also the psycho-social issues affecting People Living with HIV since they play a critical role in HIV prevention, care, treatment and support. They should also be aware of stigma and discrimination and how these social ills have negative impact on People Living with HIV. Research has found that nursing students who have not been provided with adequate information, knowledge and exposure, often understand HIV care and treatment as 'end of life care'. They have not gained sufficient experience to understand that PLHIV may require holistic support and care long before the onset of the visible signs of AIDS. (Health and Development Networks, 2006.) Without such

knowledge and preparation nurses often rely on their religious and socialization background as referents for dealing with the HIV patient and this may not be adequate since it can hinder their attitude and perceptions of People Living with HIV.

### **1.3 Purpose of the Research**

The purpose of the research was to explore the issue or claim that stigma and discrimination exist among health care professionals in Guyana. In an effort to explore this phenomenon, the attitudes and perceptions of professional nursing students towards People Living with HIV was examined.

### **1.4 Research Questions**

1. Do student nurses perceive HIV-related stigma and discrimination to be a problem in Guyana?
2. Do student nurses stigmatize and discriminate against People Living with HIV?
3. How do student nurses perceive People Living with HIV?
4. How does the nursing curriculum influence their attitudes towards and perceptions of People Living with HIV?

### **1.5 Significance of the Study**

This study sought to investigate final year student nurses' attitudes and perceptions of People Living with HIV in relation to stigma and discrimination. To date, no study was ever done in Guyana on this topic, targeting student nurses. This topic is of particular interest as increasing accusations are made through anecdotal reports and through various programmes especially the treatment and care programme about health care professionals stigmatizing and discriminating against People Living with HIV by refusing to provide care and treatment. It is my hope that this study will provide a baseline for future studies to be undertaken by other researchers and the Ministry of Health. In this study, I also explored the possible impact of HIV related stigma and discrimination on the wider spectrum of the health care system and the responsibility of health care providers to deliver an equitable service to all.

### **1.6 Limitations and Delimitations**

1. Guyana is now in the process of collecting data and as a result, no comprehensive data on attitudes and perceptions among nursing students is available.
2. Since one of the modes of HIV transmission is through unprotected sex and persons in Guyana do not talk openly about sex, the information

provided by the respondent may not be accurate since their responses could violate their privacy.

3. The researcher was not given permission to interview the nursing tutors of the public nursing schools on the curriculum and method of teaching HIV and AIDS in the schools hence; limited information was collected on the content of the HIV and AIDS Module of the nursing curriculum. The information collected was provided by the nursing students and the tutor of the private nursing school.

4. The researcher was not given permission to audio record the focus group discussion as a result, the discussion had to be manually recorded and as such, important data could have been omitted.

5. Some of the respondents were not active in the discussion and had to be coaxed for information.

## **1.7 Definition of Terms**

### **Attitude**

A tendency expressed by evaluating a particular entity with some degree of favor or disfavor (Eagly & Chaiken, 1993, p. 1).

A learned evaluative (like or dislike) response directed at specific objects, which is relatively enduring and influences behaviour in a generally motivating way. It is relatively enduring and is similar to personality traits (Lippa, 1990, p.302).

### **Perception**

The process used by organisms to interpret and organize sensation to produce a meaningful experience of the world. It describes one's ultimate experience of the world and typically involves further processing of sensory input. In practice, sensation and perception are virtually impossible to separate, because they are part of one continuous process. (Lindsay & Norman, 1977, pg. 5).

The process used by individuals to judge the traits (stable internal dispositions) and characteristics of others. It is an essential part of everyday social interaction (Lippa, p.61).

### **Prejudice**

A negative prejudgment that is often unwarranted and is based on limited, insufficient evidence (Lippa, 1990. p.302).

### **Stigma**

The term *stigma* refers to any attribute or characteristic of a person that is “deeply discrediting.” Stigma of any kind can result in the reduction

of a stigmatized individual or group from a “whole and usual” state to a “tainted, discounted” (Goffman, 1963, p. 3)

### **Discrimination**

To perpetrate an unjust action or inaction against individuals who belong to, or are perceived to belong, to a particular group, in particular stigmatized groups such as sex workers, men who have sex with men and injecting drug users (Pan American Health Organisation, 2005, pg.12)

### **HIV**

Human Immuno-deficiency Virus. HIV is a retrovirus that infects cells of the human immune system (mainly CD4 positive T cell and macrophages – key components of the cellular immune system), and destroys or impairs their function. Infection with this virus results in the progressive depletion of the immune system, leading to immune deficiency (CAREC, 2002, pg. 2)

### **AIDS**

Acquired Immune Deficiency Syndrome is the collection of symptoms and infections associated with acquired deficiency of the immune system. Infection with HIV has been established as the underlying cause of AIDS. The level of HIV in the body and the

appearance of certain infections are used as indicators that HIV infection has progressed to AIDS (CAREC, 2002, pg. 2)

### **People Living with HIV**

According to the UNAIDS' Terminology Guidelines, the use of the term People Living with HIV reflects the fact that an infected person may continue to live well and productively for many years. The Guidelines stated that persons should avoid the expression 'People Living with HIV and AIDS' and the abbreviation PLWHA (UNAIDS, 2007, p.11).

### **Student Nurses**

A student in a program leading to certification in a form of nursing; usually applied to students in an registered nurse or [practical nurse](http://cancerweb.ncl.ac.uk/cgl.bin/omd) program.(<http://cancerweb.ncl.ac.uk/cgl.bin/omd>)

## CHAPTER 2

### LITERATURE REVIEW

The purpose of this literature review was to assemble scientific evidence on HIV- related stigma and discrimination globally, regionally and in the local context with particular emphasis on health care providers to address the research topic: **stigma and discrimination: investigating final year student nurses attitudes and perceptions of People Living with HIV in Guyana**

The study does not take the mammoth task of bringing to the attention of the audience all that have been written on this subject but rather seeks to highlight those pertinent issues. In addressing stigma and discrimination, I also examined prejudice since the term is synonymous with attitude which can contribute to stigma and discrimination.

Areas relevant to the inquiry were as follows:

1. Understanding HIV/AIDS- related stigma and discrimination.
2. Sources and manifestation of stigma.
3. Responses towards People Living with HIV and AIDS by Health Care Providers.
4. Consequences of HIV/AIDS-related stigma and discrimination

## 5. Education and HIV-related stigma and discrimination

### **2.1 Understanding HIV- related Stigma and Discrimination**

Researchers have opined that, there are many similarities between HIV- related stigma and discrimination and stigma and discrimination related to other diseases such as tuberculosis, leprosy, mental illness, physical disabilities, cancer and even suicide (Sontag, 1998; PAHO, 2005). HIV/AIDS is one of the latest diseases to be stigmatized (Brown et al. 2001).

According to Aggleton, Parker and Maluwa, (2003), the stigma and discrimination associated with HIV/AIDS are more manifestly expressed than to other health conditions. They stated, all over the world, and especially in Latin America and the Caribbean, stigma and discrimination have systematically played to, and reinforced existing prejudices. Stigma and discrimination were also recognized as barriers to the provision of adequate health care, psychological and social support, and appropriate medical treatment (Kohi et al 2006). Stigma and discrimination are inter-related and often the terms are used synonymously.

For the purpose of this study, stigma and discrimination as well as prejudice will be discussed since these terms have negative impact on

behaviours of individuals and society. The term *stigma* refers to any attribute or characteristic of a person that is “deeply discrediting.” According to Sociologist Irving Goffman (1963), stigma often results in the reduction of a stigmatized individual or group from a “whole and usual” state to a spoiled and despicable one. Goffman further posited that stigma, reduces the life chances of the stigmatized individual due to discrimination. Stigma occurs when four interrelated factors converge in social, economic and political power contexts. These factors are labeling and distinctions to differences; association of human differences with negative traits; separation of “us” from “them,” and status loss and discrimination. According to Aggleton, Parker & Maluwa, (2003), HIV-related stigma do not reside in the minds of individuals; it is a social product with deep societal origins. However, although stigma is a social product with deep societal origins, I will like to refute the claim made by the writers that it does not reside in the minds of individuals. In my opinion, whatever happens in our society/environment affects us psychologically and can influence the way we think and act. Moreover, society is not something apart from the individual; it is in the mind of the individual. Therefore, the society and individuals cannot be separated.

Stigma is considered a social process, which is used by some groups and individuals to reinforce existing social inequalities (such as gender, sexual orientation, race, class, religion, ethnicity and wealth). This

inequality creates an environment for such groups and individuals to dominate and exert power (social control) over other individuals, based on these differences (PAHO 2005 citing Parker & Aggleton, 2001; UNAIDS, 2005b). Weiss & Ramakrishna (2001) in reviewing the medical perspective of stigma posited that stigma is a social process or related personal experience characterized by exclusion, blame, or devaluation which results from poor social judgment about a person or group. According to terror management theory, the awareness of one's own mortality or vulnerability can create an overwhelming existential anxiety in people. This anxiety motivates people to reinforce their cultural world view and reject those who violate this worldview. Perceptions of deviance or difference seem also sufficient to arouse existential anxiety (Bos, 2001, citing Dovidio, et al., 2000). In such circumstances, stigmatization of deviant individuals is a way to provide a worldview that buffers against this anxiety (Bos, 2001, citing Crocker et al., 1998). Existential anxiety-buffering seems to be especially important for stigmas based on abominations of the body, because these marks immediately remind perceivers of their own vulnerability.

At the individual level, stigmatization may serve as a self-enhancement strategy (Bos, 2001, citing Dovidio, Major & Crocker 2000). People can enhance their self-esteem through downward comparison. According to downward comparison theory (Bos, 2001, citing Wills,

1981), people can boost their own self-esteem by comparing themselves with others who are worse off. This downward comparison process can also take an active form, when people try to disadvantage others through stigmatization. At the inter-group level, stigmatization may enhance people's social identity (Bos, 2001, citing Dovidio, Major and Crocker 2000). According to social identity theory (Bos, 2001, Tajfel & Turner, 1986), people make favorable inter-group comparisons to maintain a positive social identity. Self-enhancement therefore can be viewed as the underlying motivations for individuals to stigmatize People Living with HIV. Goffman (1963) distinguishes three dimensions of stigma: tribal stigma, abomination of the body, and blemishes of individual character. This study will utilize the latter two: abominations of the body (which relates to physical conditions), and blemishes of individual character (which relates to moral conduct). Abominations of the body are associated with AIDS-related illness such as wasting, sores and cancers. Blemishes of individual character are associated with promiscuity/lifestyles.

Discrimination is the outcome of stigma, this Goffman (1963) calls "enacted stigma." Enacted stigma relates to an actual act or experience of discrimination whilst "felt" or "perceived" stigma denotes a real or imagined fear of societal attitudes towards a particular undesirable trait (Malcolm et al., 1998). There are many negative expressions of stigmatization of various degrees and discrimination is only one of them

(Bos, 2001). Discrimination occurs when persons attempt to exclude, discount and discredit a stigmatized individual. It generally refers to treating someone or a group worse than another. According to Lippa (1990), discrimination refers to overt acts that treat members of certain groups unfairly. Discriminatory behaviour can be as subtle as certain nonverbal behaviours such as standing apart or it can be blatant as referential hiring in business and industry. HIV-related discrimination occurs when someone living with the virus is unfairly or unjustly treated by another person based on their status. It is important to note that discrimination can be legislative (enshrined in law or policy) or community (actions or inactions in less formal contexts) such as workplaces and social settings such as marketplace (PAHO, 2005). Often, the stigmatized individual belongs to a group that has been stigmatized such as men who have sex with men, sex workers and injecting drug users.

Prejudice is defined as “a negative prejudgment that is often unwarranted and is based on limited, insufficient evidence” (Lippa, 1990. p.302). Prejudice is an evaluative response directed at some object. It is often an over generalized attitude that is applied to a group or to individual members of a group (Hilgard, 1980). Unlike attitude which has often been most centrally defined in terms of its affective or emotional component, prejudice is characterized by a host of negative feelings. It includes emotions such as disgust, repulsion, fear and hatred (Lippa, 1990).

Therefore, prejudice can lead to emotional reactions resulting in discrimination.

Allport (1954) examined prejudice from six levels. These levels are:

1. Historical – instances of prejudices in specific historical periods for example, the Nazi Era when the Germans viewed the “Poles” – the predominantly Roman Catholics ethnic majority as “sub-humans” and killed many of the religious and intellectual leaders.
2. Socio-cultural - focus on sociological concepts such as urbanization, class mobility and population shifts and density.
3. Social situation – individual’s social situation as a cause of prejudice, for example prejudice and discrimination against blacks in the South of USA was for many, a matter of conforming to group norms and behaviour.
4. Personality – focuses on traits and characters of an individual as a cause of prejudice, for example, some people may be prejudiced because they were raised by punitive parents and as a result may develop defensive, prejudiced personalities.
5. Phenomenology – deals with stereotypes which are what people believe to be true of other groups even though the evidence of these beliefs is often weak and lacking.

6. Stimulus Object – prejudices and inter group hostilities may be based at times on real characteristics of the target group; this idea has sometimes been called the “earned reputation theory”

Therefore, prejudice is agreement with negative stereotypes such as People Living with HIV are promiscuous and deserved to be infected. It leads to emotional reaction among persons in society such as fear of being infected if they associate with People Living with HIV; withholding care, treatment and support; avoidance which includes denial of employment because of HIV status; isolation which includes putting infected persons out of the homes and placing them in shacks (old pens) in the yards and segregation which includes given infected persons their own eating utensils. Prejudice can also have negative emotional reactions of People Living with HIV such as low self-esteem and low self-efficacy which could lead to self-stigma. This will be further discussed later in this study.

## **2.2 Sources and Manifestations of Stigma**

People’s behaviours and attitudes toward stigmatized individuals are numerous, distinct and varies in terms of severity and levels of condemnation. Stigma is often manifested through cognitive behaviours and can be measured along a continuum from the subtle and unobservable to the very overt and damaging. Generally, overt damaging behavioural manifestations of stigmatization include dehumanization, discrediting,

discounting, aversion, avoidance, ostracization, social rejection and depersonalization of persons through labeling and branding (Bos, 2001, citing Dovidio, Major and Crocker 2000; UNAIDS 2005 and Herek & Capitanio 1998). Subtle stigmatizing behaviours are less observable, and are sometimes expressed as non-verbal signs of discomfort during interactions between stigmatized and non-stigmatized individuals (Bos, 2001 citing Hebl et al. 2000). Bos further posited, human behaviour is by nature complex and because of this people rarely behave in purely negative or positive ways towards stigmatized individuals. The Weiner's attribution-emotional model was used by Bos to describe how pity and anger, motivate certain social reactions by perceivers, towards marked individuals. For example, emotional reactions of pity usually evoke "pro-social" behaviours, such as sympathy and support; whereas anger often motivates hostile and stigmatizing behaviours (Bos, 2001 citing Weiner, et al., 1998).

Researchers have found that People Living with HIV are stigmatized based on how they acquired the infection and their physical condition (having sores, Kaposi's sarcoma and wasting). Persons maintain physical distance from HIV-infected persons, although they were generally sympathetic to their condition. Generally, persons are of the view that People Living with HIV who became infected due to "moral misconduct" should be "avoided or excluded from society". They are

labeled as “degraded,” “deviant” “bad”. Whereas those who became infected due to circumstances beyond their control such as blood transfusions or by their infected spouses were categorized as “unlucky.” Persons were usually sympathetic and supportive of persons from the latter group (Hong et al., 2004; Bos, 2001 & Mc Lean, 2004). Other studies found that stigmatizing behaviours are usually more intense during the advanced stages of the infection, when persons are unable to conceal their medical condition (Brown, 2001 & Cao et al., 2006). In contrast, negative reactions can be avoided if the individuals are able to hide their condition, or when the condition itself is not evident (Bos, 2001 citing Jones et al. 1984). Similar findings were found in Goffman (1963) who posited that an individual can encounter two distinct social atmospheres. First, the individual is discreditable which means that his/her stigma is not yet revealed, but may be revealed by him/her intentionally in which case the individual will have control how and to whom he/she discloses. Second, the individual is discredited which means that his/her stigma has been disclosed without consent which can have a negative impact on his behavior. This type of attitude and behaviour can lead to what Goffman called “spoiled identify”. Spoiled identity according to Goffman reduces a person confidence and self esteem resulting in the affected person being ashamed and withdrawn from society. Hence, the reason many individuals refuse to disclose their status. I have encountered many such individuals during my career.

HIV-related stigma also results from fear of becoming infected through casual contact such as shaking hands, eating from the same utensils and sharing toilet facilities. This fear feeds the non-infected persons belief that staying away from an infected person will prevent the transmission of HIV (Hong et al. 2004). Such fear is perpetuated by misinformation and lack of knowledge about HIV transmission. These perceptions can result in unintentional stigmatizing behaviours by family members, neighbours, religious personnel and health professionals (Mahendra et al., 2007; Hong et al., 2004; National AIDS Committee, 2008). Related behaviours can include isolation of HIV-positive patients in hospitals, within families, avoidance by neighbours and other community members (Mahendra, et al., 2007; Hong et al., 2004; Walton et al, 2005 & Cao et al., 2006). Fear of death also adds to the sources of HIV-related stigma, which can render the perceiver powerless to enact different attitudes towards People Living with HIV (Mc Lean, 2004; Brown et al., 2001).

### **2.3 Responses towards People Living with HIV by Health Care Professionals**

People Living with HIV often suffer discrimination from non infected persons. Some of them are targets to derogative name calling such as “maiti inayotembea or walking corpse” “walking dead”, “big truck” and “Aidsie” (ICRW, 2006; Mc Lean, 2004). In reviewing the literature on

HIV-related stigma and discrimination in the health care setting, some very negative attitudes and behaviours were found. These include markings or labels on beds and files with words such as 'High Risk', 'Barrier Precautions' and 'DANGER' posted on top of patient's beds to indicate their HIV status. Other labels included placing the bed at the end of the room or next to the toilet, placing a cloth screen around the patient's bed, and placing the patient in a separate ward or room (Mehendra et al. 2007). Lester and Beard (1988) cited in Boswarva (1991) found that of 177 baccalaureate nursing students in the United States of America, fifty percent preferred not to care for AIDS patients, with a sixth preferring to resign rather than do so. A third said students should not be assigned AIDS patients. Wiley, Heath and Acklin (1988) cited in the same document, questioned 142 postgraduate and undergraduate nursing students to find that over half of them thought that health care workers should be allowed to refuse to treat HIV positive clients (Boswarva,1991). In Barbados, attitudes to People Living with HIV varied among physicians. Research has found that while a lot of physicians would not perform an HIV test without the patients consent, 32 % would test without consent if the patient were seriously ill. Also, 15% would test without consent if they had to perform an invasive procedure on persons suspected from high-risk groups. (Massiah et al, 2004). In 2005 a group of University of Guyana students conducted a study among HIV/AIDS patients. The study found that stigma and discrimination continued to be a

challenge for the HIV/AIDS programme in Guyana. It also found treatment of HIV positive patients in hospitals to be poor. Thirty-two percent (32%) of the respondents felt that they were not attended to regularly by health care workers while twenty-one percent (21%) said they were isolated from other patients and thirty-one percent (31 %) complained of excessive precautions used when being cared for. 9.5 % and 2% of patients were denied care and treatment respectively (Walton et al, 2005).

Other studies conducted have shown ignorance and lack of knowledge, fear and intolerance to be contributing factors to the negative attitudes and behaviours towards People Living with HIV (Mc Lean, 2004; Cummings, et al., 2005; National AIDS Committee, 2008). Cummings, et al, (2005) further found that doctors were more comfortable attending to patients with migraine, diabetes and syphilis than patients with HIV/AIDS. A significant number of nurses felt that HIV can be transmitted by giving blood, French kissing and touching infected blood. All categories of health care workers surveyed felt that they should be given risk allowance for caring for HIV positive patients and a significant amount of them felt that they were at risk for contracting the disease. This clearly indicates that the level of comfort among health care provider is very low when treating HIV/AIDS patients. Another study conducted in Benin, found 98 % of the nursing students surveyed had a good

knowledge of AIDS and 77% reported fear of contagion during their in-service training for the care of HIV infected patients. 23.4% thought that HIV positive persons should be quarantined (Fourn, et al., 1993). A similar study conducted in Kenya found 46% of health workers expressed fear in handling AIDS patients (Karani, et al., 1990). In China, persons both HIV-positive and negative persons were refused services by health care workers if they were from high prevalence areas (Cao et al. 2006).

In a study conducted in Cameroon, it was found that 70.1 % of the nurses scored highly in knowledge as compared to 50.5 % in the attitude and practice section. However, there were several misconceptions and malpractices about HIV/AIDS. 15% of the patients indicated that they were attended to with signs of disgust and/or hatred. The major health service factors thought to influence Knowledge, Attitude and Practice (KAP), included: lack of adequate information, the lack of commitment to alter attitudes and practices. Low income also seemed to have an influence on KAP (Mbanya, et al. 2001). Roseval, (2007) in his study on HIV/AIDS Stigma and Discrimination among Nurses in Suriname found that even though 47.2 % of the nurses surveyed had specific training on HIV/AIDS, the nurses were singling out HIV/AIDS patients from those with other diseases in the hospital. Some of the nurses in the study had passed information about patients HIV status to their colleagues and members of the public. Roseval concluded that although the nurses were

surrounded by information, there were other obstacles within the organization that prevented the information from being used in their practice.

In a qualitative study done by Choy, Jacobs & Thomas, (2008), it was found that stigma and discrimination existed among nurses in Guyana. Nurses reported disclosing patient's HIV status to other health care professionals, testing of patients without their consent and isolate or separate patients. Other forms of stigma and discrimination by health care professionals were reported by People Living with HIV. These include: denying patients treatment, placing patients among those with tuberculosis, refusing to care patients during hospitalization. Research has found that nursing students who have not been provided with adequate information, knowledge and exposure, often understand HIV care and treatment as 'end of life care'. They have not gained sufficient experience to understand that PLHIV may require holistic support and care long before the onset of the visible signs of AIDS. (Health and Development Networks, 2006.)

A report by the Pan American Health Organization (PAHO) revealed that patients with HIV or AIDS experienced stigma and discrimination from doctors, nurses and other health care providers as well as from members of society at large. The report reviewed research on the

attitudes and practices of health care providers and the experiences of HIV/AIDS patients in the Americas and other regions. According to the report, examples of discrimination in the health sector included: Refusal to admit patients to health care facility, delayed treatment, other forms of care (e.g. presentation of food, hygiene) delayed or withheld, premature discharge of patients, testing without consent, breach of confidentiality within or outside the health care, inability to inform patients of HIV-positive results, inappropriate behaviour (e.g. shouting, rudeness etc.) and use of excessive precautions such as wearing two gloves. The research also found, in the city of Cochabamba, in Bolivia, high levels of ignorance about HIV/AIDS diagnosis and treatment among health workers. More than a third of 305 respondents were afraid of HIV/AIDS patients and believed they should be isolated. In Venezuela, there were higher rates of discriminatory attitudes among dentists (45 percent) and nurses (46 percent) than among doctors and students (both 42 percent). In the Dominican Republic, nearly a third of surgeons in a 1994 study reported feeling anxiety over treating HIV patients, and one in 10 said they did not accept HIV-positive patients. The report further mentioned that discrimination against people with HIV persists because it has additional deeply rooted causes. Among them is the prejudice against groups hardest hit during the early stages of the epidemic, such as men who have sex with men, sex workers and drug users.”

([http://www.paho.org/English/DD/PIN/hiv\\_factsheet.htm.para 21-23](http://www.paho.org/English/DD/PIN/hiv_factsheet.htm.para 21-23)).

In another study conducted among five African countries, it was found that denial of health care or home care services was reported by 48 focus group participants. One nurse described the following incident:

*One day, the Medical Superintendent came to the ward and read his [an HIV-positive patient] chart. While he was still on oxygen, he then give the instruction, which he even wrote down, to say the patient must not be given oxygen.*

Other clinical nurses and volunteers described similar experiences:

*If they need oxygen, we do not administer it. When they have low hemoglobin of 4 they are not given a transfusion. We conclude that it is useless to give it because they are going to die anyway.* (Kohi, et al, 2006, pg.408). However, it is noteworthy to know that PAHO Report cited positive findings in relation to health care providers. The report mentioned that “there is evidence of changing values, together with increased pragmatism, care and compassion by health care providers. Moreover, increased familiarity with patients with the disease helps most health workers to feel more comfortable working with people with the virus.” (<http://www.paho.org/English/DD/PIN/ptoday para.8>)

## **2.4 Consequences of HIV-related stigma and discrimination**

Stigma and discrimination can result in many negative consequences for People Living with HIV. Some of these consequences which I will address in this research are fear of finding out one's sero-status; fear of disclosure and self stigma.

### **2.4.1 Fear of finding out one's sero-status**

Leary & Schreindorfer, (1998) posited that people may hesitate or resist to be tested for HIV, because they are afraid to become stigmatized and of the social repercussions if they are tested positive. This could result in persons infecting others and not accessing treatment in time for the infection. Studies have found that people who do get tested sometimes do not return for their results for fear of being seen at a clinic, which could raise suspicions about their health. (ICRW, 2006 & Bos, 2001).

### **2.4.2 Fear of Disclosure**

People Living with HIV fear disclosure for a number of reasons. These include becoming the target for gossip and taunts, loss of social contact, loss of personal income, loss of jobs and lack of understanding on the part of the person he/she discloses to. According to Bos (2001), individuals need to decide to whom they will disclose. Disclosure of sero-status is normally higher among symptomatic than asymptomatic persons. Studies found, stigma to be a contributory factor to the low levels of

access to testing, care and treatment sites by People Living with HIV (White & Carr 2005; ICRW 2006).

The studies have found that individuals did not disclose their status to their most intimate partners and significant others for fear of physical violence and abandonment (ICRW 2006; Choy, Jacobs & Thomas, 2008; Mahendra et al 2007; Hong et. al., 2004, NAC, 2008 & UNAIDS, 2001). However, in Guyana, it was found that reactions to disclosures were improving (NAC, 2008).

#### **2.4.3 Self stigma**

Our behaviour along with environmental and personal factors interacts with each other to influence how we interact with each other. Bandura, (1970) in his Social Cognitive Theory (SCT) explains how people learn not only through their own experiences, but also by observing the actions of others and the results of those actions. Hence People Living with HIV may see themselves different from other non-infected persons. For example, in China, former plasma donors (FPDs) develop a kind of reverse discrimination towards non-FPDs since they see them as outsiders and do not want to have contact with them (Cao, et al., 2006).

According to Hong et al., (2006) almost all People Living with HIV, at some point, felt self-hatred, guilt and shame that can be expressed

as depression and despair and can lead them to withdraw from family and social life to simply await their death. People Living with HIV often reduce contact with people who are close to them. They perceive themselves as victims of a deviant behaviour. They begin to interpret what other individuals may think or act towards them (Cao, et al 2006). Emotions such as anxiety, depression or hostility are psychological consequences that may be demonstrated by patients. (Bos 2001 citing Jones et. al.,1984). This process is painful as the individual is forced to act against his or her natural character. Further, the awareness that one's identity is devalued in the eyes of others may also be a threat to one's self-esteem (Bos 2001 citing Crocker et al., 1998).

## **2.5 Education and HIV-related stigma and discrimination**

However, in reviewing the literature, it was found that HIV-related stigma and discrimination can be reduced by educational programmes. These programmes should include accurate knowledge of the modes of transmission, bodily fluids that have a high concentration of the virus, skills to interact with HIV positive patients and human rights laws which protect infected persons and values and norms in society which contribute to stigmatizing and discriminatory behaviours. The programmes should also include ways in which HIV is not transmitted. The programmes should be provided in an interactive way and moderated by a competent and trustworthy facilitator. Efforts must be dedicated towards creating an

environment that will facilitate discussion and questions, to dispel myths about HIV (ICRW, 2006). According to PAHO (2005), people who are aware that casual contagion is impossible are less likely to have negative attitudes to People Living with HIV (PAHO, 2005).

In conclusion, the literatures reviewed have shown that stigma and discrimination are not isolated phenomena. They are perpetuated by individuals and society to create differences, social control and inequality. Stigma and discrimination are also recognized as barriers to the provision of adequate health care, psychological and social support, and appropriate medical treatment to People Living with HIV. Goffman (1963) argued that discrimination is the outcome of enacted and perceived stigma which means that discrimination often follows stigmatizing behaviours. Behavioural manifestations of stigmatization include dehumanization, discrediting, discounting, aversion, avoidance, ostracization, social rejection and depersonalization of persons through labeling and branding. People Living with HIV are stigmatized based on how they acquired the infection and their physical condition (having sores, Kaposi's sarcoma and wasting).

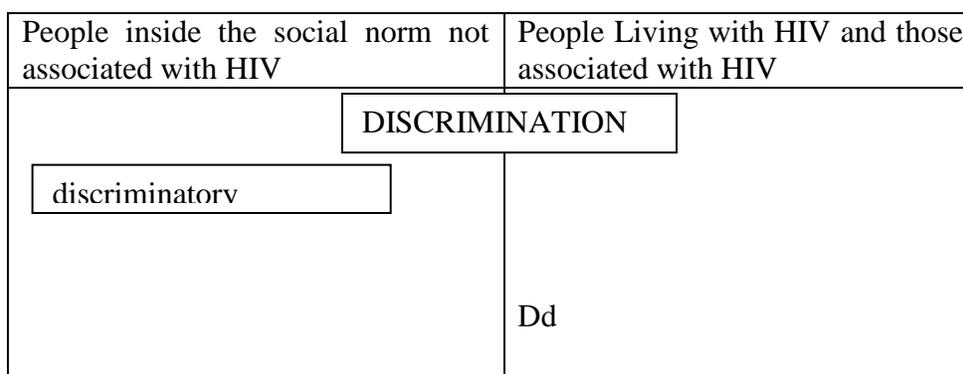
HIV-related stigma and discrimination often results from fear of becoming infected through casual contact such as shaking hands, eating from the same utensils and sharing toilet facilities. This is fear of infection

can be credited to ignorance and lack of knowledge regarding the disease. HIV-related stigma and discrimination also result from perceived responsibility of becoming infected. People respond with pity to those who are infected through blood transfusion or from mother-to-child transmission, they however have less pity for those who are infected through what they term “immoral behaviour”. Stigma and discrimination among health care providers include disclosing patient’s HIV status to other health care professional, testing of patients without their consent and putting patients at the back of the ward.

Stigma and discrimination can result in many negative consequences for People Living with HIV. Some of these consequences are fear of finding out one’s sero-status, fear of disclosure and self stigma. Leary & Schreindorfer, (1998) posited that people may hesitate or resist to be tested for HIV, because they are afraid to become stigmatized and afraid of the social repercussions if they are tested positive. People Living with HIV fear disclosure for a number of reasons. These include becoming the target for gossips and taunts, loss of social contact, loss of personal income, loss of jobs and lack of understanding on the part of the person he/she discloses to. People Living with HIV often reduce contact with people who are close to them. People Living with HIV perceive themselves as victims of a deviant behaviour. However, some of the literature reviewed indicated that there is evidence of changing values,

together with increased pragmatism, care and compassion by health care providers. Moreover, increased familiarity with patients with the disease can help most health workers to feel more comfortable working with people with the virus.

Diagram (1) below was adapted from PAHO (2005) and it shows the effect of HIV-related stigma and discrimination on society and individuals.



### **CHAPTER 3**

#### **RESEARCH METHODOLOGY**

This study was conducted among final year professional nursing students from four (4) nursing schools in Guyana. These nursing schools were: St. Joseph Mercy School of Nursing which is privately owned by the St Joseph Mercy Hospital and is located in Georgetown; Georgetown School of Nursing located in Georgetown, Charles Rosa School of Nursing located in Linden and New Amsterdam School of Nursing located in New Amsterdam Berbice. The latter three (3) schools are government owned. These schools are tasked with the responsibility of preparing student nurses, who are between the ages of 16 - 25 for the world of nursing. On successful completion of the programme student nurses are

promoted to professional and assistant nurses and are distributed to the various hospitals across the country.

The purpose of the research was to explore the issue or claim that stigma and discrimination exist among health care professionals in Guyana. In an effort to explore this phenomenon, the attitudes and perceptions of professional nursing students towards People Living with HIV were examined.

### **3.1 Methodology**

Approval to conduct this study was sought from the Chief Nursing Officer (ag.), Ministry of Health and Administrator of the St. Joseph Mercy Hospital. The quantitative (survey) and qualitative (focus groups) approaches were used for data collection and analysis.

According to Green (2005) research topics in public health often generates a lot of questions that requires more than one method to address them adequately. Therefore, for this research, the qualitative method was used in tandem with the quantitative data collected to help validate the research finding. The data collected was validated using *triangulation*.

Triangulation is built on the assumption that using two different 'readings' of one phenomenon will improve accuracy (Wolff et al. 1993). Wolff et al. (1993) further posited that when surveys and focus groups are concurrently designed and implemented they provide asymmetrical but independent observations of the study population that strengthen the ability to draw conclusions as well as confidence in the conclusions themselves. This theory was substantiated by Neuman (2003) who posited that these methods or styles have different complementary strengths and since there is only partial overlap, a study using both methods is fuller and more comprehensive.

## **3.2 Review of Theoretical Concept**

### **3.2.1 Theoretical Foundation of the study**

The theoretical underpinnings in this study were symbolic interactionism and positivism. Symbolic interactionism explores the understanding of culture. It is an approach of understanding and explaining the society and human world (Crotty, 2006). It deals with the use of language as a tool for verbal communication and also includes non-verbal communication. This theory stems from pragmatist philosopher and social psychologist, George Herbert Mead whose work was accredited to Blumer, (1969). Symbolic interactionism has its genesis in pragmatism (way of rendering ideas clear). According to Blumer 1969 cited in Crotty 2006, there are three basic interactionist assumptions:

- Human beings act toward things on the basis of the meanings that these things have for them.
- The meaning of thing is derived from, and arises out of the social interaction that one has with one's fellows.
- The meanings are handled in, and modified through, an interpretive process used by the person in dealing with things he encounters.

The symbolic interactionism approaches utilized in this study were the dramaturgical approach. The dramaturgical approach which is associated with Goffman (1963) seeks to explain interaction between individuals (actors) and society. The theory views the actors and society as an active process and it is the responsibility of the actors to interpret the social world in which they live. Social meaning of things is derived from interactions between individuals (actors) and society. Human behaviours are based on symbols and HIV/AIDS is one such symbol. Therefore, HIV/AIDS can have different meanings based on the social context and way it is interpreted by individuals.

The positivist philosophical tradition is used for inquiry in the natural and social sciences and has much influence in nursing and medicine. Positivism assumes that reality is stable (is always the same, whoever is looking at it) and that research ought to measure observable

features of that reality (Green, 2005). According to Neuman (2003), a positivist approach implies that a researcher begins with a general cause-effect relationship logically derived from a possible causal law in general theory.

The theories I reviewed and described above are pertinent to this study. Although they are grounded in two different philosophical traditions; they support the two approaches (qualitative and quantitative) used in this study. I saw these approaches as viable because social issues do not always conform to only one approach. Therefore, the approaches, will improve the validity and accuracy of the findings. The social issue addressed in this study was HIV-related stigma and discrimination. This issue can affect health seeking behaviours of People Living with HIV (not wanting to access care and treatment). It can also influence health care providers' attitudes and perceptions of People Living with HIV.

### **3.3 Design of Study**

Data were collected using both the quantitative (survey) and qualitative (focus group) methods of data collection. For the quantitative method, a cross-sectional design was used. This method was used because it is fast and a large sample can be used with a minimal cost to the researcher. Also, the researcher does not have to worry about patients dropping out during the course of the study. Questionnaires for the

quantitative component of this study were developed using questions from the following two articles:

(1) Development of a brief scale to measure AIDS-Related Stigma in South Africa by Kalichman, S.C., Simbayi, L. C., Jooste, S., Toefy, Y., Cain, D., Cherry, C., & Kagee, A. (2005).

(2) "Can we measure HIV/AIDS-Related Stigma and Discrimination?" by Nyblade, L. & MacQuarrie, K. (2006).

There were twenty-six (26) questions per questionnaire which included demographic and stigma type questions using the Likert-type scale (summated-rating or additive scales). The Likert-type rating scale was chosen because it is commonly used in studies and according to (Green, 2005), the scale is the most appropriate method used when measuring attitudes (see appendix 1). For each questionnaire, four choices were given for respondents to rate; these were "strongly agree," "agree," "disagree," and "strongly disagree." The questionnaires were divided into two (2) sections: Demographics and the stigma type questions which basically addressed attitudes towards People Living with HIV, knowledge of HIV and fear of transmission.

An interview guide was developed for the focus group discussion with the nursing students. The guide was adapted from a research done on "The Dynamics of HIV-related stigma and discrimination in Guyana"

conducted by Choy, Jacobs and Thomas (2008). Ten (10) interview questions were used to ascertain the interviewees understanding of stigma and discrimination; manifestation of stigma and discrimination which include lack of confidentiality, isolation, fear of transmission and values, norms and moral judgment; and consequences of stigma and discrimination which include fear of disclosure and self-stigma (see appendix 2).

The researcher found the instruments very useful since they were used in previous research efforts to gather information on stigma and discrimination and measure attitudes and perceptions towards People Living with HIV. These instruments are effective when measuring respondents' attitude since they allow the respondents to express themselves. Disadvantages of these instruments are: for questionnaires - low levels of literacy and unfamiliarity in filling questionnaire and focus group discussions – data collected can be time consuming to analyze and it is time consuming. The other method which I examined for this study was participant observation. This instrument however was not used because given the nature and sensitivity of my research topic, it would require the researcher to be discreet in gathering the data and follow the student nurses over a long period of time. The instruments used were very simple and user friendly.

### 3.4 Sample and Sampling Procedure

The primary purpose of sampling is to collect specific cases, events, or actions that can clarify and deepen understanding (Neuman, 2003). For the purpose of this study, the researcher used the non-probability or *nonrandom* sampling method to gather data. The purposive or judgmental sampling technique was selected for this study.

In an effort to conduct the research, a request was made to the nursing instructors via the Chief Nursing Officer, Ministry of Health for the government nursing schools and the Matron of the St. Joseph Mercy Hospital. The total number of students in the final year professional nursing programmes from the four (4) schools was eighty-six (86) at the time of the data collection. The researcher had requested ten (10) respondents from each nursing school however, the nursing tutors of two nursing schools requested that all the final year students be surveyed. The nursing students were selected by the nursing instructors for the study. See breakdown of sample size below:

1. Twelve (12) - St. Joseph Mercy School of Nursing
2. Ten (10) – Georgetown School of Nursing
3. Ten (10) – New Amsterdam School of Nursing
4. Twenty-two (22) – Charles Rosa School of Nursing

The researcher was introduced to the student nurses by the nursing instructor at the nursing schools. After the introduction, a background on the purpose of the study and some personal information about the researcher as well as the research assistant were given. The researcher took an assistant to the schools to assist with the recording of the focus group discussions since permission was not given by the Ministry of Health for audio recording. After the introductions, the students were encouraged to ask questions about the research, the researcher and the research assistant. The researcher felt this would have made them comfortable and willing to participate in the study.

The interviewees were assured of confidentiality prior to the commencement of the focus group discussions. For the focus group discussions, a focus group guide was used (see appendix 2). The discussion lasted for approximately one (1) hour and was very interactive with a few student nurses wanting to dominate the discussion. The manual recording of the focus group discussion was very tedious since both the researcher and assistant were new to the process. Respondents were asked often to repeat their answers to the interview questions since their responses were sometimes not clear. After the focus group discussions, structured self-administered questionnaires were distributed for completion. Fifty-four questionnaires were distributed to the respondents and all were completed and returned to the researcher. (See appendix 1)

### **3.5 Data Analysis Techniques**

The data collected for the quantitative component of the study was analyzed using SPSS (Statistical Package for Social Science) version 12.0. SPSS is a widely used program for statistical analysis in social science. It is used by researchers in marketing, health, education and other social sectors. The data collected was inputted into the database. The data was presented and analyzed using tables, graphs and charts (see pages 41-48).

The transcripts of the data collected by the researcher and assistant for the qualitative component of the study were collated and typed electronically. The researcher then printed and read a hard copy of the data in detail making line by line notes and highlighting the notes based on the aspect of stigma and discrimination the respondent was referring to e.g. fear of infection, isolation of patients, lack of confidentiality. Upon completion of this aspect, the researcher reverted to the electronic copy and with guidance from the hard copy, cut and paste the extracts from the transcripts under various themes. These themes are discussed in chapter 4.

### **3.6 Process of research**

HIV/AIDS is still a sensitive issue in Guyana. To study the attitudes and perceptions of student nurses was a challenge for the researcher. Some of the respondents were shy and reluctant to provide

information during the focus group discussion and had to be coaxed by the researcher. On the other hand, many of the respondents were very vocal and knowledgeable of the topic. They engaged the researcher during the discussion and at times dominated the discussion. One thing that was found to be very interesting was that a few respondents did not know anyone living with the virus. This was revealed by respondents at three of the four nursing schools used for the study. The researcher felt that with a 2.4% infection rate in the country, respondents would have known someone who was infected.

## **CHAPTER 4**

### **ANALYSIS OF DATA**

The research questions were analyzed from survey and focus group discussions conducted among final year nursing students of four (4) nursing schools in Guyana. The research questions are as follows:

- ✚ Do student nurses perceive HIV-related stigma and discrimination to be a problem in Guyana?
- ✚ Do student nurses stigmatize and discriminate against People Living with HIV?
- ✚ How do student nurses perceive People Living with HIV?
- ✚ How does the nursing curriculum influence their attitudes towards and perceptions of People Living with HIV?

Unfortunately, the researcher was not able to access relevant data from the school administrators of the Government run schools to answer question 4 since permission was not granted by the Ministry of Health for the researcher to review the nursing curriculum. However, based on discussions with students and professional nurses, the researcher was informed that HIV and AIDS are taught as part of subjects such as Pediatrics, Gynecology, Personal and Community Health, Anatomy and Physiology, Clinical Nursing, Nutrition, Health and Safety and management of the client and not as a separate module.

The analysis comprises two (2) sections: Section one (1) deals with the quantitative analysis of the data collected and section two (2) deals with the qualitative analysis. In section one (1), HIV-related stigma and discrimination were examined in three (3) main categories. These were attitudes of student nurses towards People Living with HIV; knowledge of HIV and fear of transmission. In addition to these categories, demographic data along with data on self stigma were collected and analyzed. The data on self stigma was collected since the researcher felt that most of the stigmas reported were often directed at self stigma which is self-hatred, guilt and shame that can be expressed as depression and despair and can lead to withdrawal from family and social life. The demographic data provided background information on the respondents. For section one (1),

the analysis of the data collected was presented in tables and graphs using uni-variate analysis. The uni-variate analysis examines one variable at a time - the responses were analyzed based on each question in the questionnaire. In the uni-variate analysis, responses were quantified using numerical data. The output of the data analysis was expressed in percentages. These percentages were used to interpret the data. In section two (2), HIV related stigma and discrimination were analyzed under various themes in accordance with qualitative data analysis.

## **Section 1**

### **1.1 Socio-demographic characteristics of the respondents**

Data collected on the socio-demographics of the respondents were analyzed and presented in the Table 1. 88.9% of the respondents were female with the majority, 44.4% belonging to mixed race. 79.6% were not married and Christianity accounted for 85.2%. Of those who attended religious services, 53.7% attend fairly regularly.

Table 1 –Respondents socio-demographic characteristics

<b>Demographics</b>	<b>Frequency(n=54)</b>	<b>Percentage</b>
<b>Sex</b>		
Male	6	11.1
Female	48	88.9
<b>Marital Status</b>		

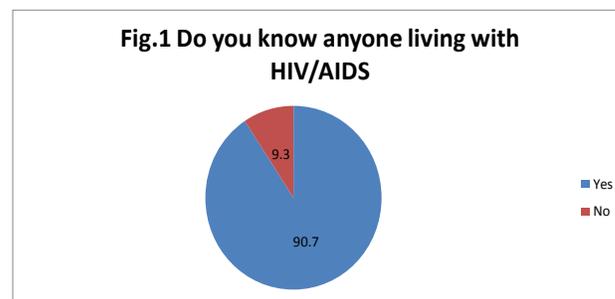
Married/ Common Law Single/ Dating	11	20.4
Single/Dating	43	79.6
<b>Have Children</b>	<b>12</b>	<b>22.2</b>
<b>Ethnicity</b>		
African	18	33.3
East Indian	7	13.0
Amerindian	5	9.3
Mixed	24	44.4
<b>Religion</b>		
Christian	46	85.2
Muslim	1	1.9
Hindu	4	7.4
Other	2	3.7
Not Stated	1	1.9
<b>Attend Religious Services</b>		
Never	1	1.9
Occasionally	24	44.4
Fairly Regular	29	53.7

This socio-demographic data has provided a background of the respondents and guided the researcher in further analysis and interpretation of the data collected. It provided possible perspective on the respondents' attitudes and perceptions of People Living with HIV. It is unclear how the demographic constitution of the study population may have impacted on the results. It is possible that the low representation of Hindus and Muslims among nursing students may suggest that the characteristics of these groups where stigma related attitudes and practices are concerned have not surfaced. Further study however is needed to clarify the impact of religion and ethnicity on stigma and discrimination in Guyana.

## 1.2 Knowledge of HIV/AIDS

Of the fifty-four student nurses sampled, an overwhelming majority knew someone living with HIV and AIDS (90.7%). These were likely to be patients (44.5%); whilst others knew friends and relative (see figures. 1 and 2).

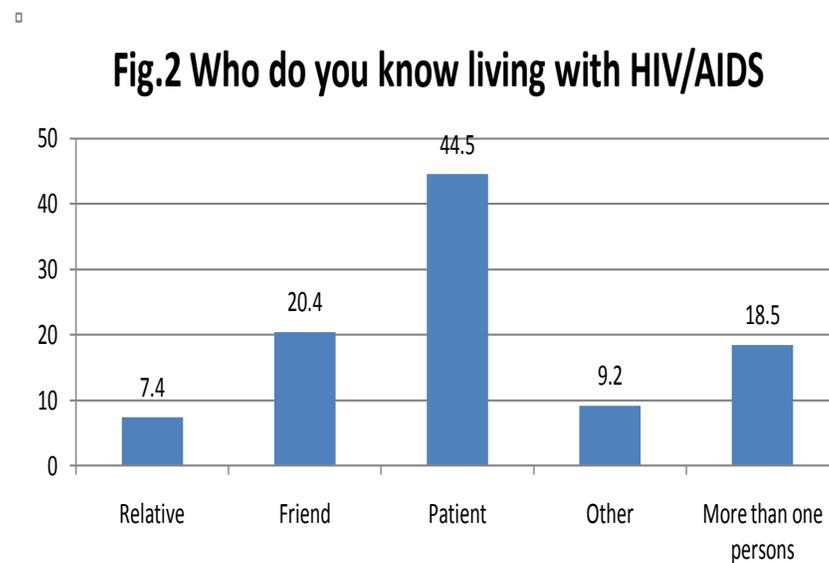
Fig 1 – Knowledge of People Living with HIV



Given this high knowledge of someone who is infected as well as the relationship with those who were infected, it suggests that HIV for these student nurses is not strange, since they have been in contact with people living with the virus. It can therefore be reasonable to expect that

these respondents would have been less likely to stigmatize and discriminate against those who are infected.

Fig 2 – Respondents who know someone living with HIV/AIDS



### 1.3 Attitudes of respondents towards People Living with HIV

Student nurses had mixed attitudes to People Living with HIV (PLHIV). They did not agree that HIV was a gay disease, nor did they feel that PLHIV should suffer the consequences of their actions (Table 2). They were however concerned about People Living with HIV having children, 72.2% strongly disagreed. Based on the response, it may be that they were concerned about transmission of infection to unborn children or that they were expressing discriminatory attitudes. The information suggest, the respondents were not very knowledgeable on the ways to reduce mother to child transmission such as the Prevention of Mother-to-child transmission (PMTCT) which has coverage of 85 % in Guyana. In this programme, pregnant mothers who are HIV positive are placed on antiretroviral therapy from 36 weeks of their pregnancy. The babies are also placed on therapy within 72 hours of birth. Additionally HIV exposed children are screened for HIV using DNA PCR (Polymerase Chain Reaction) from as early as 4 weeks of age.

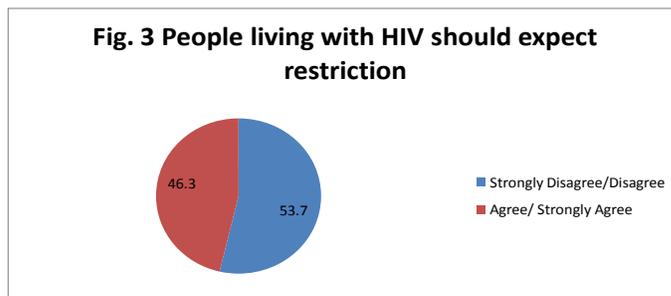
Table 2 – Attitude towards People Living with HIV

<b>Attitude towards people living with HIV</b>	Frequency (n=54)	Percentage
<b>People Living with HIV should suffer the consequence of their actions</b>		
Strongly Disagree/Disagree	52	96.3
Agree/strongly Agree	2	3.7
<b>People who have HIV are gay</b>		
Strongly Disagree/ Disagree	50	92.6
Agree/strongly Agree	4	7.5
<b>People Living with HIV should have children</b>		
Strongly Disagree/ Disagree	39	72.2

Agree/strongly Agree	14	25.9
Not Stated	1	1.9

If however their concerns were related to discrimination, they would be expressing views that contradict the convention of Human Rights Laws which states that People Living with HIV have a right to marry and to found a family (Office of the United Nations High Commissioner for Human Rights, 2006).

Fig.3 – Restriction of People Living with HIV



The results indicated that (46.3%) of the respondents agreed that People Living with HIV should be restricted. Restriction in this sense means participation and activity restriction/limitation (having sexual relationships with non-infected persons). The respondents felt that People

Living with HIV will infect others if they are allowed to interact with them. The response seems to be a strong discriminatory attitude and likely to suggest that the respondents are not fully knowledgeable of the modes of transmission. More educational programmes should be done to educate persons on the modes of HIV transmission. Restriction of People Living with HIV can result in denial, depression and failure to disclose one's HIV status which can lead to increased infection among the population. Any restrictions on the on the basis HIV status, are discriminatory and cannot be justified by public health concerns (Office of the United Nations High Commissioner for Human Rights, 2006).

#### **1.4 Fear of HIV Transmission**

The results have shown that 66.7% of the respondents agree/strongly agree that it is safe for People Living with HIV to work with children whilst 88.9% agree/strongly agree that they are comfortable assisting or being assisted by a colleague who is HIV infected. 79.6% are comfortable sharing a bathroom with a colleague who is HIV positive and 61.1% are comfortable performing an invasive procedure on clients whose HIV status is unknown. 92.6% are comfortable touching the clothing or belongings of clients known or suspected to have HIV. In examining the most frequent mode of HIV transmission among health care workers,

55.5% agree/ strongly agree that health care workers could be infected through work related exposure.

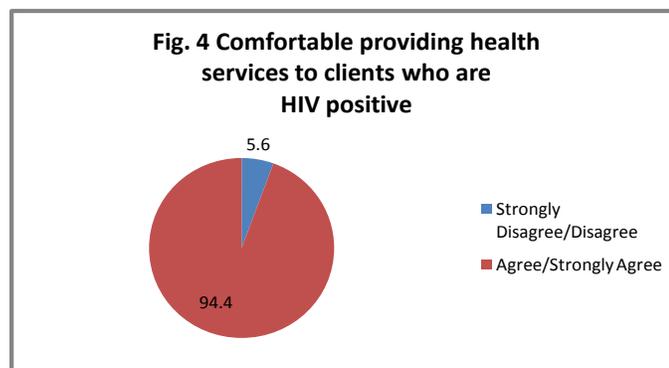
In examining the results from table (3) below, it suggested that the respondents are comfortable being around and caring for People Living with HIV and have portrayed non-discriminatory attitudes. However, the results are in contradiction to those in fig.3 which dealt with restriction of People Living with HIV since almost half of the respondents (46.3%) felt that People Living with HIV should be restricted. The findings indicate that although the respondents are comfortable providing services, they are fearful of contracting the infection because of the stigma associated with the infection and also, HIV is viewed by many to be a death sentence.

Table 3 – Fear of HIV Transmission

<b>Fear of HIV Transmission</b>	<b>Frequency (n=54)</b>	<b>Percentage</b>
<b>It is safe for people who have HIV/AIDS to work with children</b>		
Strongly Disagree /Disagree	18	33.4
Agree/ Strongly Agree	36	66.7
<b>I am comfortable assisting or being assisted by a colleague who is HIV infected</b>		
Strongly Disagree /Disagree	6	11.1
Strongly Disagree /Disagree	48	88.9
<b>I am comfortable eating from someone who is HIV positive</b>		
Strongly Disagree /Disagree	25	46.3
Strongly Disagree /Disagree	29	53.7
<b>I am comfortable sharing a bathroom with a colleague who is HIV positive</b>		
Strongly Disagree /Disagree	11	20.4

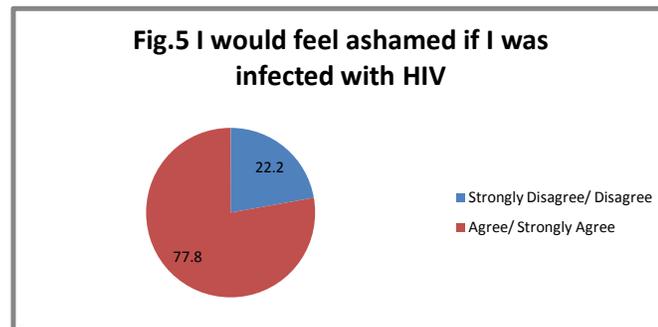
Strongly Disagree /Disagree	43	79.6
<b>I am comfortable performing an invasive procedure on clients whose HIV status is unknown</b>		
Strongly Disagree /Disagree	21	38.9
Strongly Disagree /Disagree	33	61.1
<b>I avoid touching the clothing or belongings of clients known or suspected to have HIV for fear of becoming infected</b>		
Strongly Disagree /Disagree	50	92.6
Strongly Disagree /Disagree	4	7.4
<b>The most frequent mode of contracting HIV among health workers is through work related exposure</b>		
Strongly Disagree /Disagree	24	44.4
Strongly Disagree /Disagree	30	55.5

Fig. 4 – Respondents who were comfortable providing health services



The results indicated 94.4% of the respondents are comfortable providing services to People Living with HIV. The result suggests that the respondents showed non-discriminatory attitudes.

Fig.5 – Respondents who were ashamed to live with HIV



The result shows that 77.8 % of the respondents said they would feel ashamed if they were infected. This result is directed towards self stigma. According to Bos (2001) citing Crocker et al. (1998), the awareness that one's identity is devalued in the eyes of others may be a threat to one's self-esteem.

## Section 2

This section deals with the qualitative analysis of the key findings from the focus group discussions. The discussions were analysed around themes related to HIV/AIDS stigma and discrimination. The discussions examined the respondents understanding of HIV/AIDS-related stigma and

discrimination; sources and manifestations of stigma and discrimination which include, lack of confidentiality, isolation and desertion, fear of transmission and values, norms and moral judgement of People Living with HIV and consequences of HIV/AIDS-related stigma and discrimination which include, fear of disclosure and self stigma.

Four focus groups discussions were held with a sample size of fifty-four student nurses. The transcripts of the data collected were collated and typed electronically based on the nursing schools from which they were collected and based on the questions asked in the interview guide. The researcher then printed and read a hard copy of the data in detail making line by line notes and highlighting the notes based on the aspect of stigma and discrimination the respondent was referring to e.g. fear of infection, isolation of patients, lack of confidentiality. Upon completion of this aspect, the researcher reverted to the electronic copy and with guidance from the hard copy, cut and paste the extracts from the transcripts under various themes.

The report in this section seeks to highlight the respondents' feelings and experiences as it relates to stigma and discrimination of People Living with HIV from the individuals (actors) and societal perspective.

## 2.1 Understanding of HIV/AIDS-related Stigma and Discrimination

Most of the respondents had a clear understanding of stigma and discrimination as discussed in the literature and felt that it is a problem in Guyana. They understood that the words were related but different and that stigma leads to discrimination. One respondent mentioned that stigma has a negative connotation. According to the respondent, stigma is *degrading or devaluing and labeling an individual (putting persons in categories such as gays and sex workers and excluding them from society)*. This was similarly put by Goffman (1963) who posited that stigma often results in the reduction of a stigmatized individual or group from a “whole and usual” state to a spoiled and despicable one. Weiss & Ramakrishna (2001) also posited that stigma is a social process or related personal experience characterized by exclusion, blame, or devaluation which results from poor social judgment about a person or group

According to some respondents, stigma is the attitude towards someone living with the virus whilst discrimination is the action or behaviour.

*I think that because of the person gender or what they believe in or maybe because of this condition you treat them differently than a normal person.*

*It means to talk against or to have a negative attitude towards that individual living with HIV.*

*The person is shunned or seen as an outcast in society and treated differently than others. That's mostly discrimination.*

*It is a negative approach to someone living with HIV.*

Some respondents also described stigmatization of individuals by name calling such as “*you get de truck*”. Similar findings were found in Mc Lean, (2004) who posited that People Living with HIV were targets to derogative name calling such as, “big truck” and “Aidsie”. One respondent mentioned that the two terms are difficult to distinguished and concluded that there was no difference between the terms. Also, some respondents concluded that stigma and discrimination cannot be removed until a cure is developed for the infection. One respondent stated:

*Don't think we could stop stigma and discrimination in this time maybe years to come when a cure is developed.*

Most of the respondents felt that the major causes of HIV-related stigma and discrimination are as follows:

1. Poor education about the causes of HIV.

2. Myths about the infection e.g. if there is no blood visible during sexual intercourse HIV is not transmitted
3. Ignorance with regards to transmission.
4. Fear of transmission of the disease
5. Lack of knowledge and information
  - Persons are listening but not hearing the information that are available
  - Persons not taking information and putting it into practice
  - People are not aware about HIV and condom usage especially in Region 1 (Barima Waini) and parts of region 10 (Linden/Soesdyke Highway).
  - Lack of communication (persons are not sharing the information with others who need to know).
6. The disease cannot be cured.

Despite the afore-mentioned, it is important to note that one respondent felt that due to the many educational programmes done by the Ministry of Health there is not much stigma and discrimination in Guyana.

Stigma and discrimination are not new; these concepts are as old as history. Pre-existing stigma and discrimination were associated with not only medical issues but also social issues such as gender, class, race, sexuality and poverty. HIV/AIDS is the latest disease to be discriminated against. The responses given are in keeping with the findings of Sontag, (1998) who posited that there are major similarities between the two

words and include some of the negative social reaction to diseases such as leprosy, mental illness, physical disabilities, cancer and even suicide.

Falk (2001) helps us to understand this phenomena by positing that all societies will always stigmatize some conditions and behaviours because doing so provides for group solidarity by delineating “outsiders” from “insiders”.

## **2.2 Sources and manifestation of stigma and discrimination**

Stigma and in particular discrimination is manifested in many forms. The study examines the following forms:

- Lack of confidentiality
- Isolation and desertion

### **2.2.1 Lack of Confidentiality**

This is a serious issue in the Guyanese society. People living with the virus are fearful that if their HIV status is known by health care providers, other persons in the society will know. Hence, they act as though they are not infected and continue to live normal lives and refuse to access treatment. The focus group discussions revealed the following information.

*When people discriminate, people tend not to want come and get help which is a problem because without help life is shorter.*

*Despite the education on HIV/AIDS you still find that persons are not willing to go out and get treatment. Even though there is education on an individual basis society still not accepting someone who contracted HIV.*

*Clients refuse to go to the hospitals for treatment because they fear they would be pointed out and would prefer to go to a centre out of the district where no one knows them.*

*HIV counselors are not holding patients' confidentiality, do not treat them nice and this prevent them from accessing medication.*

One respondent mentioned that she used to talk about HIV infected persons before studying nursing. During the discussion, the issue of shared confidentiality was discussed. This is a term widely used by care-givers who care for People Living with HIV. It is said to be a way of sharing the patient's information with colleagues who are a part of the care process for the person living as HIV. The respondents provided their version of shared confidentiality:

*When we see things on the floor we would come down and discuss it among ourselves. We relate how they got infected and learn from them but we don't go out the group and talk about them.*

*Some HIV patients are aggressive (may want to bite or scratch you when providing care) and there is a need to inform other nurses about their behaviour and status.*

*HIV infected persons status are shared with colleagues in order to safeguard each other. Nurses don't disclose HIV positive status of patients to nursing students rotating on the wards of the hospital.*

Despite the issue of shared confidentiality, it was mentioned that gossip is a common occurrence among many health care providers. According to some of the respondents, health care providers gossip about People Living with HIV “**all the time**”. One respondent reported:

*Some health care professionals who are in the profession for a number of years still do not maintain confidentiality.*

One respondent concluded “*you cannot stop persons from gossiping about persons with HIV*”.

Roseval, (2007) in his study on HIV/AIDS Stigma and Discrimination among Nurses in Suriname found similar traits where some nurses in the study had passed information about patients HIV status

to their colleagues and members of the public. Failure to respect confidentiality by clearly identifying patients with HIV/AIDS and revealing their status appear to be problems in some health services (Singh, 1991). This according to Major & O' Brien (2005) is one of the most common forms of societal stigma and can occur in various locations such as workplace, health care, education, and even in families.

Confidentiality is very important to preserving human rights of individuals including persons living with and affected by HIV/AIDS. Lack of confidentiality by health care providers was found to be in breach of the Revised National Policy Document on HIV/AIDS in Guyana on Medical and Ethical considerations which mentioned "All health personnel who may be privy to information on the individual's condition must hold personal information concerning individuals with HIV infection and/or AIDS in strictest confidence. This obligation endures after death (National AIDS Committee, 2006, pg.9 para. 2.1.2)

### **2.2.2 Isolation and Desertion**

Many respondents reported isolation of People Living with HIV both in and out of hospitals. Some of their comments were:

*There was this guy when his family found out he was HIV positive, they put him out and he lived by himself. He was ill and had nobody to care for*

*him, his family deserted him. It had this little shack that belonged to his brother where he lived.*

*Someone lives at the Night Shelter because he has no home to live and he's sick.*

*A young man was warned about having a relationship with an HIV infected female but ignored the advice and got involved with the girl. He later was HIV positive and when the persons who had warned him about getting involved with the girl found out he was HIV positive they stopped talking to him.*

*A patient was discriminated by his family who would usually 'chase' him back to the hospital after his discharge.*

*There was a man who was admitted to hospital with a stroke and his wife was very supportive. She visited during visiting hours with meals and clean clothing and interested in providing care for him. When she found out that he was HIV positive she immediately stopped visiting. Contact was made to her via telephone informing her of his death, she told the caller to contact his mother.*

*A patient died on the ward and no one (relatives) visited him despite numerous telephone calls by the nurses.*

*I know someone with HIV. The wife was being unfaithful but it was the husband who was also unfaithful who had contracted HIV. The wife only knew when she asks her lover to do an HIV test. The husband had put his wife out of the home after abusing and humiliating her. He had blamed her for contracting the virus.*

Isolation of HIV patients was found to be present at the Georgetown Public Hospital. Respondents at the Georgetown School of Nursing revealed the following:

*HIV patients don't get much attention when on the wards at the hospital (GPHC).*

*While at the MOPD (Medical Out- Patient Department), I met an HIV positive patient whose relatives don't want him to live with or use the same cup with them. He was seen by one of his fellow colleague at the clinic (HIV treatment centre) who told other employees and they kept away from him.*

Although, the respondent did not go into detail about the treatment of HIV patients in the wards at the Georgetown Hospital, a study done by Walton et al, (2005) among HIV/AIDS patients found, thirty-two percent

(32%) of the respondents felt that they were not attended to regularly by health care workers while twenty-one percent (21%) said they were isolated from other patients and thirty-one percent (31%) complained of excessive precautions used when being cared for.

Two respondents also gave examples of self-isolation:

*A young girl was infected and isolated herself to the point where she did not access treatment and subsequently died.*

*A young boy who was infected and had sores and abscesses on his skin was constantly being hit in the head at school by other students. He subsequently was depressed, isolated himself and died.*

Isolation of HIV positive persons are not new and often degrades the individual and can cause more pain and suffering than the actual disease. A study done by Mehendra et al. (2007) found, HIV positive patients' beds were placed at the end of the room or next to the toilet, cloth screens were placed around the patient's bed, and the patients were placed in a separate ward or room (Mehendra et al. 2007, p.5)

Although the respondents reported lack of confidentiality including gossip and isolation of patients among health care providers, all of them

reported that health care providers do not deny patients medical treatment and care. Despite the reports of isolation, one respondent provided a positive report in relation to someone she knows living with the virus.

*I know a guy whose family did not desert him but supported him. He's still alive I saw him a few days ago.*

Studies have found that in an effort to avoid stigma and discrimination, many individuals tend to hide their infection by isolation themselves. Bos, 2001 citing Jones et al. 1984, reported that negative reactions can be avoided if the individuals are able to hide their condition, or when the condition itself is not evident. This negative attitudes and behaviours can lead to what Goffman called “spoiled identify”. Spoiled identity according to Goffman reduces a person confidence and self esteem resulting in the affected person being ashamed and withdrawn from society. This is evident for HIV and AIDS when health care providers breach the code of ethic by indulging in gossip.

### **2.2.3 Fear of transmission**

Majority of the respondents mentioned that prior to receiving HIV education; they were fearful of HIV and used more than one pair of gloves when caring for patients during their first and second year. They reported the following:

*Before knowledge, I wore more than one pair of gloves when providing care for HIV infected persons.*

*Initially during the first and second year young students are not matured enough to deal with the situation e.g. some may not want to willingly provide care for HIV infected persons once their HIV status is known.*

*There is some amount of fear of being around a person who is HIV positive. You don't want to be apart of it. Or where you would try to provide some kind of support but you don't want to be apart of this stigma and be discriminated against.*

*Before I had so much education and so much knowledge about HIV I always thought that HIV happens to persons who had multiple sexual partners. People never use to say they have HIV but you use to be the one to say that persons had HIV and because of that you use to keep yourself away from that person not realizing that the person needs the same things you need. You need love and you need support and you need a job. I used to discriminate and stigmatized.*

*When you weren't educated enough you thought that by being among the persons, there is something that will cause you to get it. Once I was stuck (when I just started) and since then I have this fear. I don't want to deal with sharps because if you get stuck I feel I can become infected.*

*Because of their physical appearance, I did not want to hug, hold or shake hands.*

*I fear contracting other diseases that can be contracted from HIV positive persons.*

*You don't always know if the person is HIV positive so you have to use protection.*

Universal precautions must be adhere to when caring for patients whether HIV positive or not. “All health care workers must take precautions to protect themselves and patients from transmission of the HIV. These precautions must include satisfactory hand washing, proper handling of specimens, the use of appropriate protective apparel and the proper disposal of needles and other sharp instruments (National AIDS Committee, 2006, pg.18 para. 2.5.8)

Many of the respondents reported that they are not ashamed to be associated with someone living with the virus and will care for an infected relative. However, some of them were afraid of touching body fluids such as sweat and saliva whether the patients were infected or not. Two of the respondents' views were:

*Because of the body secretion I am fearful, blood could be caught in the saliva, semen and breast milk.*

*I am afraid of touching anybody's saliva whether HIV positive or not.*

The stigma and discrimination related to HIV/AIDS has its genesis in the existing fears about contagion and disease. This is linked to earlier perceptions of the disease as death, shame and guilt. These perceptions have increased the fears and therefore reinforce the stigmatization and discriminative treatment meted out to those living with the virus. People are afraid of contracting the disease because it is life-threatening and there is no cure. According to Hong et al. (2004), HIV-related stigma results from fear of becoming infected through casual contact such as shaking hands, eating from the same utensils and sharing toilet facilities. This fear feeds their belief that staying away from an infected person will prevent the transmission of HIV. Similar responses were given by the respondents.

#### **2.2.4 Values, Norms and Moral Judgement**

According to researchers, people were of the view that those who became infected due to “moral misconduct” should be “avoided or excluded from society”. They are labeled as “degraded,” “deviant” “bad”. Whereas those who became infected due to circumstances beyond their

control such as blood transfusions or by their infected spouses were categorized as “unlucky.” Persons were usually sympathetic and supportive of persons from the latter group (Hong et al., 2004; Bos, 2001 & Mc Lean, 2004). Similar findings were found in the focus group discussions:

*Many persons think HIV is spread only by persons who have numerous sex partners, drug users and homosexuals. They feel people with multiple partners as well as homosexuals are responsible for the spread of it.*

*In the Guyanese community in my opinion if the females are HIV positive, they get the blame for it. The males don't get the blame for it. For most of the times the female has to be the bad partner.*

The lifestyles of individuals were discussed and persons living with the infection were blamed for their lifestyles as follows:

*“Wild persons”, those having sex with every “Tom, Dick and Harry”*

*I know a friend who is HIV positive and face both advantages and disadvantages. The HIV infected person got a job with no discrimination but was discriminated by friends who threw hints at him such as “he wild”, “he got de truck”, “he didn't like to hear”.*

*With all the information available about HIV and AIDS when someone decides to go and live risky lifestyles they should be blamed.*

*Single persons having unprotected sex every night and knocking about no one asked for it but they know it is a high risk.*

*Those who say, "She is safe I can't get the virus" and have unprotected sex with the 'safe girl'*

*Those who are not prepared to use a condom.*

*Sometimes you look at the age of the person and make assumptions e.g. if a school girl is infected right away you say she was "bus riding"*

Many of the respondents felt sympathy for persons who have contracted the infection through the following methods and see them blameless:

1. Babies who got it from mother
2. Persons being transfused with HIV infected blood
3. The faithful partners who get infected from the other partner who was sleeping around should not be blamed.

The respondents were asked whether they think HIV is a punishment from God. Two persons responded as follows:

*“I feel so sometimes. Sometimes I wonder if it’s God way of slowing down persons who know about HIV and still living reckless lifestyles”*

*Sometimes I want to think it is some kind of plague.*

One respondent mentioned that one of the HIV messages advertised on the radio and television which “big up’ people with HIV give the impression that HIV is a cool thing and you should not be ashamed. To her, the advertisement was sending an incorrect message and was promoting HIV and promiscuous lifestyles. The researcher will however like to disagree with this statement. The Ministry of Health who develop and promoted the advertisement meant the reverse of the respondent views. The ministry had promoted numerous advertisements and conducted numerous workshops over the years to educated people on the issues of stigma and discrimination. The message actually portrayed that People Living with HIV can live normal and healthy lives.

HIV/AIDS is often associated with marginalized groups and behaviours and therefore, individuals who are HIV positive are often assumed to belong to marginalized groups hence they are stigmatized and discriminated against. For example, a woman who is HIV positive may be viewed as a sex worker or living a promiscuous life. A man who is

infected may be viewed as a homosexual since from the discovery of the disease, it was associated with homosexuality.

### **2.3 Consequences of stigma and discrimination**

Stigma and discrimination can result in many negative consequences for People Living with HIV. Two of these consequences found in the focus group discussions were fear of disclosure and self stigma.

#### **2.3.1 Fear of disclosure**

Leary & Schreindorfer, (1998) posited that people may hesitate or resist to be tested for HIV, because they are afraid to become stigmatized and the social repercussion if they are tested positive. This was echoed by the respondents in the focus group discussions.

*When persons become infected with HIV and they know or fear stigmatization it prevent them from telling persons or going and seek help and they want to continue spreading the disease.*

*Persons don't want to disclose their status because of fear. I also feel that they won't tell their families. Mostly the health workers would know and because people will discriminate against them, they stand alone with this disease instead of having cooperation from their families.*

To put the respondents in the place of the People Living with HIV, they were asked whether they would inform their loved ones if they were infected. The respondents had mixed feelings about disclosing their status. Some said they would disclose their status to their loved ones only if they were comfortable with the relationship. Others felt that they would need the support from their loved ones so they would disclose their status. One person mentioned that she will tell her partner and ask him to get tested. Four respondents mentioned that they cannot tell their parents and grandparent. According to one, her grandmother with whom she lives with might cry to death. Another person said that she will put it over in a case scenario to see their (loved ones) reaction before disclosing. A few respondents said they will inform their loved ones if they (loved ones) become infected.

The sharing of information about HIV status by the person living with HIV with others remains a matter of individual choice. However, this practice should be encouraged through appropriate counselling and education and through the creation of a supportive environment and appropriate services to those affected by this disclosure (National AIDS Committee, 2006, pg.10, para. 2.1.5).

### **2.3.2 Self stigma**

In examining self-stigma, the respondents were asked whether they would be ashamed if they or a loved one had HIV/AIDS. Most of them mentioned that they would be ashamed if they were infected for the following reasons:

- Fear of being discriminated
- Afraid of what people would think and say
- Persons would have their own point of view and not even think about the way I get the disease.
- People associate HIV infected persons with having multiple sexual partners and may say “She is like that”, “But she know better”
- People still think HIV is a curse and it is for a certain group of persons and so they’ll be thinking of my family that way.
- As nurses the stigma would be more. As a health worker taking care of people it will be embarrassing if you do not protect your self. Also persons would not want you to take care of you.
- I think I would deteriorate fast because you are preaching what to do and then get it.

Two respondents mentioned physical violence towards the persons who infected them. One comment was:

*I will look for the person who gave me the disease and kill them.*

Another person mentioned personal violence - *I will kill myself.*

It is important to note however that none of the respondents mentioned they would be ashamed if a loved one was infected and said they would care for and defend them. Two respondents stated:

*I will be defensive against persons who may want to stigmatize and discriminate against them.*

*I will say to people “don’t even go there” if they are about to talk negatively about my relative.*

One respondent mentioned that when you work in the wards where AIDS patients are placed, you are stigmatized.

*When persons know that you work in the wards with HIV patients, they approach the nurses on the road asking, “who deh in deh?”*

Self-stigma exists when people are aware of the infection and its effects on them. Sociologist, Goffman (1963) posited that stigmatized persons will agree with the stigma and apply it against themselves, suffering low self-esteem.

In concluding this chapter, it was found that the respondents demonstrated a clear understanding of the terms stigma and discrimination. The respondents felt that some of the major causes of stigma and discrimination in Guyana were fear of contagion, myths surrounding infection and lack of knowledge. An overwhelming majority of student nurses demonstrated high level of knowledge on HIV and AIDS. This high level of knowledge was derived from educational programmes in and out of training, association with relatives, friends and HIV infected patients. This has led to a large majority of the respondents in the study expressed non-discriminatory behaviours towards people living with HIV. They mentioned that they were comfortable providing health services to HIV positive patients. However, the fear of contagion has led many of the respondents to conclude that restrictions should be placed on People Living with HIV.

Lack of confidentiality, isolation and desertion were found to be present in health institutions especially the Georgetown public hospital. It was reported that HIV positive patients do not get much attention on the ward and health care providers do not hold patients information in confidentiality. Self-stigma was also reported by the respondents. Many of them indicated that they will kill themselves and the person who infected them.

## **CHAPTER 5**

### **DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS**

The study was representative of the nursing population in Guyana where the majority of nurses are Afro-Guyanese. The study will be discussed according to the research questions to provide insights to the attitudes and perceptions of the student nurses in relation to HIV/AIDS stigma and discrimination. Fifty-four student nurses participated; forty-eight females and six males. The majority (44.4%) was of mixed race and

belongs to the Christian religion. Except for a few persons, most of the respondents knew someone living with the virus.

**1. Do student nurses perceive HIV-related stigma and discrimination to be a problem in Guyana?**

Data collected in the qualitative and quantitative components of this study has suggested that the respondents felt stigma and discrimination to be a problem in Guyana. They gave examples of stigmatization and discrimination from their personal and related experiences. HIV-related stigma and discrimination are demonstrated in labeling, isolation, disclosure of People Living with HIV status and self stigma. They have cited a number of factors which they felt contributed to negative behaviour trait such as lack of knowledge and fear of transmission.

The Medical Out-Patient Department of the Georgetown Public Hospital was cited as one of the health institutions in Guyana where stigma and discrimination occurs. Stigma and discrimination has led to People Living with HIV refusing to visit the health care facilities in their area of residence to access treatment which can prolong life due to fear that their status will be disclosed by health care providers. Due to stigma and discrimination, People Living with HIV are isolated by family members, friends, spouses and health care providers.

People are afraid to have contact with People Living with HIV especially when there are visible signs and symptoms on their bodies. Society also views People Living with HIV as “wild” and reckless especially young girls and some view the disease as a plague and/or punishment from God.

## **2. Do student nurses discriminate against People Living with HIV?**

Many of the respondents demonstrated non-discriminatory attitudes towards People Living with HIV. The majority (94.4%) of them were comfortable providing health services, touching the clothing and belongings, eating and sharing bathroom with someone living with HIV. They also felt that it was safe for People Living with HIV to care for children and should not suffer the consequences of their actions.

Many of the respondents reported that they have discriminated against People Living with HIV during their early years of training and used more than one pair of gloves. They have however desisted from this practice due to the knowledge they now have. Most of the respondents knew a patient, relative or friend living with the virus and mentioned that they would care for and protect the infected individual. Some of the respondents mentioned that they were discriminated against when they worked the wards with HIV patients.

### **3. How do student nurses perceive People Living with HIV?**

Most of the respondents had positive perceptions of People Living with HIV. They were sympathetic to babies who got it from mother, persons being transfused with HIV infected blood and the faithful partners who get infected from their spouses who were engaging in unprotected sex with numerous partners “sleeping around” should not be blamed for their infection. Respondents mentioned that persons who engage in risky sexual practices should be blamed and are responsible for their infections.

### **4. How does their training influence their attitudes and perception towards People Living with HIV?**

This question was not addressed in the study because permission was not given by the Ministry of Health to review the nursing curriculum. Although information was received from students and professional nurses, the information could not have been used to answer because it was not made available by the official source. The information provided did inform the researcher that HIV and AIDS are not taught as a separate module but is incorporated in other modules.

## **CONCLUSIONS**

HIV/AIDS is an incurable disease and is transmitted mainly through unprotected sex. It is often associated with promiscuous life styles. Those who are infected are judged by society as being immoral, sinful and polygamous. The findings provided an insight into the attitudes and perceptions of student nurses towards People Living with HIV in Guyana. The study has revealed, the respondents were aware of and acknowledged that stigma and discrimination is a problem in the

Guyanese society and that it prevents People Living with HIV from disclosing their status and accessing treatment and care.

The major causes of HIV-related stigma and discrimination in Guyana are as a result of poor education about the causes of HIV; myths about the infection; ignorance with regards to transmission and fear of transmission of the disease. One respondent concluded that stigma and discrimination cannot be reduced until a cure is developed. This seems to indicate that high levels of fear of transmission exist. Other respondents expressed positive attitudes to person living with HIV. They were comfortable caring for and associating with persons living with the virus. They did not agree that HIV was a gay disease and felt that PLHIV should not suffer the consequences of their actions. The respondents did not believe that certain categories of persons such as babies, who contracted the virus from their mothers, faithful partners and those who contracted the virus due to blood transfusion, should be blamed for their infection.

The issue of self stigma was discussed and was found to be a serious issue among the respondents. The seriousness was evident in their body languages and was expressed verbally through comments such as: “I killing myself and I will kill the person who infected me”. Additional work still needs to be done to address stigma and discrimination of People Living with HIV in Guyana. This could be done both at the programme

and policy levels and must include a multi-sectoral approach (government, civil society and donor agencies). Training is also vital for the reduction of stigma and discrimination. Health care providers, community workers, family members as well as the People Living with HIV need to be trained/education so that those who are infected can access care, treatment and support. The print and electronic media must also be utilized to reach a wider cross section of people in addressing this issue. More researches must also be conducted to study the impact of ethnicity, religion, culture, sex etc on stigma and discrimination. New findings must be explored and implemented to help reduced the spread of stigma and discrimination. If not all the plans that the multi sectoral approach may have will be superficial as persons will not visit the various health center for treatment or disclose their status to health care providers.

## **RECOMMENDATIONS**

The researcher will like to recommend the following:

1. A study on the impact of religion and ethnicity on stigma in Guyana to provide an in-depth view on the attitude on the persons belonging to those groups in relation to stigma and discrimination. This will assist programme planners and policy makers to develop suitable programmes in response to the epidemic.

2. There needs to be stronger emphasis on nursing ethic with special focus on HIV/AIDS. HIV/AIDS with emphasis on patient care should be taught as a separate subject. This will address attitudes and perception of People Living with HIV.
3. More educational programmes should be done to educate persons about the infection. These programmes should address the modes of HIV transmission, myths surrounding the infections and other social and bio-medical issues of HIV/AIDS.

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## APPENDICES

### Appendix 1



The University of the West Indies

Masters in Education (Health Promotion)

**Student Nurses Stigma & Discrimination Survey**

**(Quantitative Questionnaire)**

*This is a survey of Stigma & Discrimination among Nursing Students in Guyana. It is being conducted by Melanie Thomas, student of the University of the West Indies. The survey is anonymous and you are free to decline to answer any question you wish. I am very grateful for your assistance.*

### **Demographics**

1. What is your sex?  
 Male       Female
  
2. What is your age?
  
3. Where do you live?-----
  
4. What is your marital Status?  
 Married     Single     Common Law     Other
  
5. If other, please state-----
  
6. Do you have any children?  
 Yes     No
  
7. What is your ethnicity?  
 African     East Indian     Portuguese     Chinese   
          Amerindian     European     Mixed     Other
  
8. To what religion do you belong?  
 Christian     Muslim     Hindu     Other
  
9. If Christian, please state denomination-----

10. How often do you attend religious services?  
 Never  Occasionally  Fairly regular
11. What is the highest level of education attained?  
 Primary  Secondary  Tertiary
12. Do you know anyone living with HIV/AIDS?  
 Yes  No
13. If yes, who?  
 Relative  Friend  Patient  Other

**The following sections deal with stigma, discrimination and personal views, therefore you are asked to provide your honest opinion. You may tick one box**

14. People who have HIV/AIDS are should suffer the consequences of these actions

Strongly Disagree  Disagree  Agree  Strongly Agree

15. People who have HIV/AIDS are gay

Strongly Disagree  Disagree  Agree  Strongly Agree

16. It is safe for people who have HIV/AIDS to work with children

Strongly Disagree  Disagree  Agree  Strongly Agree

17. People with HIV/AIDS must expect some restrictions on their freedom

Strongly Disagree  Disagree  Agree  Strongly Agree

18. I am comfortable assisting or being assisted by a colleague who is HIV infected

Strongly Disagree  Disagree  Agree  Strongly  
Agree

19. I am comfortable eating from someone who is HIV positive

Strongly Disagree  Disagree  Agree  Strongly  
Agree

20. I am comfortable providing health services to clients who are HIV-  
positive

Strongly Disagree  Disagree  Agree  Strongly  
Agree

21. I am comfortable sharing a bathroom with a colleague who is HIV-  
positive

Strongly Disagree  Disagree  Agree  Strongly  
Agree

22. I am comfortable performing invasive procedures on clients whose  
HIV status is unknown

Strongly Disagree  Disagree  Agree  Strongly  
Agree

23. You avoid touching the clothing and belongings of clients known  
or suspected to have HIV for fear of becoming HIV-infected

Strongly Disagree  Disagree  Agree  Strongly  
Agree

24. I would feel ashamed if I was infected with hiv

Strongly Disagree      Disagree      Agree      Strongly  
Agree

25. The most frequent mode of contracting HIV among health care workers is through work-related exposure

Strongly Disagree  Disagree  Agree  Strongly  
Agree

26. People Living with HIV should have children?

Strongly Disagree  Disagree  Agree  Strongly  
Agree

## Appendix 2



The University of the West Indies

Masters in Education (Health Promotion)

**Student Nurses Stigma & Discrimination Survey**

**(Interview Guide)**

1. When you hear the words stigma and discrimination, what comes to mind?-Is there a difference between the two terms [refrain from asking this – leave it up to the respondent – and then if its not clear to you use it as a ‘probe’]
2. Do you think HIV-related stigma and discrimination is an issue in Guyana?
  - a. Probe: Why
3. What role can you play to reduce HIV-related stigma and discrimination
  - a. Do you feel that you are powerless to enact a meaningful change in the way people think about PLHIV?
4. What, in your opinion, are the major causes of HIV-related stigma and discrimination in Guyana?
5. Have you ever stigmatized a PLHIV?
6. Do you know of any PLHIV who has been treated unfairly, stigmatized, discriminated against because of their illness? Follow-up: how were they treated? Were they excluded from family gatherings? Were they denied medical care? Did nurses/doctors use extra precautions when treating them? Did health care providers gossip about them?
7. Do you think PLHIV are to be blamed for their illness?
  - a. Probing questions: Do you think they deserve it because of the lifestyle they lead? Do you think HIV is a punishment from GOD? Do you think that HIV is spread only by persons who have numerous sexual partners, drug users and homosexuals?
8. Would you be ashamed if you or a loved one had HIV/AIDS?
  - a. Would you inform your loved ones if you had HIV/AIDS? Should persons be ashamed if they have HIV/AIDS? Are you ashamed to be associated with a PLHIV?
9. If a relative of yours became sick with HIV/AIDS, will you be willing to care for him/her  
Are you fearful of touching the saliva, sweat and clothing of a PLHIV?