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The Lived Experiences of Jamaican Nurses Caring for Patients with Human Immunodeficiency Virus or Acquired Immune Deficiency Syndrome in Jamaica

Blondel Martin

THE LIVED EXPERIENCES OF JAMAICAN NURSES  
CARING FOR PATIENTS WITH HUMAN IMMUNODEFICIENCY VIRUS OR  
ACQUIRED IMMUNE DEFICIENCY SYNDROME IN JAMAICA

DISSERTATION

Presented in Partial Fulfillment of the  
Requirements for the Degree of  
Doctor of Philosophy in Nursing

Barry University

Blondel Martin

2013

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2013

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## Abstract

**Background:** At the beginning of AIDS, no one could have predicted how the epidemic would spread across the world and how many lives would be impacted or changed.

Devastating families, communities, and countries, HIV/AIDS is an international epidemic crossing all oceans and all borders. HIV/AIDS patients present complex challenges for health care professionals who are at the forefront of prevention, care, and treatment. An important aspect of health care that has emerged is how nurses will adapt to these challenges and care for these HIV patients.

**Purpose:** To explore and describe the lived experiences of Jamaican nurses caring for patients diagnosed with AIDS or HIV and give voice to those nurses in articulating their own experiences to gain an understanding of the meaning of their lived experiences.

**Philosophical Underpinning:** The philosophical underpinning that will be used to guide the study is embedded in the interpretivism paradigm, which explores the meaning of a particular perspective for different individuals or group of people using a qualitative research approach.

**Methods:** A qualitative research design following van Manen's hermeneutic phenomenological traditions was used to explore the lived experience of Jamaican nurses. Data collection was obtained with the use of an audio-tape recorder to conduct semi-structured face-to-face interviews with selected participants.

**Results:** Four related themes of fear of infectiveness, transitioness, powerlessness and anger, and compassioness emerged through this phenomenological investigation. These themes illuminated the Jamaican nurses experiences caring for patients with HIV/AIDS,

and Starck's (2003) middle range theory of meaning provided a framework for gaining a deeper understanding of this phenomenon.

**Conclusion:** This research study exposed the challenges Jamaican nurses face when caring for patients with HIV/AIDS in Jamaica and their efforts to find meaning in their duties. The findings of the study highlighted the essence of their experiences by revealing that despite their fear of contracting HIV/AIDS, they displayed compassion in caring for this vulnerable population. Therefore, understanding the depth at which this experience affects health care providers can be fundamental in providing effective and culturally sensitive support to nurses.

## ACKNOWLEDGMENTS

I am truly indebted to my participants who shared their time and stories with me in completing this journey. Words cannot express my gratitude and deep appreciation for their contributions in understanding the meaning of caring for patients with HIV/AIDS in Jamaica.

I want to thank my doctoral committee who offered me support and guidance in my pursuit of this degree:

*Dr. Jessie M. Colin*, my committee chair. I wish to extend my sincere gratitude for continued guidance, encouragement, and support along this journey. The strong faith and belief placed in me helped to propel me in succeeding. Thank you for the challenges to persevere and overcome the many obstacles that I faced. The confidence you placed in me and the words of wisdom shared fueled my desire to complete my dream. I thank you.

*Dr. Ferrona Beason and Dr. Paula Delpech*, my committee members. Special thanks for your tireless efforts in reading and rereading this dissertation, guidance, and encouragement along the steps of this journey. As I accomplish this monumental educational task, your words of wisdom were cherished and always welcome.

*My family and friends*, I have been overwhelmed with your prayers, support, patience, love, and understanding; I thank you. My fellow colleagues of the “*The Palm Beach Cohort*” your support and encouragement helped me to fulfill my dream. To my friends Caroline Smikle and Ronica Subramoney, we started the educational journey together, cheering each other on until the very end: “Congratulations, we made it!”

## **DEDICATION**

To my Heavenly Father who reminded me each day “I can do all things through Christ which strengtheneth me” (Philippians 4:13. KJV).

I share this accomplishment with my wonderful sons, Jordan and Tyler, who loved me endlessly throughout this journey, even when I forgot the birthday cakes. I love you.



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## CHAPTER ONE

More than three decades have passed since the disease Acquired Immune Deficiency Syndrome (AIDS) and the associated virus, human immunodeficiency virus (HIV) were first identified by the United States Centers for Disease Control and Prevention. AIDS is now classified as a chronic, life-threatening condition caused by the human immunodeficiency virus, which damages the immune system and decreases the ability of the body to fight infections (Centers for Disease Control and Prevention, 1999). The World Health Organization (WHO) estimated in 2009 that there were more than 33 million people worldwide living with HIV/AIDS with three million new HIV infections reported in 2009 and more than two million deaths as a result of the disease (The WHO & AIDS, 2009). The primary means of transmission for HIV/AIDS is blood-borne through sexual contact, exposure to infected needles, and through the administration of infected blood or blood products. Any exposure to contaminated blood or secretions can increase the risk of becoming infected with the virus (Lyons, 2009).

Individuals in our society continue to react strongly to those diagnosed with HIV/AIDS. Fear of contagion and associated behaviors such as homosexuality, drug addiction, and prostitution that are stigmatized by our society provide fodder for discrimination worldwide (Herek & Capitanio, 1993).

Discrimination will impact HIV/AIDS prevention and care worldwide. In the Caribbean, the prevalence of AIDS is among the highest in the world (Rutledge, Abell, Padmore, & McCann, 2008). Health care professionals in Jamaica believe this impact to be so severe that many individuals consider suicide when they are first diagnosed. Rooted in the fear of isolation and discrimination, these suicidal ideations come as a

result of having others finding out about their disease, not necessarily from the potential agonizing death associated with the disease (White & Carr, 2005).

Nurses are the largest professional group caring for patients diagnosed with the disease. The stigma and fear of contracting the disease has helped to contribute an elevated level of stress and duress among nurses. Some nurses have considered changing their profession to avoid caring for these unfortunate patients. Discrimination by medical professionals has a direct impact on access, utilization, and quality of care for people affected with the disease (Wiley, Health, Ackline, Earl, & Barnard, 1990).

The attitude of nurses caring for people living with HIV/AIDS has been further examined. The result of their negative attitude is their reluctance to provide care to infected individuals. Unfortunately, poorer quality of nursing care is the usual result (Pickles, King, & Belan, 2009). However, thankfully, there are nurses who believe in providing comfort and support to those living with HIV/AIDS. By educating patients, staff, and family members, more nurses provide extraordinary care to infected people and their loved ones (Valimaki et al., 2008). Nurses in general may share the same values and goals in their daily tasks, but education, ethical responsibilities, and cultural values may vary according to country of residence. This phenomenological inquiry explored the lived experiences of nurses who care for HIV/AIDS patients in Jamaica.

### **Background of the Problem**

At the beginning of AIDS, no one could have predicted how the epidemic would spread across the world and how many lives would be impacted or changed. Devastating families, communities, and countries, HIV/AIDS is an international epidemic crossing all oceans and all borders. Related illnesses to the disease have caused the deaths of more



than 30 million people since 2010. Currently, there are approximately more than 34 million people living with HIV, the virus that causes AIDS, as indicated by Figure 1 (UNAIDS, 2010).

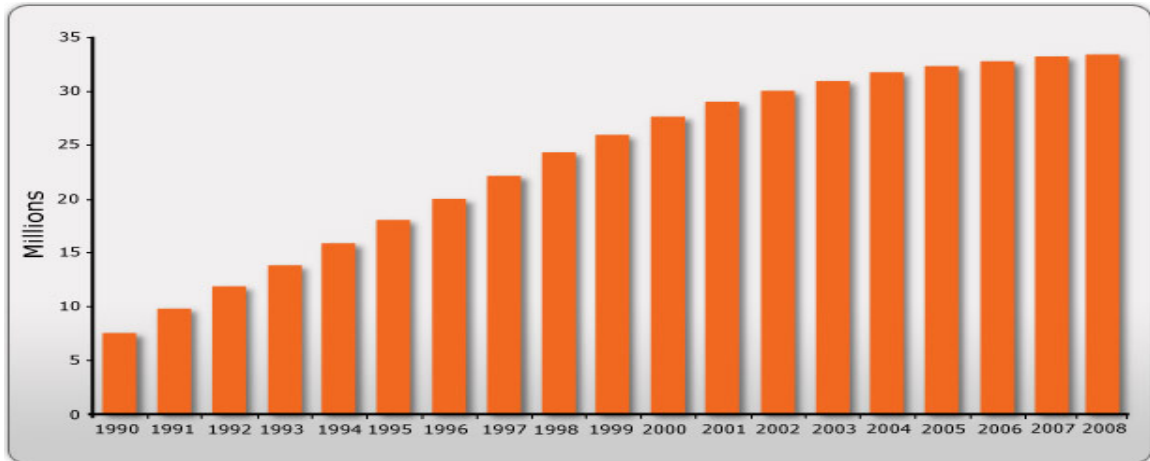


Figure 1. Global number of people living with HIV by years (UNAIDS, 2010).

### **Globally**

Caring for AIDS patients continues to be a major problem for many countries. On the continent of Africa, where some of the poorest countries in the world are located, the impact of HIV/AIDS has been more severe. Presently, more than 22.9 million people are infected with the virus. The World AIDS Day global report estimated that by the end of 2009, there were more than nine African countries, where more than one-tenth of their population was affected. In many of these countries, at least one adult in five is living with the virus. South Africa, part of this cluster of nations, has more people living with HIV than any other African country. Plagued with lack of appropriate health care and basic needs, this country has seen more deaths associated with AIDS than other diseases. Women account for more than 50% of those affected, commonly contracting the disease through sexual encounters (UNAIDS, 2010).

Asian countries, such as China, Thailand, and India, reported that more than 4.8 million people are living with HIV. The epidemic has affected particularly high-risk groups, such as homosexual men, IV drug abusers individuals involved in the sex trade, and subsequently their partners. The mobility and migration of people within these countries associated with the increase in the sex trade industry and use of illegal drugs have helped facilitate the spread of the HIV virus (UNAIDS, 2010).

There has been a rapid increase of 250% in the number of people living with the HIV virus in Russia, Eastern Europe, and Central Asia. In 2001, less than half a million people were affected, but by 2010, an estimated 1.5 million people were identified to be living with the disease. The use of illegal drugs and sharing of contaminated needles is the number one method of transmission in these countries. Sex workers primarily have an overlapping habit of drug use as well as participating in unsafe sexual behavior contributing to the epidemic (UNAIDS, 2010).

Initially uncovered in the early 1980s in the United Kingdom, there has been with a steady increase in the number of individuals diagnosed with HIV infections. The Health Protection Agency reported that by the end of 2009 there were more than 86,000 people living with the HIV virus, and 6,000 new infections were diagnosed by the end of 2010. The first groups of individuals affected in the early discovery were men who have sex with men (MSM), Intravenous (IV) drug users, and recipients of blood products. However, by 1999, the major contributor to the rapid increase had changed to heterosexually acquired infections. Although the number of AIDS-related cases and deaths decreased with the introduction of antiretroviral medications, subsequently, the

number of people living with HIV infections has increased steadily as reflected in Figure 2 (Health Protection Agency, 2010).

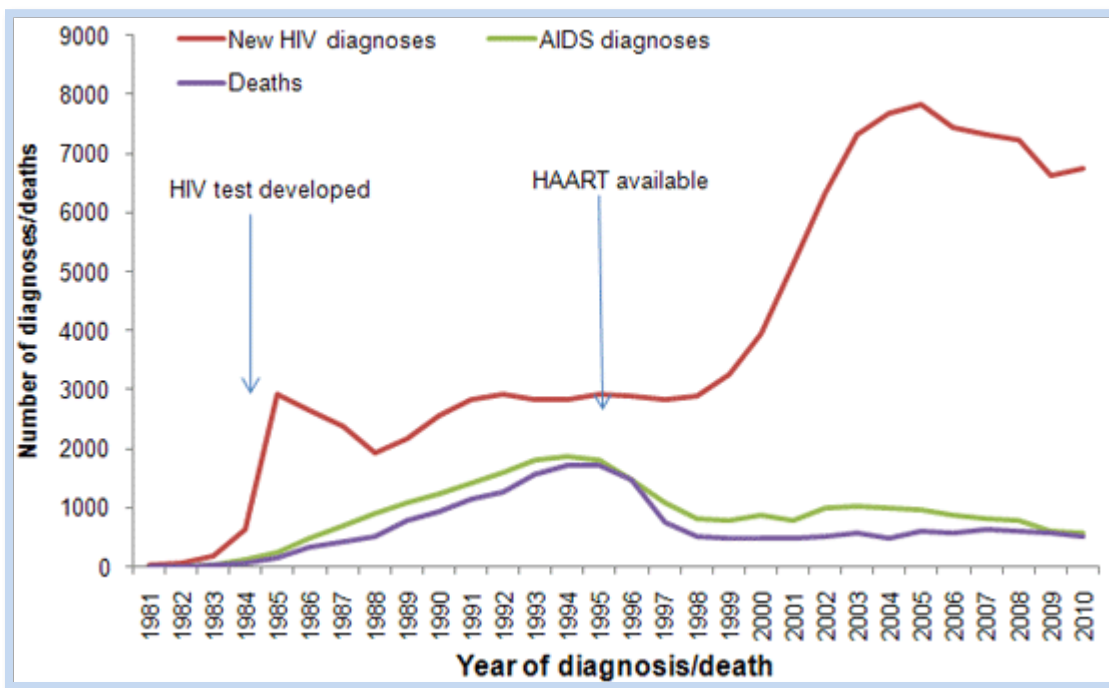


Figure 2. Trend of HIV/AIDS in United Kingdom (Health Protection Agency, 2010).

The experiences of nurses have been documented in many studies. Nigerian nurses were hesitant to care for HIV/AIDS patients who were admitted with significant burns to a burn unit. The contact with these patients caused a heightened fear of contagion. This ultimately resulted in fewer nursing interventions and as a result poorer patient outcomes (Olaitan, Dairo, & Ogbonnaya, 2005). Moral biases, negative attitudes, and the fear of contracting the disease were some of the described feelings of nurses working in a Swedish hospital. These factors resulted in some nursing staff declining to care for HIV-infected patients (Rondahl, Innala, & Carlson, 2002).

### **The United States**

One of the most developed countries in the world, the United States (U.S.) has been significantly affected by the HIV/AIDS epidemic. The Centers for Disease Control

and Prevention (CDC) has estimated that more than one million people are living with HIV infections in the U.S. More than half a million individuals have died since 2009. Among women, the highest method of transmission was through heterosexual contact, while in the male population, it was through male-to-male sexual contact. Similar to the effects of the use of antiretroviral medications in the United Kingdom, there has been a decline in the numbers of deaths but an increase in the number of people living with HIV infections within the United States as seen in Figure 3 (CDC, 2010).

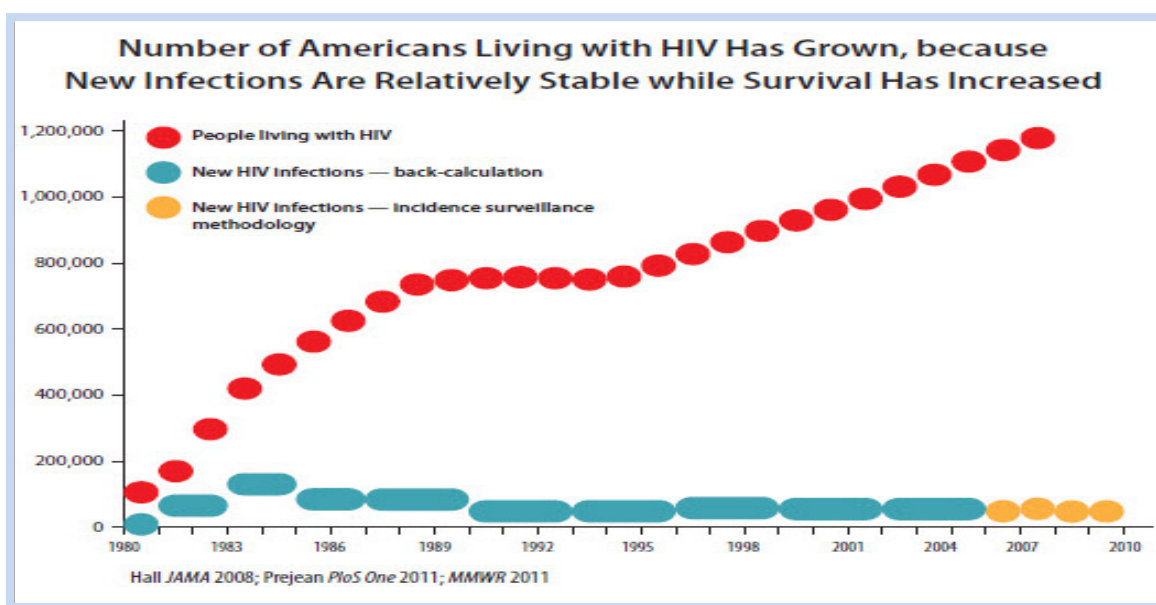


Figure 3. Number of Americans living with HIV (HIV Prevention in the United States High-Impact Prevention: Saving Lives and Money, 2011).

Now viewed as a chronic illness, the infected population is rapidly increasing in age, creating long-term care issues. Concerns about contracting the disease, negative attitudes displayed toward patients, and maltreatment of patients were some of the findings reported. In one reviewed study, nurses provided care that was considered below acceptable standards (Hueston & Pearson, 2004). Health care professionals,

including nurses, have identified inadequate and inappropriate care as a common problem in care giving experiences for patients with this disease (Mullins, 2009).

### **Caribbean**

There is not one area of the world that this devastating disease has not affected. The Caribbean nations account for more than 250,000 people living with HIV, and more than 12,000 deaths from AIDS-related illnesses have occurred since 2009. The main route of transmission in the Caribbean is through unprotected sexual activity. A plethora of issues have contributed to the high prevalence and vulnerability to HIV and AIDS in the Caribbean. Included in these issues is sex being a taboo subject in family discussions, causing subsequent early promiscuity, homophobia, and economic disparity as well as the stigma of the infection (WHO/UNAIDS/UNICEF, 2010).

Efforts are being made to decrease the prevalence and limit the impact by providing antiretroviral medications through the cooperation of the Pan Caribbean Partnership with various pharmaceutical companies. Although access to therapy is readily available in this region, there are some countries such as the Dominican Republic, Haiti, and Jamaica where less than 50% of those in need receive any sort of treatment (WHO/UNAIDS/UNICEF, 2010).

### **Jamaica**

The island of Jamaica is the third-largest island in the Caribbean and is located approximately 600 miles south of Florida, southwest of Hispaniola, and south of Cuba. Jamaica, once under the British rule, has an English-speaking population close to three million. Many of the cultural and moral values are deeply rooted in Christianity. These values guide the social norms. Health care consists of both modern medicines and

cultural rituals. Traditional values use fruits, vegetable, and herbs for healing measures. Naturalistic medicines are very popular in this country with herbal medicine practitioners providing treatments for a variety of ailments (Witherbee, 2011).

Like any country, Jamaica is faced with multiple diseases that significantly impact its health system. Health care in Jamaica, free to all of its citizens, is provided at government hospitals and clinics. However, these underfunded government hospitals and clinics often have long waiting lines and insufficient medical personnel. After waiting all day seeking medical care, many individuals are eventually turned away. Private physicians and clinics are available throughout the country, but insurance coverage and out-of-pocket fees can be costly (McCaw-Binns & Moody, 2001).

HIV/AIDS is one of the major diseases affecting this country. Currently, there are more than 25,000 individuals living with HIV, and there have been more than 1,500 deaths, according to the World Health Organization (WHO, 2010). Heterosexual contact is the main mode of transmission, commonly associated with prostitution within the country as well as bisexual men who transmit the disease to their female partners. However, transmission of the disease through intravenous drug use is very rare on the island (White & Carr, 2005).

Recognizing that HIV/AIDS finally reached Jamaica in the early 1980s, the Jamaican Ministry of Health implemented programs to further educate health care providers as well as the public. The need to involve all sectors of society in combating this disease was the establishment of the National AIDS Committee (NAC) in 1988. The responsibility of NAC was to increase the awareness of the disease in both the private

and public sector, such as religious, health care, and community organizations, through HIV/AIDS outreach programs (Figueroa et al., 2008).

Examining the response to HIV/AIDS in Jamaica, Figueroa et al. (2008) in their study concluded that although the Jamaican Ministry of Health supported national programs to combat the disease, some political and local leaders were unwilling to speak about the disease. This further fostered fear and ignorance toward the disease, increasing the strong stigma associated with AIDS. Many health professionals were so fearful of the disease that they became reluctant to get involved in HIV prevention or AIDS care.

Because of the strong association between AIDS and sexual deviant behavior, those infected with HIV are routinely ostracized by their families. HIV-positive individuals are considered “dirty,” a concept describing people who have participated in sexual activities with prostitutes or homosexuals. Because of this association, most HIV-positive Jamaicans did not consider themselves vulnerable to the virus prior to being infected (White & Carr, 2005). The common assumption is that “HIV infection and AIDS happened to other persons like homosexuals and sex-workers and not to a normal person like me” (Figueroa et al., 2008, p. 572).

White and Carr (2005) examined the relationship of homophobia to HIV/AIDS-related stigma in Jamaica. They found that there is a strong and consistent relationship between them. The result is a reluctance of individuals to get tested, seek treatment, or reveal their HIV status to their partners. The health care workers stated that infected individuals who contracted the disease through heterosexual activity are tolerated by the community, but if they were suspected of being homosexual, they were often treated poorly.

Nurses in Jamaica come in contact with patients living with HIV or AIDS through two main avenues, community clinics and hospitals. The main focus of treatment strategies in the community clinics is to educate individuals about the disease and encourage methods to prevent contracting or transmitting the disease (Figueroa et al., 2008). However, individuals with the disease often do not seek care in a hospital until the disease has ravaged their bodies, and they can no longer care for themselves, which is a behavior associated with the stigma of having HIV/AIDS in Jamaica (White & Carr 2005).

HIV patients present complex challenges. The increasing number of people living with HIV in has brought an urgent need for appropriately trained nurses to provide counseling, education, and care to this vulnerable population. An important aspect of health care that has emerged is how nurses will adapt to these challenges and care for these HIV patients. As the leading health care provider, Kendall-Raynor (2006) contended that nurses are essential to counteracting the myths and stigma surrounding HIV/AIDS and ensuring equality in treatment modalities.

### **Statement of the Problem**

Even though scientific breakthroughs have made encouraging strides in the diagnosis and treatment of this disease, there still remains significant negative impact from this disease in the Jamaican society. Jamaica is considered to be an extremely homophobic Caribbean country, causing a hidden gay population. Sexual preference-based oppression in Jamaica is evident throughout the legal, health, and social welfare systems, which are populated with anti-gay biases. As a result of this highly stigmatized



disease, individuals refrain from seeking medical treatment and unfortunately continue to participate in unprotected sexual encounters (Williams, 2000).

Regardless of which region in the world an individual is living with the disease or how he or she contracted it, seeking health care is a common denominator. However, with the emphasized stigmatization of the disease, some may refrain from seeking help based upon their country of origin and what moral issues they may face. Nurses remain the number one group of health care professionals who continue to care for individuals in various stages of the disease (Kendall-Raynor, 2006).

Health care and social service providers that primarily work with HIV/AIDS individuals revealed that they are often targeted with violence by the community members as well. White and Carr (2005) in their study have found that workers have been accused of promoting homosexuality and promiscuity. These accusations came in response to a public announcement that condoms would be distributed in the prisons on the island to help decrease transmission of the disease.

With such strong aversion to the disease, health care professionals, including nurses, are reluctant to provide care to this population. As the infected population increased in Jamaica, caring for this vulnerable population became a duty Jamaican nurses were called upon to fulfill. As a result, their experiences of caring for the infected population has not been voiced, providing the need for exploration as there is limited published literature that has documented this issue in Jamaica.

### **Purpose of the Study**

The purpose of this study was to obtain a more in-depth understanding of Jamaican nurses' personal experiences in caring for HIV/AIDS patients in Jamaica. This

study's aim was to give a voice to those nurses in articulating their own experiences, feelings, and thoughts about what it is like to provide nursing care to infected patients. Through dialogue with these nurses, by exploring their personal experiences and identifying significant themes; this research may lead to a better understanding of how to care for patients. Investigating this problem from a qualitative perspective may provide the researcher with significant new knowledge, to fully describe the experience of caring for patients infected with HIV/AIDS. This study highlighted the Jamaican nurses' lived experiences and provided an expression of their life world in caring for a HIV/AIDS patient.

### **Research Question**

The question that guided this research is: "What is the lived experience of Jamaican nurses caring for patients with HIV/AIDS in Jamaica?"

### **Philosophical Underpinnings**

The decision to study, describe, ask a question, and seek answers in nursing research necessitates the need to collect and analyze some form of data in order for the researcher to come to a conclusion or interpretation. The philosophical underpinning that was used to study the phenomenon of Jamaican nurses caring for patients with HIV/AIDS is embedded in the interpretivism paradigm, which explores the meaning of a particular perspective for different individuals or group of people using a qualitative research approach. According to Creswell (2007):

Qualitative research involves an interpretative and natural way to examine the world, and allow the researcher to study things in their natural settings, make

attempts to understand or interpret a phenomenon in terms of the meanings or essence that the participants bring to them. (p. 36)

However, there are five main research approaches associated with qualitative research. They are narrative research, phenomenological research, grounded theory research, ethnographic research, and case study research. Each method has distinct and specific procedural steps when completing research. Creswell (2007) emphasized that a researcher must know when it is appropriate to use qualitative research, such as conducting a qualitative research because a problem needs to be explored, a detailed and complex understanding of the issues is needed, and the detailed information can be obtained only by conversing directly with those experienced the problem. This researcher has chosen the research method of phenomenology to explore the experiences of the Jamaican nurses as they care or have cared for patients with this incurable disease.

Creswell (2007) outlined the basic philosophical assumptions commonly associated with the qualitative perspective of phenomenology. They are ontology, epistemology, axiology, rhetorical, and methodological. The focus of phenomenology is directly studying a single phenomenon with the intention of describing the “lived experience” for several individuals. The outcome is to examine the individuals’ experience with the phenomenon and recognize any universal essence or common themes about the experiences. This description of the essence means looking for the inner meanings of what individuals experienced and how they experienced it. Rooted in the foundation of philosophy, phenomenology has been used to better understand other sciences, such as social science, health sciences, psychology, education, and nursing.

Phenomenology has become a significant dominant method in creating knowledge development in nursing as it provides credible evidence of living knowledge in nursing (Jones & Borbasi, 2004). Rather than a natural science, phenomenology is seen as a human science, with phenomenological research examining the meaning of the lived world through its subject matter. It differs from other sciences, as it attempts to gain insightful descriptions of the way individuals experience the world (van Manen, 1990).

Phenomenology has been interpreted both as a philosophy and an approach to human science research (van Manen, 1990). The philosophical aspects of can be seen in the works of German philosophers Edmund Husserl (1931), Martin Heidegger (1999), with expansions from French philosopher Maurice Merleau-Ponty as discussed by Creswell (2007). Max van Manen (1984), a Canadian social scientist and educational philosopher, viewed phenomenology more as a human science research method than a philosophy.

Widely regarded as the father of phenomenology, Edmund Husserl (1859-1938), a German mathematician, defined the term as the “science of pure consciousness” (Mohanty, 2008). His philosophical teachings indicate that the reality of the happening is only understood by the experiences of the individuals involved and ultimately leads to a search for wisdom. The experiences being investigated must be subjective, based upon those of the participants, and any objective experiences need to be eliminated in order for the research to be valid.

Discontented with natural science that studied only material things, Husserl developed a type of phenomenology called transcendental phenomenology that takes into

account conscious experiences of individuals. Transcendental phenomenology adheres to what can be discovered through reflection and is a study of the appearance of things, or phenomena just as we see them and as they appear to us in our consciousness. Husserl contended that the challenge is to explicate the phenomenon in terms of its components and possible meanings, therefore extracting the features of the consciousness and arriving at an understanding of the experiences (Mohanty, 2008).

Other philosophers have extended the views of Husserl, such as Martin Heidegger (1859-1938), whose main interest was based upon ontology or the study of being. Although fascinated with the concept, he developed his own approach known as hermeneutic phenomenology. Contrary to Husserl's theory of phenomenology as a philosophy, Heidegger viewed phenomenology as a method by analyzing human existence. He later redefined hermeneutics phenomenology as way of studying all human activities, which is the basis for interpretation, with the aim of allowing the text to speak for itself. He emphasized that the focus is on the language as the tool through which the questions can be unfolded (Heidegger, 1999).

Maurice Merleau-Ponty (1908-1961), a contemporary French philosopher, was also influenced by Husserl's and Heidegger's works. In contrast to Husserl's transcendental phenomenology, his main works focused on existential phenomenology (Dowling, 2007). Expressing his philosophical insights in writings on art, literature, and politics, Merleau-Ponty was extensively focused on phenomenology through descriptions. Unlike Husserl who focused on interpretations, Merleau-Ponty's emphasis was for phenomenologist to rediscover their world and look at their experiences prior to philosophical and scientific distortions (Earle, 2010).

Building upon the hermeneutics views of Heidegger, Max van Manen was more concerned with phenomenology as a method, rather than a philosophy. He urges researchers to view the experiences through their own lenses to understand the experiences of others, as research using phenomenology seeks to uncover the meanings or essence in our everyday existence. van Manen believes that the ultimate goal is to understand better who we are as humans. “The essence of phenomenon is universal which can be described through a study of the structure that governs the instances or particular manifestations of the essence of that phenomenon” (van Manen, 1990, p. 10).

Expanding on his theory of phenomenology as a method, van Manen encourages researchers to explore their phenomenon of interest using six main activities interrelated in completing a phenomenology research (Munhall, 2012). The aim is to understand the experience and see what themes or essences emerge.

1. Turn to a phenomenon which seriously interests us and commits us to the world.
2. Investigate the experience as we live it rather than as we conceptualize it.
3. Reflect on the essential themes which characterize the phenomenon.
4. Describe the phenomenon through the art of writing and rewriting,
5. Maintain a strong and oriented pedagogical relation to the phenomenon.
6. Balance the research context by considering parts and whole.

(van Manen, 1990, p. 30)

To produce in-depth lived-experience descriptions, van Manen (1990) further suggested that the researcher:

1. Describes the experience as you live or lived through it avoiding as much as possible causal explanations, generalizations, or abstract interpretations
2. Describes the experience from the inside as it were, almost like a state of mind: the feelings, the mood, the emotions, etc.
3. Focus on a particular example or incident of the object of the experience: describe specific events, an adventure, a happening, and a particular experience.
4. Focus on an example of the experience which stands out for its vividness, or as it was the first time.
5. Attend to how the body feels, how things smell or smelled, how they sound or sounded, etc.
6. Avoid trying to beautify your account with fancy phrases or flowery terminology. (p. 66-67)

All phenomenological research involves, as explained by van Manen (1990), “an exploration into the structure of the human life world, the lived world as experienced in everyday situations and relations” (p. 101). He suggested that there are four existential life world themes that help to guide reflection in the research process: “lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality or communality)” (p. 101).

Munhall (2012) further explained that these four existential life worlds are other dimensions needed in the processing of phenomenological information to give meaning

to the experienced phenomenon. She stated that it is important to understand that the four life worlds are united and reflect an interconnection, as reflected in Figure 4, which helps the researcher further understand the person in his or her world (p. 143).

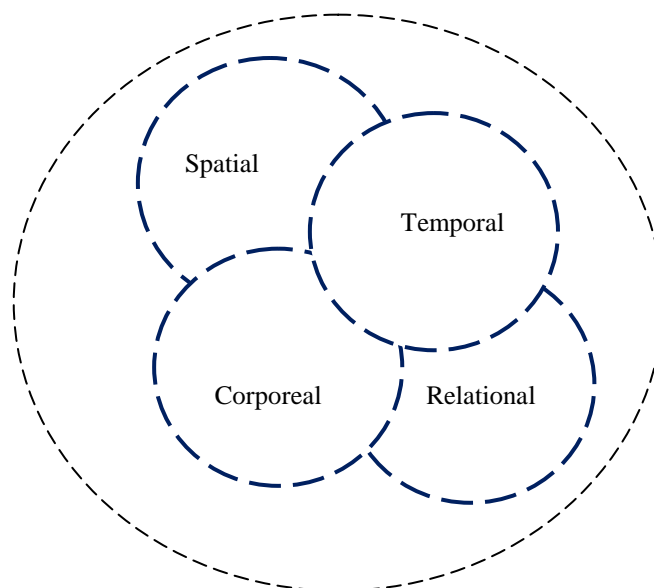


Figure 4. Four existential life worlds interconnectedness (Munhall, 2012, p. 143).

The lived space, or spatiality, refers to the space we occupy or our environment that the experiences occurred in. Investigating a phenomenon through the experiences of individuals in a particular environment can produce different meanings (Munhall, 2012). Conducting the proposed study with nurses on the island of Jamaica may present different meanings from the data to be collected. Values and cultural practices in this particular environment may have a significant impact on the caring experiences of these nurses toward patient with HIV/AIDS.

Corporeality, or lived body, refers to the existence of our body in the world, and through the unification of our body and mind, we are able to experience a phenomenon. Through this unity, perceptions are developed in the mind and can be manifested through



the body (Munhall, 2012). Perceived fear of contagion could influence the quality of care that is provided to these patients, as nurses are aware of how the natural body is affected from the disease.

According to Munhall (2012), lived time or temporality, is the time in which we are living, and our body as we know it occupy space, which is located in time. In the proposed study, this time could be related to how many interactions nurses had with these patients as they describe their experiences.

Relationality refers to the lived relations that we encounter with others in the interpersonal spaces that we may share with them. Examining relationships within the experiences being studied as articulated by the participants is very significant in the phenomenological process (Munhall, 2012). To understand the phenomenon of interest from the Jamaican nurses, the researcher must ask for their interpretations of the relationships they have experienced with these patients in order to fully understand the meaning of the experiences.

The interpretation of the study should allow the reader to understand the phenomenon and what is like for someone to experience it (Crotty, 1998). Health research is one of the most common areas for the utilization of phenomenology using human participants to help understand disease processes. The relevant population is one that has experienced the phenomenon that is being studied and is able to provide the researcher with significant information to facilitate the study. Therefore, phenomenology seeks to emphasize people's subjective experiences and how they interpret the world. Using this method a researcher can explore different populations in different settings. This type of research is appropriate to address the meanings of the lived experiences of

Jamaican nurses caring for HIV/AIDS patients in Jamaica, as it may provide the researcher with underlying meanings of the nurses shared experiences.

### **Significance to Nursing**

This study may have significance for nursing in the integrated dimensions of education, research, practice, and health/public policy. Education provides a means for nursing to understand relevant theories and concepts applicable to diverse populations that may emerge through this study. Through research, we are able to understand the phenomenon and how it impacts the delivery of care to those afflicted with this disease. Studying this aspect of the HIV/AIDS experience is significant as it may identify how important Jamaican nurses are in providing social support and care for a vulnerable population.

### **Implications for Nursing Education**

Implementing practices through education to meet the needs of this vulnerable population is very important, as the results of this study may help guide the process. From the descriptive and reflective accounts of these nurses, this process may help assist nursing educators to anticipate supportive or educational needs for nurses who serve in this capacity. With an adequate understanding of the phenomenon the possibility exists for educators to revise nursing curriculum to incorporate HIV/AIDS education to better prepare nurses to care for this population.

### **Implications for Nursing Practice**

Munhall (2012) indicates that there is no value in nursing research unless it is relevant to clinical practice. Nurses are the primary healthcare providers who come into contact with patients and are most likely to experience the described phenomenon. This

study documented and provided the experiences of these nurses, which may impact nursing interventions in caring for these patients. Understanding the experiences from the voices of these nurses may serve as a guide for other nurses to assist in implementing ethical standards in caring for these patients without any biases. Through practice, the nurses' responsibility is to carry out the social mission of contributing to the public's improved health by working toward greater client independence.

### **Implications for Nursing Research**

Through research, we are able to understand the phenomenon that is experienced and how the results can impact the delivery of care to those afflicted with this disease. Understanding the experiences through research can impact nursing interventions implemented in caring for these patients. Evidence-based research continues to be the building blocks for the nursing profession, and this study may identify other potential research topics.

### **Implications for Health/Public Policy**

Understanding the concept of caring from the perspectives of nurses in this study may provide a foundation for public policies to provide resources to meet the needs of the affected population. Having the opportunity to share their stories may empower the nurses to make a difference in the health policies in their immediate environment. Policymaking can provide a forum for these nurses to advocate for more effective standards and programs to challenge government and communities toward better health and protection from HIV/AIDS in Jamaica. Understanding the nurses' experiences may provide an opportunity for the Jamaican Nursing Council to assess and implement strategies in preparing nurses to care for this population. van Manen (1990) emphasized

that studies that described the lived experience can add a human understanding of the knowledge received, which can serve as a foundation for political action.

### **Scope and Limitations of the Study**

In this study, the objective was to gather data that support the proposed research question, the exploration of the lived experiences of nurses in Jamaica. It included nurses who currently practice on the Island of Jamaica and have taken care of patients with AIDS or HIV.

Limitation in the proposed study may be attributed to the novice experience of the researcher, as specific limitations in data collection and analysis may occur. The proposed study was conducted on the Island of Jamaica, and the researcher lived in South Florida. A significant amount of travel and time was needed to conduct this study, requiring appropriate financial resources. The interviews for the study were conducted face-to-face in Jamaica. Based upon geographic location of the researcher and potential participants, accurate and complete arrangements had to be made prior to the interview process. However, experts' experiences and advice were sought to help decrease some of the potential limitations.

### **Chapter Summary**

This chapter provided a summary of the exploratory study that used the qualitative perspective of phenomenology to understanding the meaning of the lived experience of Jamaican nurses who care for patients who are diagnosed with AIDS/HIV. Studies were discussed that highlighted the impact of this disease in countries and the impact toward health care providers. The dominant effect of this disease as it traveled across nations, reaching the Caribbean and eventually the island of Jamaica was

reviewed, revealing common characteristics associated with HIV/AIDS and health care providers. Significance of the proposed study was discussed as it relates to nursing education, nursing practice, nursing research, and health/public policy. The scope of the study was highlighted, and limitations the researcher may face were mentioned.

## **CHAPTER TWO**

This chapter will provide the context for the basis of this qualitative research study to explicate the meaning of Jamaican nurses' experiences caring for patients with HIV/AIDS in Jamaica. The purpose of this study was to obtain a more in-depth understanding of Jamaican nurses' personal experiences in caring for HIV/AIDS patients in Jamaica. This study's aim is to give a voice to those nurses in articulating their own experiences, feelings, and thoughts about what it is like to provide nursing care to infected patients.

Using the search engines provided by accessing the Barry University online library, the following computerized databases were used for this study: Cumulative Index to Nursing and Allied Health Literature (CINAHL), ProQuest, Medline in PubMed, and EBSCO. Criteria used for study selection were those published in English language in peer-reviewed journals, were primary research studies, and addressed the problem of nurses caring for patients with HIV/AIDS. Literature published between 1995 and 2011 were reviewed to provide a more current perspective of the issues. The keywords used in the searches were: nurse and caring, HIV/AIDS, literature review, nurse education, and attitudes of nurses. The following themes were identified in the review: education and knowledge of HIV/AIDS impacted care, fear of contracting HIV/AIDS, homophobia, and stigma associated with HIV/AIDS.

### **Historical Context**

As the lasting impact of this disease affects countries around the world, nurses are a common factor in caring for these infected individuals. The discovery of HIV/AIDS has prompted many countries to investigate and explore various spectrums of this disease

and how care is provided to these patients. Research studies focus on the effects of caring for these patients and how they are treated by health care providers they encounter while seeking treatment modalities. The fear of contagion is a main concern by nurses who care for patients infected with HIV/AIDS. The implementation of different educational interventions, according to researchers may have some impact on the level or type of care provided. However, other studies indicate that even with educational interventions, stigma surrounding the disease still present in the health care environment.

### **Education and Knowledge of HIV/AIDS Impacted Care**

With more than 42 million people infected globally with the HIV virus, and more than 20 million deaths, there still remains no cure for this disease. Despite the high numbers of deaths worldwide, individuals living with the disease are surviving longer as a result of the development of more effective treatments (Green, 2007). Subsequently, these individuals require care from nurses who may be reluctant to care for them.

The attitudes of nurses toward people living with HIV/AIDS have been under scrutiny for a long time, with researchers recommending improved HIV/AIDS education to assist in desensitizing the disease. Past studies have indicated that HIV/AIDS educational interventions should help decrease the negative attitudes and provide sufficient knowledge of HIV/AIDS to enable nurses to deliver safe and compassionate care to people with the disease (Taher & Abdelhai, 2011). However, one major cause of fear, negative attitudes, and reluctance to care for people with HIV/AIDS was identified as lack of education (Earl & Penny, 2003).

To understand the disease in this context, McCann and Sharkey (1998) examined the relationship between educational intervention with nurses and changes in their

knowledge, attitudes, and willingness to care for patient with the virus. Participants in the study were nurses from Australia, and other international registered nurses enrolled in a Bachelor' of Nursing course in an Australian university.

To evaluate the value of an educational intervention, a six-week course was taught that focused on knowledge, health promotion, infection control, care, and treatment of patients with HIV/AIDS, and nurses' attitudes. A total of 74 nurses completed the pre-test questionnaire, and 65 nurses completed the post-test questionnaire after the educational intervention.

The researchers found that even though educational intervention was provided for nurses, they still had certain attitudes toward caring for HIV/AIDS diagnosed patients. Findings of the study indicated that with some increase in knowledge regarding AIDS/HIV through educational interventions, there were some benefits. With an increase in knowledge, some of the nurses would care for patients with AIDS/HIV; however, the fear of contagion remained high; thus, the attitudes were still present. The researchers also identified that education should include attitudinal concerns as well as examination of conditions of work and consideration of broader cultural influences. They also confirmed that there is clearly a great need for further research and study of this problem.

Kemppamen, Dubbert, and Williams (1996) also identified the importance of education in caring for HIV/AIDS patients in their study. The purpose of the quantitative experimental study was to determine the effects of different approaches to increase nurses' willingness to provide care to patients with AIDS. The study was conducted at a 400-bed Veterans Administration hospital with 42 nurses participating in the study. The



nurses were randomly placed in three different groups: (a) three group discussion sessions about patients with AIDS, (b) three sessions of caring for patients with AIDS, or (c) an assessment tool to evaluate knowledge about patients with AIDS. The interventions were conducted by a nursing instructor experienced in caring for patients with the disease and also knowledge of infectious disease.

At the end of the three or four educational intervention period, the nurses were given questionnaires to assess if any prejudicial attitudes toward patients with AIDS exist, rate themselves about infectious disease knowledge, rate perceived comfort and confidence in caring for patients with AIDS, and measure willingness to provide care to patients with AIDS. Nurses who participated in the group discussion sessions and completed the assessment tool only were more willing to care for patients with HIV/AIDS than those nurses who had contact with the patients during the study. The result of the study indicated that the attitudes of nurses did not decrease significantly toward caring for patients with AIDS, although the educational intervention included universal precautions, changing negative attitudes, and handling prejudices.

No part of the globe has proved immune to the epidemic of HIV, and its challenges for nurses were revealed by William et al. (2006) in their quantitative experimental design study in China. The purpose of the study was to examine the effect of a HIV/AIDS educational intervention in the knowledge, attitudes, and willingness of Chinese nurses to care for patients with HIV. It included 208 Chinese nurses from seven Chinese provinces from staff to management positions.

All participants in the study were female nurses with ages ranging from 21 to 63; 59% ( $n = 123$ ) were in their 30s, and 21% ( $n = 44$ ) in their 40s, with the majority ( $n =$

138, 66%) possessing an associate degree in nursing. Forty-three percent of the nurses ( $n = 89$ ) reported caring for HIV/AIDS patients, and 42% ( $n = 87$ ) indicated at least one needle stick injury. Although the participants lived in regions of China where the disease was prevalent, 35% ( $n = 73$ ) reported that the educational intervention workshop was their first structured HIV/AIDS professional educational experience. Of the 208 nurses, 187 completed the pre- and post-workshop questionnaires.

The educational intervention consisted of a five-day workshop that included didactic lectures and discussion activities to determine participants' values and personal feelings about HIV/AIDS. Pre-test and post-test included: *HIV/AIDS Knowledge Questionnaire*, *The AIDS Attitude Scale*, and *The Nurse Willingness Questionnaire*. The results of the questionnaires indicated that the effect of the intervention was very significant ( $P < 0.001$ ), as pre-workshop HIV/AIDS knowledge was not high, and attitudes and willingness to care were neutral; however, there was significant improvement in each area in the post-test.

More recently, Taher and Abdelhai (2011) concluded that information education and communication programs are the most effective approaches in combating the HIV/AIDS pandemic among nurses. They conducted a prospective interventional design study to assess nurses' knowledge, perceptions, and attitudes towards HIV/AIDS before and after a health education intervention program. The sample was two different nursing groups at Cairo University in Egypt: post-graduate nursing staff (67) nurses and undergraduate nursing students (73).

The participants' knowledge, attitudes, and perceptions towards HIV/AIDS were assessed prior to the educational intervention. The health education intervention

consisted of lectures with active group participation using videos, PowerPoint presentations, and discussion. Each participant was asked to complete a self-administered pre-test questionnaire prior to the intervention and later complete a post-test with the same interview questionnaire after the intervention two months later. All participants who originally participated at the beginning of the study participated in the post-test. Results indicated that there was a significant ( $P < 0.001$ ) improvement in the general knowledge and perception score in the pre-test and post-test score, and the educational intervention also succeeded in improving the transmission and prevention scores. It also showed that favorable attitudes toward patients increased, negative perceptions and attitudes lessened, and knowledge of HIV/AIDS also significantly improved after the educational intervention.

In comparison to McCann and Sharkey (1998) and Kemppamen et al. (1996) studies, which indicated no change in nurses' attitudes after an educational intervention, Taher and Abdelhai (2011) and William et al. (2006) acknowledged that structured HIV/AIDS education programs provided some changes. They indicated that it helped to improve the participants' knowledge, decrease some of the existing negative attitudes and misconceptions regarding the disease, and increase nurses' willingness to care for patients with HIV/AIDS.

Each article was analyzed and provided the general consensus that education is the empirical pathway to reduce the percentage of health care providers who could potentially be affected by this disease. The expanding HIV/AIDS epidemic has challenged nurses to increase their knowledge to provide effective HIV/AIDS prevention and care to patients. The research findings indicated that educational interventions can

have some effect in changing the attitudes and willingness of some nurses in providing care to this population in various cultural and social backgrounds. However, no research data represented the voices of Jamaican nurses experiences. Therefore, further investigation is needed to explore how they care for patients with HIV/AIDS, as a thorough understanding of their experiences may reveal any knowledge deficits or gaps in the literature.

### **Fear of Contracting HIV/AIDS**

The fear of contracting HIV/AIDS has also impacted caring in various health care settings and is probably the number one factor associated with caring for patients with HIV/AIDS. With the increase of health care workers being exposed to patients in various stages of HIV or AIDS, the assumption is made that healthcare workers will eventually become infected. However, even as an occupational risk, some studies reveal that the risk remains low.

To address this concern, a public health based prospective study was conducted Kuhls et al. (1987) to investigate the occupational risk of HIV, HBV, and HSV-2 infections in health care personnel caring for AIDS patients. The sample consists of 246 female health care workers with a significant high level of exposure, 43 with a low exposure rate, and 101 with no exposure to AIDS. A detailed self-administered questionnaire was used as an instrumental tool to collect the required data. The variables identified were an estimation of intensity and frequency of exposure, and the number of infected specimen handled.

The participants were followed over a 12-month period and had blood work drawn to determine their initial HIV status and after the exposure. The result of the

findings indicated that approximately 292 of the participants tested negative within a six-month period and within the next six months remained negative. The researchers indicated that there were no differences between the participants in the high and no exposure groups. Some of the participants were not followed up as they were no longer employed at the health care facility where the study was being conducted.

During the study, random observations of the nursing staff were to done to verify the use of standard universal infection procedures during patient care. The researchers did indicate that the participants were not at any risk during the process of the study, and the results of the study confirmed that there was a very low occupational risk acquiring the HIV infection. However, they did conclude that because the transmission of HIV may be related to frequent and multiple exposure to patients with AIDS, there is need for further evaluation of the nurses who participated in the study.

A similar study by Mullins (2009) identified that the fear of contagion was a common factor among nurses who participated in a qualitative study in a rural part of West Virginia. The purpose of the study was to explore the experiences of registered nurses caring for patients with HIV/AIDS. Over 200 nurses were randomly selected through the Virginia Board of Nursing with zip codes within the rural city. They were mailed a study booklet about caring for patients with HIV/AIDS, along with a demographic questionnaire, and a request for comments regarding caring for patients with HIV/AIDS.

A total of 204 participants responded to the survey, but only 76 (37%) completed the request for comments or concerns about caring for patient with HIV/AIDS. Content

analysis, developed by Lincoln and Guba (1985), was used to analyze the written comments or concerns and identified similar themes.

There were several themes that emerged from the written responses, such as a lack of concern about HIV/AIDS because universal precautions were often used when providing care. However, the high level of stress and burnout in units that care for these patients have caused some nurses to refrain from providing care to these patients. Others recounted overwhelming emotions as they watch these patients being ostracized by family or neglect by nursing staff but still felt the need to care for them as human beings. The nurses' statements and concerns about care giving to patients with HIV/AIDS are consistently related to the risk of acquiring the virus from an occupational exposure. Even with compassionate caring, the overall results indicated that the fear of contagion remains one the biggest concern for these nurses.

In Thailand, there is no exception that the fear of HIV infection motivates negative responses to people living with HIV or AIDS by health care workers as discovered by Chan, Rungpueng, and Reidpath (2008) in their qualitative study. The purpose of the study was to examine how perceptions of risk behaviors shape health care workers' perceptions of patients living with HIV/AIDS.

Twenty semi-structured, in-depth interviews were conducted with nurses at a Bangkok nursing college. Fifty percent of the nurses were in their final year of undergraduate training, and 50% were nurses pursuing post-graduate training. Interviewed transcripts were translated into English by an independent Thai-English translator, and the transcripts were coded and analyzed for emerging themes by using NVivo. The main themes that emerged were despite knowledge that the risk of

occupational exposure to HIV is low, the fear of HIV infection among the nurses were significant. The anticipated social ostracism and rejection were also a driving force for the fear that these nurses expressed in the interviews.

Considerable fear of contracting HIV/AIDS from patients was a common conclusion from the authors in the articles reviewed. Even though the risk of occupational exposure was low, there still remains fear among the participants. The studies revealed that the perceptions of fear may be different for nurses around the world. In Jamaica, nurses caring for patients with HIV/AIDS may have a different perception. This study sought to understand Jamaican nurses' experiences as they relate to the fear of contracting the virus from their patients.

### **Psychological Stress**

Caring for HIV/AIDS patients can also have an effect on those providing care, such as nurses, parents, or other relatives who are primary caregivers. There are significant factors that affect these individuals; significant grief after death and emotional stress and psychological stress. Often, the progressive and terminal nature of the disease compounds the stress that caregivers encounter.

In a qualitative study, D'Cruz (2002) examined the experiences of the caregivers of children with HIV/AIDS. The study indicated that caregivers of these children experienced a number of stressful events related to the diagnosis of the children. The study conducted within the phenomenological perspective explored both the subjective and objective meanings and experiences from the participant's point of view. Interviews were conducted as the method of data collection using a researcher-developed interview guide.

Through purposive sampling, a number of participants were chosen with the voluntary assistance of a health sector organization working in the field of HIV/AIDS in India. Caregivers with past or present experiences of caring for HIV-positive children regardless of transmission mode were chosen. This selection resulted in 12 participants, aged 27 to 60, who were the primary caregivers for these children. The overall findings of this study indicated that the types of support that these caregivers received were the main focus of the stress associated with their situation. There was a lack in counseling services, available financial resources, limited medical resources, and support groups. The researcher concluded that there is a need for public awareness about AIDS/HIV that would diminish the stigma associated with this disease. Social support is an important aspect for caregivers of people living with HIV/AIDS as it can lessen the stress endured.

Another study that highlighted psychological stress associated with caring for people diagnosed with HIV/AIDS was conducted by Bachanas et al. (2001). The purpose of this quantitative study was to examine the significant difference in psychological functioning between caregivers of HIV-infected children and those of healthy children. This study was done from a quantitative perspective and included caregivers of HIV-infected children ( $n = 36$ ) and a control group ( $n = 32$ ). The sample for this study was obtained with permission through a pediatric clinic that treated patients with AIDS and those diagnosed as HIV positive in Atlanta, Georgia. During clinic visits, the participants were asked to complete various assessment tools that included: demographic data, stress factors, coping strategies, family factors, and psychological adjustments as they relate to caring for a child with HIV/AIDS.



The findings of the study revealed that psychological stress experienced by caregivers of the children with the disease were not less than those in the controlled group. However, the types of stress were different for each group. The caregivers of the children with the disease or diagnosis experienced society stress, while those in the control group experienced more of a financial stress. Feelings of anger and grief when the child died also increased the psychological stress that they experienced.

To further understand the issue, Sherman (2000) conducted a qualitative study to investigate the experiences of AIDS-dedicated nurses in alleviating the stress of AIDS care giving. Participants were 12 nurses from a large medical center in New York City working on the AIDS units. All participants were baccalaureate prepared nurses, with the majority having more than five years' experience working on the unit.

Data was collected and analyzed from in-depth interviews by the researcher, which yielded major themes that emphasized that nurses were aware of the risks in caring for these patients; however, they were not fearful. The results indicated expressions of commitment in caring were evident, but physical and emotional stressors were associated with care giving. The researcher concluded the emotional stress of AIDS care giving, such as witnessing the suffering of patients, dealing with unresolved grief, and being emotionally attached to patients, can produce a plethora of psychological stress for nurses. Coping strategies included balancing their personal and professional life, asking for help, and maintaining a spiritual perspective as they care for these patients.

Studies of stress and burnout in AIDS care have been done in hospitals, but Hayter (2000) conducted a descriptive exploratory study to measure the burnout rate of HIV/AIDS community nurses caring for homebound patients. Using Maslach Burnout

Inventory (MBI) tool, the researcher sought to measure the level and components of burnout in a sample of 47 community-based HIV/AIDS specialist nurses. Using a two-phase sample selection method, participants were sent the MBI questionnaire with a 77% (n = 47) response rate out a possible sample of 61 subjects.

The results of the study indicated that there was high burnout rate associated with caring for these patients in communities. The number of patients that the nurses visited has no correlation with emotional exhaustion that the nurses may have experienced. The researcher concluded that a support system is integral in assisting these nurse alleviate some of the stress and burnout they may experience.

From the beginning of the AIDS epidemic, nurses have been caring for these patients in various countries and health care systems. The articles reviewed indicated that psychological stress is a factor that can occur during nurses' interaction with patients with HIV/AIDS. Although some nurses may be dedicated to caring for this vulnerable population, researchers still believe that coping strategies are needed to help provide emotional support to nurses. This research study may allow Jamaican nurses to openly voice the meaning of psychological stress as it relates to their experience in caring for patients with HIV/AIDS.

### **HIV/AIDS-Related Stigma**

The impact of AIDS around the world has left millions dead and many more trying to survive a disease that makes them social outcasts. The populations that have being affected by this disease range from children to adults and can be found in almost every part of our world. As nations battle this disease, there is one common factor that they are facing, the associated level of stigmas that having this disease brings. AIDS-

related stigmas and discriminations exist worldwide and are manifested differently across countries. They can result in individuals being shunned by their families and communities and receiving poor treatments in health care settings.

Nigeria has an estimated 3.6 million individuals living with AIDS/HIV, and it is a common practice for health care providers to shun or neglect to provide any substantial care to these patients. Reis et al. (2005) conducted a cross-sectional quantitative study using a 104-item health care professional survey to investigate the discriminatory attitudes and practices by health workers towards patients with HIV/AIDS in Nigeria. The sample was taken from approximately 1,021 Nigerian health care professionals consisting of 324 physicians, 541 nurses, and 133 midwives who practices in health care facilities in four Nigerian states.

Data analysis was done using Stata 7, a statistical program, to compare negative practices and attitudes among the three health care providers (physicians, nurses, and midwives) in each of the Nigerian states. The results of the study identified several factors that contribute to the discrimination and stigmatization that is common in this African nation.

Fifty-nine percent of the participants agreed that people with HIV/AIDS should be placed on a separate ward or floor, while 40% believed that the HIV status of an individual could be determined by their appearance. The majority of the participants (91%) concluded that a patient's HIV status should be revealed in order to protect them, and 40% believed that health care colleagues who are infected should not be allowed to work. Some of the participants (20%) agreed that treating the opportunistic diseases associated with the disease is a waste of precious resources, while 8% of those surveyed

indicated that treating someone with HIV/AIDS is indeed a waste of precious supplies that the country cannot afford.

The researchers concluded that there were no significant differences between the groups; however, the negative attitudes were higher among individuals who worked in facilities that had limited resources or supplies to care for this population, as they felt their risks were greater. Most health care professionals surveyed comply with their ethical obligations; however, discriminatory behavior and attitudes toward patients with HIV/AIDS were prevalent among the majority of health care professionals.

In 2001, the government of Tanzania acknowledged that stigma was a key factor fueling the transmission of HIV in that country. Amuri, Mitchell, Cockcroft, and Anderson (2011) conducted a quantitative study to investigate socio-economical status and HIV/AIDS stigmas in Tanzania. Over 1,130 men and 1,803 women were interviewed for the study, from both urban and rural areas. Approximately 2,934 individuals were interviewed from 1,782 households.

A researcher-developed questionnaire examined the association between poverty and other variables, such as place of residence, education level, experience of intimate partner violence, condom-related choice disability, and how individuals obtained their information regarding HIV/AIDS. The questionnaire also assessed participants' stigmatizing attitudes and beliefs that HIV/AIDS is punishment for sinning.

Associations between the variables were analyzed using Mantel and Haenzel (1959) procedures, with the analysis of associations with stigma based on one particular statement: "HIV/AIDS is punishment for sinning." More than half of the participants (58%) agreed that "HIV/AIDS is punishment for sinning," while 20% indicated that

people with the virus or disease should live apart from the regular populations. Another 12% would not provide care for someone with HIV or AIDS, even if they had the financial means.

The researchers concluded that although the infection rate was higher in urban areas, where individuals were more educated and women most affected; higher levels of stigma were more prevalent in rural areas, where the population was poorer and less educated. Results revealed that the level of HIV and AIDS stigma in Tanzania was high with independent associations with several disadvantages: poverty, less education, and living in rural areas.

To further address this issue, similar research was conducted in Sweden by Rondahl, Innala, and Carlsson (2002) to examine the differences in the attitudes of nurses, nursing students, and nursing assistants towards HIV-infected and homosexual HIV-infected patients, after they were exposed to an HIV/AIDS educational intervention. The research method used was a descriptive, comparative quantitative design, which consisted of The AIDS Attitude Scale and a researcher-developed demographic questionnaire. The participants were nurses and nursing assistants working in an infectious disease clinic and nursing students enrolled in a university who previously had some HIV/AIDS education. The inclusion criterion was that they work directly in patient care, and the students were seniors completing their last semester. A total of 48 nurses and 37 nursing assistants from the clinic and 268 nursing students were asked to participate in the study.

Using an anonymous data collection method, the response rate between nurses and nursing assistants were 67% ( $n = 57$ ) and for the students 62% ( $n = 165$ ). The *AIDS*

*Attitude Scale* developed by Froman, Owen, and Daisy (1992) used to measure health professionals' attitudes towards patients with HIV/AIDS, and a researcher-developed questionnaire were used to collect data.

The findings of the study indicated that there were expressions of empathy for the patients with HIV/AIDS, but approximately 54% the nursing staff and nursing students would refrain from caring for this population. The statistics were even higher (62%) for those who would refrain from nursing HIV-infected patients if there were given the opportunity to refuse. The researchers concluded that the stigma of having this disease can prevent infected patients from seeking help from those who are required to take care of them, resulting in neglect and suffering among patients.

As the quality of care diminishes and patients' mortality rates increase, researchers feel that the health care community has not made any great stride toward decreasing the stigma associated with this disease over the past three decades. Many believe that the need is even greater in education in order to break down the societal stigmas and barriers. This study sought to uncover some of the underlying factors that have affected the way in which nurses provide care by gaining an understanding of their lived experience.

### **Experiential Context**

Nursing experiences as an Intensive Care and Surgical Nurse provided an opportunity to care for patients who were diagnosed with HIV/AIDS. With preconceived ideas and forms of discrimination and stigmatization, my nursing practices consisted of many of the eluded attributes indicated in the literature. However, the death of two family members and the care they received from Jamaican nurses with two different

cultural emphases raised my level of curiosity to investigate the experience of caring for these patients from the perspective of nurses who currently practice in Jamaica. Through their voices, I want to tell their personal experiences of caring for patients with HIV/AIDS.

van Manen (1990) indicates that in a phenomenological inquiry, the researcher and the participants are considered co-creators of the concept, and thus it is impossible to completely bracket or have total *epoche*. Described as an assumption, *epoche* is translated as bracketing in math (Creswell, 1998) and requires setting aside our everyday understanding, judgments, and knowing (Patton, 2002). Bracketing is described as suspending one's experiences and preconceived ideas about the phenomenon under investigation to better understand the experiences of the participants (van Manen, 1990).

Bracketing and reflexivity are interconnected in qualitative studies, as the researcher must be reflective in order to bracket. Reflexivity is the idea of being aware of the multiple influences the researcher can have on the research process (Gilgun, 2010). Gilgun (2010) further emphasized that researchers must be reflexive in three main areas when doing qualitative research: the phenomenon they wish to investigate, the perspectives and experiences of the participants, and the audience to whom the findings will be directed.

Entering the life world of the participants, the researcher puts aside all preconceived ideas, notions, or judgments and remains open to listen to the voices of the participants as they describe their experiences (Creswell, 1988). Reflexive bracketing involves making transparent and apparent the researcher's personal values, background, and cultural suppositions. As an instrument in the study, this researcher recognized that a

continual process of self-reflection requires measures to be aware of personal biases, and all attempts should be made to set aside any learned feelings, preconceived ideas, and personal experiences.

The primary method of reflection is the use of a field journal. The researcher documented all thoughts, ideas, feelings, questions, or problems encountered during the research process. Documenting and reflecting on all of this increased the researcher's awareness of any biases or presuppositions according to Guba (1998). With this knowledge, the research may change the way data was collected or analyzed to enhance the quality of the research study.

### **Chapter Summary**

Literature reviewed provided both a quantitative and qualitative perspective of how the disease of AIDS or being HIV positive affects the care of patients. Recognized as a significant health care threat to worldwide nations, health care providers are at the forefront of this crisis, and the type of care delivered can greatly impact health outcomes. However, there is no significant literature that supports how patients with HIV/AIDS are treated by the nurses in Jamaica. This gap in the literature may provide a unique opportunity for this problem to be investigated and documented by this researcher.



## **CHAPTER THREE**

The purpose of this study was to obtain a more in-depth understanding of Jamaican nurses' personal experiences in caring for HIV/AIDS patients in Jamaica. This study's aim was to give a voice to those nurses in articulating their own experiences, feelings, and thoughts about what it is like to provide nursing care to infected patients. Understanding and interpreting experiences is what gives meaning in human science research (Munhall, 2011), while creating narrative stories obtained from interviews rich in data can produce captivating results that will help illuminate the meaning of the phenomenon for the participants and researcher (Creswell, 1998).

A qualitative research approach was used to investigate this issue, guided by van Manen's (1990) hermeneutic phenomenological activities. The six activities were used to explore, identify, describe, and uncover the meaning of the lived experiences of Jamaican nurses caring for patients with HIV/AIDS in Jamaica. Phenomenological research's purpose is to describe the experiences as they are voiced from individuals having experienced the phenomenon and the meaning of the experience in their own consciousness.

### **Research Design**

Creswell (2007) described research designs as the complete process from the identification of a problem, research question development, data collection and analysis, interpretation of the data, and eventually report of the findings. Yin (2003) stated: "The design is the logical sequence that connects the empirical data to a study's initial research questions and ultimately to its conclusions" (p. 20). This study utilized a qualitative exploratory research design using a phenomenological approach. An exploratory

research design begins with a phenomenon of interest. Its aim is to investigate the nature of the phenomenon, how it is manifested in the experiences, and contributing factors that are related to the phenomenon. Using this exploratory research design allows the researcher to fully explore an unknown or little understood phenomenon (Creswell & Clark, 2003).

### **Rationale for Qualitative Study**

Embedded in the paradigm of interpretivism, a qualitative study allows the researcher to study things in their natural settings, attempt to make sense of, or interpret a phenomenon in terms of the meaning participants make of them (Denzin & Lincoln, 2005). The researcher is the primary instrument in the research and collects data through observing and interviewing the participants. Through inductive data analysis, researchers organize their data establishing comprehensive set of themes. Data collected is subjective in nature, allowing the participants' interpretation of the phenomenon to be revealed (Creswell, 2007).

As an interpretive inquiry, qualitative research allows researchers to make interpretations of what they see, hear, and understand about the phenomenon from the participants (Creswell, 2007). Immersing themselves into the study, researchers take an active insider role to gain a better understanding of the participants' experiences. Through this qualitative research process, results are grounded in the actual experiences of individuals with personal understanding and meaning of the phenomenon.

The aim of this study was to gain a deeper understanding and find meaning and interpretation of the lived experience of Jamaican nurses caring for patients with HIV/AIDS in Jamaica. Exploring this phenomenon to understand their experiences was

best examined from a qualitative perspective, as this method is appropriate for research questions that require detail discovery (Creswell, 2007).

### **Rationale for Phenomenology Approach**

According to Crotty (1998), a phenomenological approach allows researchers to explore and understand the experiences of a phenomenon. Considered to be both a philosophy and a research method, phenomenological studies allow the described meaning of the lived experiences of individuals to provide the researcher with a new perspective of the investigated phenomenon. In phenomenology, the essence of the experiences is the essential meaning before any social or cultural meanings are attached to it as defined by van Manen (1997); it is what makes a thing what it is. This is evident in van Manen's (1997) Hermeneutic Interpretive Phenomenology that considers individuals having their own lived experience and meaning assigned through self-reflection.

Exploring an individual's experience a researcher seeks to understand how they view their experiences through rich descriptive data (Creswell, 2007). The structures of consciousness as described and experienced from the first-person perspectives or point of view, is the foundation of a phenomenology study. Without any manipulation from the researcher, the approach seeks to explain the structure and essence of the experiences of a group of people in a particular setting (Guba & Lincoln, 1995).

The use of phenomenology is an appropriate method to uncover the lived experiences and understand the meaning Jamaica nurses may attribute to caring for patients with HIV/AIDS. This research method supports human science that "aims at explicating the meaning of the human phenomena and at understanding the lived

structures of meanings” (van Manen, 1990, p. 4). “Research using phenomenology seeks to uncover the meanings in our everyday existence. Its aim is the fulfillment of our human nature: to become more fully who we are” (van Manen, 1990, p. 12). van Manen’s method of hermeneutic phenomenological inquiry was used to guide this study, which involves the integration or interplay of six research activities (van Manen, 1990) as follows:

1. Turning to a phenomenon which seriously interests us and commits us to the world
2. Investigate the experience as we live it rather than as we conceptualize it
3. Reflect on the emerging themes which characterize the phenomenon
4. Describing the phenomenon through the art of writing and rewriting
5. Maintaining a strong and oriented pedagogical relation to the phenomenon
6. Balancing the research context by considering parts and whole (p. 30)

An interpretation of van Manen’s phenomenological approach was adapted and applied to investigate the lived experiences of Jamaican nurses caring for patients with HIV/AIDS in Jamaica as depicted in Figure 5.

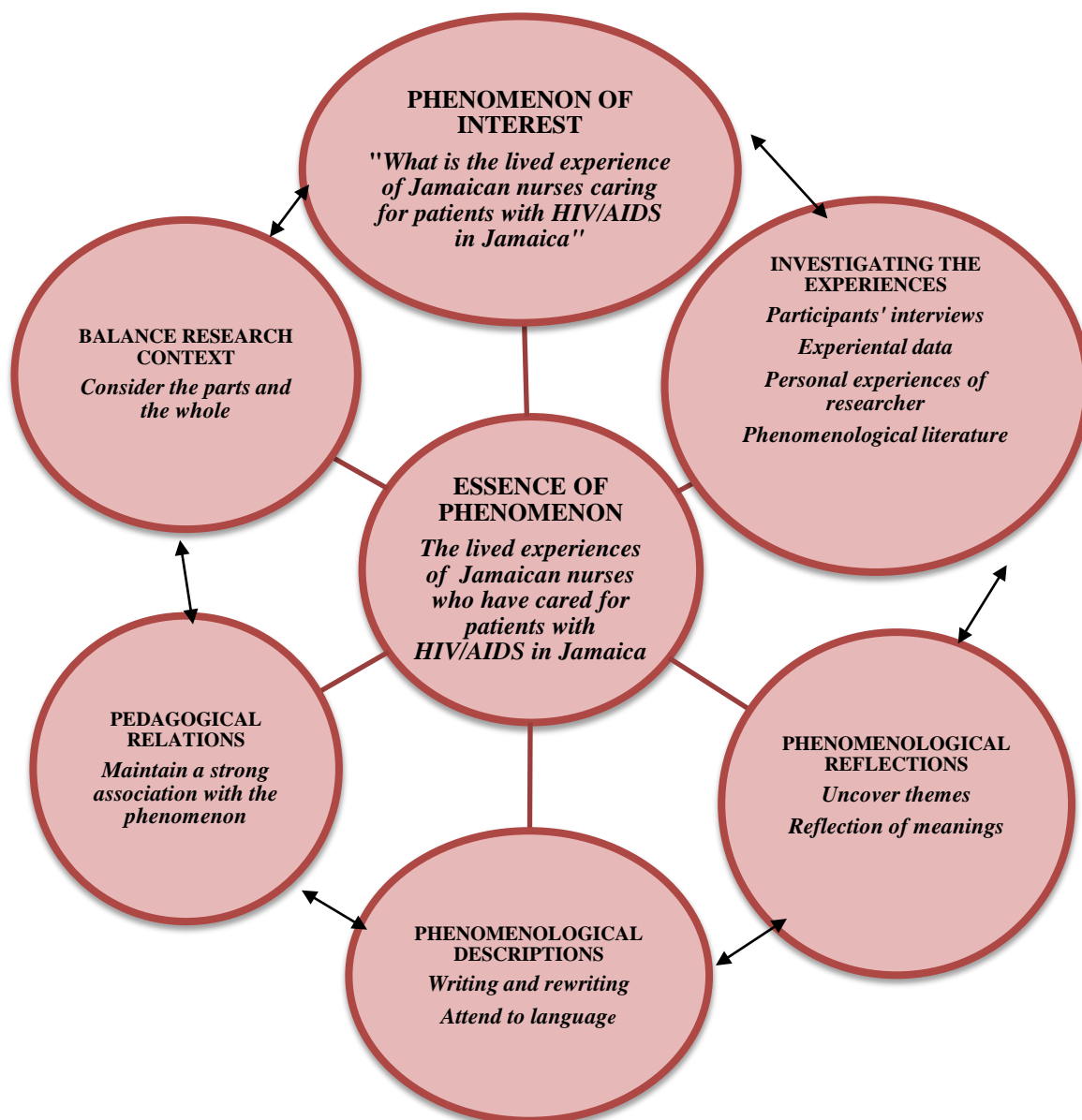


Figure 5. Martin (2013) Phenomenological approach to investigate the lived experiences of Jamaican nurses caring for patients with HIV/AIDS in Jamaica. (Adapted from van Manen, 1990).

### Sample and Setting

Developing a rich or dense description of the phenomenon being investigated is the goal of hermeneutic phenomenology. To facilitate this process, a purposeful selection method was employed to seek participants who could illuminate the phenomenon by

providing information-rich experiences. Purposive sampling is a dominant sample selection method in qualitative research and is consistent with an interpretive paradigm research (Patton, 2002).

The researcher employed purposive sampling to include Jamaican nurses who currently practice on the island of Jamaica and identify themselves of having the lived experience of caring for HIV/AIDS patients. The potential sample size to be recruited for the study was a small sample size with a maximum of 25 participants that may allow for in-depth data collection with repeated interviews and provide the possibility for saturation to be achieved. Creswell (1998) described saturation as the point whereby the researcher no longer hears any new information that relates to the phenomenon from a participant.

### **Access and Recruitment of the Sample**

Potential participants were registered nurses recruited from a hospital on the island of Jamaica. An access letter (Appendix C) was used to obtain permission to conduct the study from the administrative board of the St. Ann's Bay Hospital, located in St. Ann, Jamaica. Following Barry University Institutional Review Board (IRB) approval to conduct study and permission from the hospital, a flyer (Appendix D) was distributed within the hospital about the proposed study. Flyers were placed in the following places: lobby of hospital, nurses' stations, and nurses' lounges. Snowballing techniques were also used to recruit other potential participants.

This flyer assisted in recruiting potential participants who were asked to contact the researcher if interested in participating in the study. Information regarding the proposed study and how it would be conducted was listed on the flyer. The name and

contact information of the researcher were listed for potential participants to voluntarily initiate their interest.

The researcher confirmed inclusion criteria of potential participants, and a follow-up information session was planned to provide clear written and verbal instructions regarding the study as required by Barry University IRB, including how information should be collected and used. Interested participants were given a written consent form to be signed prior to the collection of any data. Participants were informed that their participation was voluntary, all information obtained would be confidential, and they could withdraw from the study at any time. Participants received \$10 US dollars as a token of appreciation for participation in the study.

#### **Inclusion Criteria**

Participants were registered nurses with more than one year working experience, who spoke English, and were interested in participating in the proposed study. They must have been identified as past or current health care providers caring for HIV/AIDS patients within the hospital. Participants must have been willing to be available for face-to-face confidential interviews to share their experiences and follow-up interactions with the researcher that may be necessary.

#### **Exclusion Criteria**

Exclusion criteria included individuals who were unable to speak English, were not currently practicing as a nurse, and have not had any experience in caring for patients with HIV/AIDS. Nurses practicing for less than one year and those who practice outside the hospital setting were excluded from the proposed study. Any participant unwilling or unable to commit to interview sessions with researcher was also being excluded.

### **Ethical Implications/Protection of Human Subjects**

This study explored the lived experience of Jamaican nurses who have cared for patients diagnosed with HIV/AIDS in Jamaica within the context of a hermeneutic-phenomenological research. In this type of research, the researcher is the primary research instrument and the interactions with participants could potentially generate ethical problems. According to Richards and Schwartz (2002), too often the assumption is made that involvement in qualitative research is relatively harmless; however, the actual risk to participants are actually unknown. Therefore, measures needs to be in place to minimize any risk or harm to participants.

Once permission was granted to access nurses in the selected hospital, participants were provided with information detailing the aim of the study, the proposed research process, and the opportunity to ask question about the research. Written consents were obtained from each participant prior to the collection of any data. Participants were advised that anonymity would be maintained in this confidential study, and all forms received would be kept in a locked file cabinet accessible only by the researcher. They were instructed to choose a pseudonym, which was only connected to written transcripts and not to consents. Participants were advised that there was no direct benefit from this study, except to enhance the body of nursing. Therefore, they were advised that participating in the study was voluntary with minimal risks, and they could withdraw at any time they feel uncomfortable relating their experiences. A token of U.S. \$10 was given to participants who completed the study

To ensure that no participants were at risk during the proposed study and maintaining ethical standards to protect all human-subject, the study followed the



guidelines of the Institutional Review Board (IRB) of Barry University and that of St. Ann's Bay Hospital.

### **Data Collection Procedure**

Data collection procedures began upon approval from Barry University Institutional Review Board. An access letter (Appendix C) was used to obtain permission to conduct the study from the administrative board of the St. Ann's Bay Hospital, located in St. Ann, Jamaica. Once permission was granted from the administrative board of the hospital, participants who contacted the researcher and met the inclusion criteria were fully informed about the study and their rights as research participants. Verbal instructions about the purpose of the study were discussed with each participant, and he or she was asked to sign an Informed Consent Form (see Appendix B). All participants were asked to choose a pseudonym that was used throughout the investigation in place of the name to ensure confidentiality.

The data collection process involved an initial face-to-face, semi-structured interview with each participant. According to Creswell (1998), semi-structured interviews allow for flexibility in the interviewing process, which can produce rich dialogue with the participants. Open-ended questions were used to facilitate in-depth responses from the participants. Permission for the interviews to be recorded was verified with the participants, as this assisted in verbatim transcription of information provided. The researcher used two audio-tape recorders in each interview session in case of equipment failure.

The first interview was conducted in a private, mutually agreed upon location. Each initial interview was scheduled for one hour. An interview protocol was used to

guide interviews (Appendix E). The audio-tape recorders were placed at an appropriate area between the researcher and the participants. The recorder was in full view of the researcher and participants at all times during the interview. During the interview, the researcher focused on being a listener and not interjecting any personal biases or opinions, only providing clarifications to understand concepts expressed by the participants (Creswell, 2007). Each participant was asked to complete a demographic questionnaire (Appendix F) after the interviews.

Immediately after the first interview, the researcher made observations of non-verbal behaviors, field notes obtained during the interview, and overall affect of participants. The researcher documented post-interview thoughts and reflections in her journal. According to Polit and Beck (2012), reflexive journaling can assist a researcher with bracketing and allows for self-interrogation and reflection of any biases. Field notes, poetry, other media, and researcher's observation were also used to supplement the collected data.

The audio-taped interviews were transcribed verbatim immediately by the researcher. The qualities of the tapes were reviewed to ensure that conversations were understood and heard properly prior to transcription. After transcription, the transcripts were reviewed line by line with the tapes to confirm accuracy.

After completion of the first interviews, transcriptions, and initial data analysis, the researcher conducted a member check with the participants. Participants were contacted to schedule a second meeting that lasted no more than one hour. The main purpose of this second meeting was to have participants review their transcribed interviews, discuss the themes identified by researcher for accuracy, and clarify the

descriptions of their lived experiences (Creswell, 2007). Ensuring credibility of data analysis and interpretation, member check is a vital element in data collection procedures (Creswell, 1998). This meeting was not recorded, as participants examined transcriptions for accuracy and made any changes.

The audiotapes were destroyed immediately after accuracy of transcribed data has been confirmed. If for any reason a participant could not participate in the second meeting, the audiotape was stored in a locked file cabinet in the researcher's home office and was destroyed 90 days after the initial interview. The security of electronic documents was protected with the use of an exclusive, password-protected personal computer at the researcher's home office. Five years after the completion of the study, all electronic transcripts will be deleted from the researcher's personal computer.

### **Interview Questions**

From a qualitative perspective, the main method of collecting significant data is through the process of interviews. According to Creswell (1998), these are detailed in-depth interviews or multiple interviews with participants who have all experienced the phenomenon. The questions in the interview provided a basic focus, with the possibility of other questions leading from the main question. The main question to be asked was: "Please tell me what is your experience in caring for patients who are diagnosed with AIDS/HIV." Appendix E includes questions that guided the interviews.

### **Demographic Data**

Demographic information was obtained from a researcher-developed demographic questionnaire (see Appendix D). It was used to describe the main characteristics of participants to ensure that they meet inclusion criteria. The

demographic questionnaire included: current age, gender, and years of experience as a nurse, marital status, and educational background. Participants were also asked the number of exposures to HIV/AIDS patients and the capacity in which they cared for them. This data may assist the researcher in understanding the situational context of the phenomenon for each participant by identifying and describing commonalities among the participants.

### **Data Analysis Procedure**

Creswell (2007) identified six major steps in analyzing data in a phenomenology research study. The first step is managing the collected data by creating and organizing files for the data. The next step is reading and reread data to identify any common themes. The researcher describes the personal experiences of the participants through bracketing, identifying the core meanings or essence of the phenomena. Pertinent statements are developed according to significance and meaning in the process of classifying the collected data. In the interpreting phase, a written description is done to answer “what happened” and “how the phenomenon was experienced,” which will ultimately reveal to the researcher the essence or core meanings of the experiences. Validation of the findings through member check with participants is very important in this step, as it can correct any misinformation presented.

Max Van Manen’s (1990) method of hermeneutic phenomenological inquiry was used to guide this study through his six activities: (1) turn to phenomenon which seriously interests us, (2) investigate the experience, (3) reflect on the emerging themes, (4) describe the phenomenon through the art of writing and rewriting, (5) manipulate a

strong relationship between the paradigm and the phenomenon, and (6) balance the research context by examining parts and whole.

“Research using phenomenology seeks to uncover the meanings in our everyday existence. Its aim is the fulfillment of our human nature: to become more fully who we are” (van Manen, 1990, p. 12). For this study of the lived experience of Jamaican nurses caring for patients with HIV/AIDS, a transcription of the verbatim interview was provided to the participants to verify content for accuracy. Through writing and rewriting, the researcher looked for common themes or statements that were voiced. These themes were grouped together to find the meaning of the experience or essence according to van Manen (1990).

### **Research Rigor and Trustworthiness**

Research rigor and trustworthiness is the way in which integrity, competence, and legitimacy of the research process is demonstrated in qualitative studies (Gay, Mills, & Airasian, 2009). The rigor of qualitative inquiry should go beyond questioning, challenges, to provide pragmatic scientific evidence that can be integrated into our developing knowledge (Morse et al., 2002). Trustworthiness and rigor are the unique principles used in qualitative researches to deem them researches of quality (Polit & Beck, 2012).

Lincoln and Guba (2000) indicated that trustworthiness of a research study is very important as it evaluates the worth of the study through four elements: credibility, dependability, confirmability, and transferability. These elements are considered to be the foundation of rigor and trustworthiness in a qualitative study.

**Credibility**

Credibility expresses confidence in the truth of the findings, and this was obtained by prolonged observations and engagement with the participants, member checks, and peer-debriefing. Lincoln and Guba (1989) regarded member checks as the single-most critical technique for establishing credibility in qualitative research. This was achieved by the researcher having the participants review the analyzed data for accuracy. Reflective bracketing, through journaling, is very important to this process to contain perceived ideas or feelings of the researcher. The objective is to report data through the eyes of the participants. Peer-debriefing was accomplished by having the expert members of the dissertation committee review the analyzed data to ensure accuracy and credibility of study.

**Dependability**

Dependability is used to provide an audit trail to review the research process by an outside researcher not involved with the research (Munhall, 2012). The purpose is to evaluate the accuracy of the information and that interpretation and conclusions are supported by the data collected. Dependability was achieved by keeping accurate records of all study materials, such as raw data, field notes, written summaries, or themes. To enhance dependability, the researcher will keep a daily diary as recommended by Gadamer (1996), to note information about the participants' reactions or comments made during the study. According to Holloway (2005), a diary can help to conceptualize personal actions and behaviors to help create rich data consistent with the phenomenological philosophy.

**Confirmability**

Confirmability means that another researcher can recognize the description of the experience and confirm the accuracy of the experience. This can be established by documenting the activities so any researcher may be able to follow the development of the study (Lincoln & Guba, 2000). It is important to demonstrate that the researcher's bias or preconceived ideas has not unduly influence the research outcome. The researcher will set aside all preconceived ideas or biases of caring for patients with HIV/AIDS by maintaining a journal. This will help the researcher identify and bracket any thoughts or feelings in order to keep an open mind and view during the research process. Journaling will also allow the researcher to suspend her own feelings or thoughts and be able to separate them from those to the participants. This is an important way to increase our confidence that the voice of the participants is heard.

**Transferability**

Transferability indicates that the findings of the study can be applied to different settings with different populations (Lincoln & Guba, 2000). Transferability in this study was achieved by the use of thick, detailed descriptions to describe the phenomenon, research settings, participants, and perspectives of the participants. Detailed description of sampling procedures and data collection allowed others to judge the level of transferability (Krefting, 1999). Upon completion of the study, the results were shared with colleagues and experts in the field to help promote transferability.

### **Chapter Summary**

This chapter provided information on the method that was used to guide this study from a hermeneutic phenomenological perspective, while investigating the lived experience of Jamaican nurses caring for patients with HIV/AIDS. This qualitative method helped the researcher gain a deeper understanding of the lived experience. Data collection procedures and data analysis procedures were discussed, including van Manen's six activities of data analysis that were used to guide this study. The criteria for research rigor and trustworthiness as presented by Lincoln and Guba (2000) were reviewed and maintained during the study.



## **CHAPTER FOUR**

### **FINDINGS OF THE INQUIRY**

This chapter will describe the significant findings of this phenomenological inquiry into the lives of Jamaican nurses who have cared for patients with human immunodeficiency virus or AIDS in Jamaica. Demographic representation of the participants will be discussed in aggregate, with individual descriptions of each participant who participated in the study. Through data analysis, the related themes that emerged from thoughts, feelings, and descriptions of the participant's experiences with the phenomena will be presented. A summary of the significant findings that evolved from the exploratory conversations with the participants will be discussed.

The purpose of this phenomenological inquiry was to explore the lived experience of Jamaican nurses who have cared for patients with human with HIV/AIDS in Jamaica, by viewing the phenomenon through the lens of each participant's eyes and listening to his or her spoken words. The objective of phenomenology is uncovering the essence of the participant's life world with the phenomenon in their everyday existence (Munhall, 2012). Through the subjective personal stories of each participant, the researcher was able to describe, interpret, and translate the meaning of caring for patients with HIV/AIDS in Jamaica.

The central concept of every phenomenological research is a quest for a deeper understanding of the lived experience. The emphasis is on the world as lived by the individual, not the world or reality separate from the person (van Manen, 1997). Trying to understand or comprehend meanings of human experiences is the focus of this type of research (Polkinghorne, 1983). It allows the researcher to gain a deeper understanding of

human relationships as each layer of the lived experience is peeled away to discover the ultimate essence (Racher & Robinson, 2002).

van Manen's (1990) phenomenological framework, which consists of six research activities, served as the main guideline for data collection and analysis for the researcher to delineate the meaning and description of this phenomenon. This researcher sought to explore the experiences of Jamaican nurses who have cared for patients with HIV/AIDS in Jamaica following this hermeneutic process. The phenomenological research approach allowed the researcher's senses to be engaged while in the midst of the living relationships and situations of the participants as they describe their experience. The researcher became actively engaged in the exploration of all aspects of the lived experience.

In phenomenology, the starting point is personal experience according to van Manen (1990), and these personal experiences were obtained from the narratives of each participant. The process started with data collection as the researcher entered into this phase with an open mind, eager to hear the description of each participant's experience with the phenomenon.

Data collection involved face-to-face semi-structured interviews and was conducted in an intimate and private surrounding to maintain confidentiality of each participant. Interviews conducted in privacy allowed the researcher the opportunity to gain the trust of each participant and build a collaborative relationship with him or her about the meaning of his or her experience. The participants used their stories to describe their experiences caring for patients with HIV/AIDS in Jamaica. The factual recall of each nurse experience allowed the researcher to fully understand the

perspectives of the everyday existence with the phenomenon. It provided an opportunity for the researcher to see through their lenses and hear from their voices what it is like caring for patients with HIV/AIDS in Jamaica. Data collection and analysis continued until the stories were repetitive and recurring, which indicated to the researcher that saturation had been reached. Saturation was obtained after the tenth interview, when no new themes were discovered within the subsequent interview. However, four more additional participants were interviewed to confirm that saturation had indeed occurred.

Each interview was audio-taped and transcribed verbatim to allow the researcher to listen and re-listen, read and re-read each participant's story multiple times until the researcher was certain that the collected data was accurate. Reflecting on the participants' emotions, body language, tone of voice, and nonverbal cues during the interview provided an opportunity for the researcher to grasp any hidden meanings from unspoken words to describe the experience. This enabled the researcher to become intimate with the data and narratives of each participant. A journal was used by the researcher to record post-interview reflections, thoughts, and other nonverbal cues of the participant.

The interviews began with a moment of silence after the primary question was asked of each participant. This allowed the participant to ponder and process the question, what it is like caring for patients with HIV/AIDS. This allowed for focus, consideration, and openness to the phenomenon being investigated. It is important for the researcher to remain open minded and maintain a sense of clarity of the different variations and appearances of the phenomenon as they emerge. Through this process, the

researcher began to understand the experiences and ultimately the essences of the phenomenon were revealed.

Through self-reflection, writing, and rewriting, the researcher is able grasp the participants' unique experiences, by suspending all knowledge and biases regarding the phenomenon (Creswell, 2007). The art of writing and rewriting helps to bring meaning to the surface of a phenomenon. van Manen (1990) stated that phenomenology is the application of language and thoughtfulness to an aspect of the lived experience, and it is a process of interpretation through reflection and writing. Through this method, the researcher began to understand the experience of each participant and the essence of the phenomenon.

Each interview provided new data, which allowed the researcher to compare new findings with pre-existing ones to determine if any similarities or differences existed within each interview. The researcher compared and grouped data of each participant narrative according to universal or singular essence of the experience. Numerous sessions of reading and rereading each narrative, analyzing each emerging theme was perform to arrive at the true essence of the lived experiences of Jamaican nurses caring for patients with HIV/AIDS in Jamaica. The related themes of: fear of contagion, transition with knowledge, anger and powerlessness, and empathy in caring emerged as a total representation of the Jamaican nurses' experience caring for patients with HIV/AIDS in Jamaica.

### **Demographic Representations**

This study included 14 Jamaican nurses who have cared for patients with human immunodeficiency virus or acquired immune deficiency syndrome in Jamaica. The first

five potential participants were obtained through the recruitment flyer, and the other nine participants were obtained through snowball sampling. The 14 participants identified themselves as having cared for the patient population in Jamaica, with one participant who cared for patients both in Jamaica and another Caribbean island. The ages of the 14 nurses varied: four nurses were between the ages of 20 to 29, six nurses were between the ages of 30 to 39, and four nurses were between the ages of 40 to 49.

All of the 14 research participants were born in Jamaica and currently resided on the island. Their marital status revealed seven of the participants being single, five being married, and two currently widowed. The educational level of the research participants ranged from a bachelor's degree to a Master's degree, with one participant practicing as an Advanced Registered Nurse Practitioner (ARNP). Six of the participants have additional training and certification to function as "Sisters" (equivalent to a charge nurses) on the wards. Thirteen of the research participants practiced full time in the hospital, and the participant who was an ARNP practiced both in the hospital and a community clinic.

The years of nursing practice of the 14 participants varied; three nurses have been practicing between 2 to 5 years, two nurses between 5 to 10 years, five nurses between 10 to 15 years, and four nurses with over 15 years of experience. The numbers of years caring for patient with HIV/AIDS in Jamaica were between 2 to 15 years, with equivalence to the numbers of years practicing for some of the nurses. The research participants cared for patients on various wards (units/floors) of the hospital, such as: surgical or medical ward, accident and emergency (A&E), psych, and maternity. One participant encounters patients in the community clinic setting. All of the 14 research

participants identified caring for heterosexuals, homosexuals, and children with the virus or the disease.

### **Characteristics of the Participants**

The participants will be introduced according to the pseudonyms chosen by each of them to maintain their confidentiality. Using a pseudonym allowed the participants to express their true inner experiences, feelings, and thoughts without revealing their true identity. The characteristics of the participants were taken from the narrative interviews, which provided their various thoughts, values, and lived experiences. The interactions between the researcher and the research participants as they shared their experiences were very moving and emotional. The nurses were receptive and open in answering the researcher's questions about caring for patients with HIV/AIDS. During thoughtful moments of silence in the interviews, some of the nurses would express their emotions through tears as they shared their experiences.

#### **Mishy**

Mishy is a registered nurse with 20 years of nursing experience, has a college degree, and has cared for patients with HIV/AIDS for over 10 years. She identified herself as being between the ages of 40-49 and married with children. Mishy cared for these patients in the hospital setting on the surgical or medical ward and sometimes functioned as a "Sister." A "Sister" is a nurse who has received additional training and certification to become a charge nurse on the ward.

During the interview, she constantly stated "It's just another illness you know; it's just another illness, so we have to care."

**Joy**

Joy is a registered nurse with 12 years of nursing experience and 3 years as an ARNP. She works both in the hospital and community clinic. She primarily works in the accident and emergency (A&E) ward. Joy has a Master's degree in nursing, identified herself as being between the ages of 30 to 39, is married, but has no children. Joy expressed in the interview that caring for patients with the virus and the disease can be very challenging and sometimes emotionally draining as she frequently see patients in the community clinic that are noncompliant.

**Tinker Bell**

Tinker Bell is between the ages of 20 to 29 and is a registered nurse practicing for over three years. She works in the accident and emergency department and frequently sees this population of patients when they seek urgent care. Tinker Bell has a bachelor's degree in nursing and identified herself as being single and without children. She revealed that she tries to be patient with these patients as sometimes they hide their diagnosis from the nurses. She explained:

It's just like any other person, is just a diagnosis, and it does not separate them from any other person that walks into the hospital. The only problem you find is that there are persons who are very noncompliant in taking their medications as oppose to the other patients who does.

**Pelican Grill**

Pelican Grill is a college graduate registered nurse who holds a master degree in nursing. She currently works full time at the hospital and identified herself as being between the ages of 40 and 49. She is married with children and sometimes functions in

the role as a sister or charge nurse. She has over 20 years nursing experience and has worked in several of the different nursing units. She states that her challenge with caring for patients with HIV in Jamaica is primarily surrounded by the lack of compliance with patients taking their medication and the lack of care towards methods of preventing the disease

### **Duck**

Duck is a college graduate registered nurse who holds a Master's degree in nursing. She identified herself as being between the ages of 30 to 39, currently single with one child. She recently completed a nurse midwifery course and works in the labor and delivery ward. Duck has over 13 years nursing experience and has been caring for patients with HIV or AIDS for over 10 years. She described her experience caring for this patient population as one that can be both challenge and rewarding. During the interview, she revealed that it can be rewarding to see patients who accept the fact that they are HIV-positive and are not blaming anyone respond to treatment and do well. However, she stated that her challenges came from patients who are in denial or are very angry at the world.

### **Lovely Merci**

Lovely Merci is a registered nurse who has been practicing for over 19 years and has also worked on another island of the Caribbean. She has cared for this patient population both in Jamaica and the other Caribbean island. She is a college graduate with a Master's degree in nursing and sometimes functions in the capacity as "Sister" (charge nurse). Lovely Merci is a single mother between the ages of 42 to 49 with two



teenage children and refers to the children with the virus and the disease multiple times as she reflected on her own children. Pondering reflectively, she stated:

In years gone by it was very difficult and challenging. But as the years go by, and technology and time has change, I am quite comfortable caring for them just like any other patient. So for me once I have my protective gear I am fine caring for them.

### **Ms. Miller**

Ms. Miller is a registered nurse with over nine years experience caring for patients with the HIV virus and AIDS in Jamaica. She is married with children and identified herself as being between the ages of 30 to 39. Ms. Miller is a college graduate and holds a Master's degree in nursing. She is a nurse midwife and currently works in the maternity ward where she sees mothers who are HIV-positive. She disclosed:

Especially here in the maternity unit, we find that ladies are known to be HIV-positive, and they don't disclose it. You may have a tendency to have negative thoughts towards them. However, you don't want to treat them any different.

### **Mary**

Mary is a registered nurse for over two years, is married, and has children. She has been caring for this patient population since leaving nursing school. She identified herself as being between the ages of 20 to 29 and works part-time in the hospital. She is a college graduate and holds a bachelor's degree in nursing. Mary works in the medical unit and sees patients, both male and female who are HIV-positive or diagnosed with AIDS. She revealed that she does not discriminate when caring for this patient population. However, she emphasized that the use of universal precautions is at the

forefront of her mind. She stated, “I don’t feel any different. I treat them just the same way. It’s like any other patient that I care for. Universal precautions are at the forefront of your mind, but it’s amplified when you care for them.”

### **Bobette**

Bobette is a registered nurse with over 11 years nursing experience. She identified herself as being between the ages of 30 to 39, single with children. She also holds a Master’s degree in nursing and functions in the role as a charge nurse or sister on the medical surgical unit. She described caring for these patients as an interesting experience as they are mixed with other patients on the general ward. She indicated that to maintain confidentiality as much as possible, they try not to separate the patients. She revealed that they use medical terms and medical terminology, but from time to time patients are somewhat knowledgeable and are aware of what you’re talking about.

### **Desert Rose**

Desert Rose is a registered nurse who currently works in the accident and emergency department of the hospital. She is a college graduate and has a bachelor’s degree in nursing with over 10 years of nursing experience. She identified herself as being between the ages of 30 and 39, married, with children. She described the stigma that is attached to patients who are HIV-positive or those diagnosed with AIDS.

However, she stated:

Even though I don’t have a problem taking care of them, I know that their family, dear friends and persons who they may associate with may not be as compassionate and caring as I would when I am taking care of them.

**EV**

EV described herself as being single between the ages of 30 to 39, has children, and currently works full time in the hospital. She is a registered nurse, has a bachelor's degree in nursing and over 17 years of nursing experience, and functions in the role as a charge nurse on the medical surgical ward. She encounters patients who are diagnosed with HIV and AIDS from time to time and indicated that it can be hard to care for them on a whole in most cases. She voiced her concern:

Yes, you know the symptoms, you treat the symptoms and you try to put in place social interventions, but for them to tell you exactly what they're feeling, they are not really vocal. They tend to shy away, basically they are on the depressive side, and will not open to you. So sometimes it can be hard to care for them, if they are not truthful with you.

**Nurse Beans**

Nurse Beans is a registered nurse who identified herself as being between the ages of 20 to 29. She is married with children and currently works full time at the hospitals. She has over three years of nursing experience and cares for patients with HIV/AIDS in the medical or surgical ward. Nurse Beans is a college graduate with a Bachelor's degree. She shared that although there are stigmas associated with the disease in Jamaica; essentially, it is a call of duty for nurses to care, no matter who the patient is.

**Ms. McKenzie**

Ms. McKenzie is a registered nurse who identified herself as being between the ages of 30 to 49. She is married with children and works full time in the maternity ward. She has over 14 years of nursing experience and stated that she had cared for patients

with HIV and AIDS for more 13 years. She is a college graduate and holds a Master's degree in nursing, is a certified midwife and functions in the role as a charge nurse in her department.

Working in the maternity ward, Ms. McKenzie revealed that it can be hard to see mothers who are HIV-positive having babies. She stated:

It is challenging, and dealing with the stigma, that is what causes the challenge. You have to be so discreet with these patients and you have to make things not somewhat different than how you care for the other patients. At times, once you know, even though you carry out all the necessary precautions, but with those patients you put out a little bit more precautions. But it's very challenging, you want to maintain the secret or the confidentiality, but sometimes based on the extra things that you do, it might send off some signals.

### **Deary**

Deary is a registered nurse who works full time on the medical surgical ward. She identified herself as being married and has children and has a bachelor's degree in nursing. She has been practicing as a nurse for over 15 years and during her nursing career has taking care of patients with HIV/AIDS for more than 10 years. She encounters patients with the disease on the medical surgical ward quite frequently find that it can be challenging to care for them. During the interview, she revealed that:

As a nurse, caring for HIV or AIDS patient use to be a bit stigmatizing, but since being educated it has stopped. We treat each of them just like other patients. We also try to educate the relatives about caring for the patient, so patients can get better care; because as you know there is a big stigma in most countries.

## Themes

The themes in this study emerged as the 14 registered nurses described their experiences about caring for patients with HIV/AIDS in Jamaica. Sharing their feelings and thoughts during the narrative interviews provided the researcher with a lens through which to view their experiences. An analysis of the rich data through reading and rereading of the narratives, writing and rewriting of emerging themes, reflecting on verbal and nonverbal cues during the interview, and listening intensely for revelations of feelings and emotion in their voices led to the emergence of five significant related themes. The themes identified through the analysis are fear of infectiveness, transitioness, powerlessness, and compassioness. These four themes clearly represented the lived experiences of Jamaican nurses caring for patients with HIV/AIDS in Jamaica. These themes illustrated the research participants' experiences and relationships from the perspective of the existential life world of body, space, time, and daily human interactions (Munhall, 2012).

Figure 6 is a representation of the researcher's interpretation of the lived experiences of Jamaican nurses caring for patients with HIV/AIDS, as described by the participants in the study. Through this phenomenological investigation, the four themes of fear of contagion, transition with knowledge, anger and powerlessness, and empathy in caring emerged. It was evident that the four themes were common in the experiences of the participants, as there was no clear distinction between the themes found. It was also possible to distinguish a connecting pattern among the themes within the realm of the lived experiences. A kaleidoscope of that has been depicted in Figure 6.

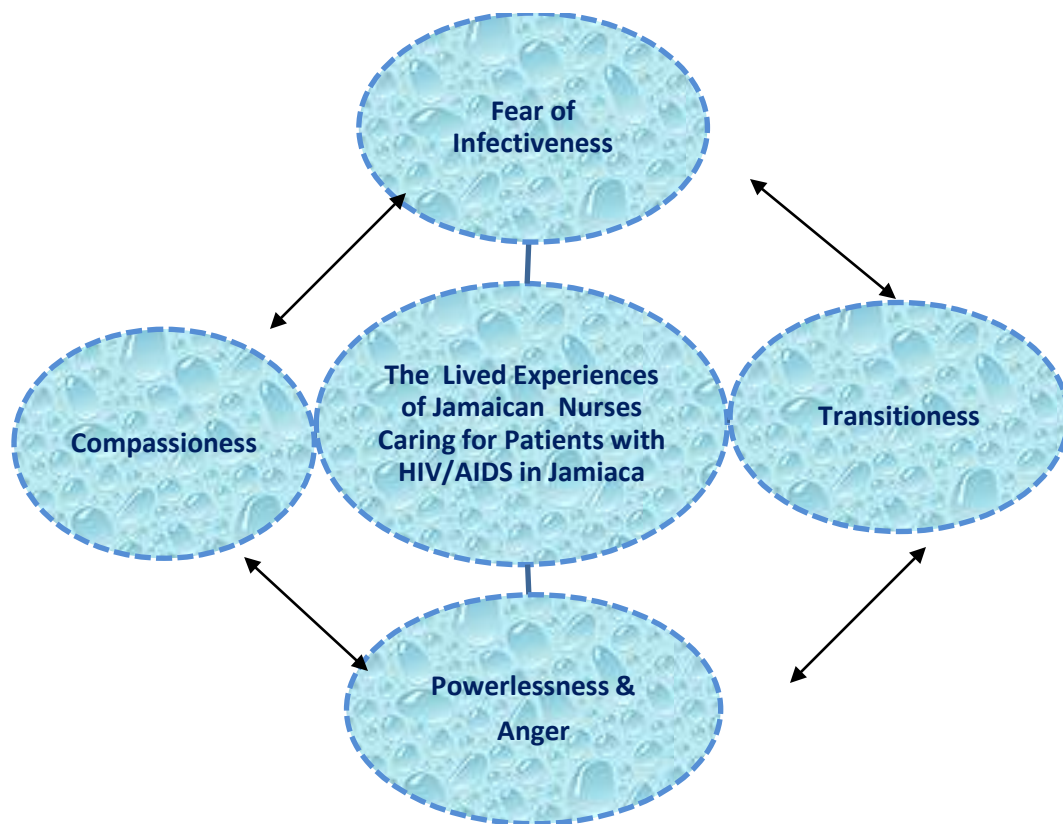


Figure 6. Martin's (2013) Representation of the lived experiences of Jamaican nurses caring for patients with HIV/AIDS in Jamaica.

### **Fear of Infectiveness**

The first theme that emerged from the data was fear of infectiveness, described as an unpleasant feeling or a paralysing fear of being infected, often producing strong emotions caused by anticipation or awareness of danger (Rutledge, Abdell, & McCann, 2009). The theme infectiveness was profoundly voiced by the participants and revealed various emotional responses to the primary question, What is your experience caring for patients with HIV/AIDS here in Jamaica? The fear of infectiveness resonated in Ms. McKenzie's response:

Oh my God, from my perspective I said, oh my God, I don't want to get this disease. I am so afraid of it. Because even given them injection, you are extra cautious, you don't want to get stuck, or get splash or anything like that. The first thing that comes to my mind is I don't want to have this.

Many of the other participants reported similar feelings and thoughts about caring for patients with the disease or virus. According to these participants, their initial reactions when they encounter patients who are known to have the disease or the virus are an increased level of anxiety. Such feelings were voiced by Mishy as she confessed:

There is such a stigma attached to this virus and disease, and there is no cure, this is one illness I would not like to get. I get so afraid when I have to draw blood from them or even to do a dressing.

Similar comments were made by Tinker Bell:

Honestly, I feel like it is a death sentence for anyone who gets a disease. It is like a death notice and you have such a short life expectancy. I care for them, but somehow you still take a little extra caution when you have to care for them. How would I tell my family if I catch this disease from caring for somebody with this disease? I would be so devastated and I know they would be also.

Mary voiced her feelings:

I would cry (laughter) I would definitely cry, I would cry, because I've seen the worse as well. And so the whole fear and everything I think I would forget I was a nurse and just become an ordinary layperson person at that time, and when the senses come back, I would be all right. It makes you feel very human at that

point. Yes, it is the natural response you will experience at that moment, but we still care.

The risk of contracting the virus as a result of accidental exposure was always something that lingered in the back of these participants' mind. They reported that they care for patients on the different wards and sometimes are exposed to body fluids more than they want to be. Ms. Miller, a nurse midwife, echoed the sentiments:

From a nursing perspective on this unit, we are constantly being exposed to body fluid. I mean, sometimes we are fearful, it is just fear. Because even though you know that the prognosis is better because of new medications, you still don't want to contract the disease because there is still going to be stigma associated with it. No matter if you get it from your job, people are still going to have their opinion, it is just fear, because a lot of mothers come in and are HIV-positive and don't get any prenatal treatment because they don't want the nurses to know, because they are pregnant again. They come in and they don't say anything. Sometimes you might have an accident in the delivery room and then they get tested and after then you find out that they are positive. Then you start retracing your steps, wondering did my gloves break? Did I touch a dirty needle? Or did I do something without a glove at any point when I was delivering that baby? It brings fear right to your doorstep of contracting the disease.

Likewise, Deary shared her feelings of fear of infectiveness:

If I got a needle stick from a HIV patient, I would be like, oh my goodness, I would start thinking as an individual, because you are human, and the human part of you start to come out. Sometimes you come across where I was taking care of



a patient two days ago after surgery, and then after that you hear that their C13 came back positive, that is the lab test we do to test for the HIV virus. So I usually think back to everything that I did to protect myself. I can make you feel scary.

EV recalled a similar experience:

I've been exposed to splashes and I've gotten needle sticks. When it happened I cried, Oh Lord, tearful, tearful, and very tearful. And then you have to get counseling, and they tell you that it's a low percentage that health care workers get it. Sometimes you say, suppose I'm in that percentage, but that's just being human. When you get expose you thank God that the patients are HIV negative when the test results come back.

Fear of infectiveness was clearly voiced as the participants initially described the emotional feelings towards caring for patients with HIV or AIDS in Jamaica. They described feelings of anxiety, apprehension, and pure terror when they have been exposed or think they have been exposed to the virus. These participants expressed that the initial reaction is seeing themselves as human beings who may contract this deadly and incurable disease.

### **Transitionness**

Transitionness is the second theme that was evident after data analysis from the root word transition, which is used to describe the experiences of the participants.

Transition is defined as "any event or non-event that results in changed relationships, routines, assumptions, and roles" (Evans, Forney & Guido-DiBrito, 1998). Transitioning from student to professional nurse is often filled with uncertainly, feelings of doubt, and

overwhelming stress (Holland, 1999). The transition from a novice to an experienced nurse caused many of the participants to change their perceptions in caring for patients with HIV or AIDS in Jamaica. An overarching subtheme that emerged during the transition process is the effect that education or knowledge had in changing participants' perceptions in caring for patients with this disease. Understanding the dynamics that surrounds the transmission of HIV that causes the disease AIDS, can help foster a caring environment for patients. This thought is shared by EV:

As the years went by education has caused a significant change. When I just came out of college as a young nurse, I did not understand the entire HIV/AIDS disease process, it was not in depth at that time. We did not meet many patients with the disease. We did not meet those that were asymptomatic and HIV-positive, per se as student nurses. What we saw were patients that were in the end stage of AIDS and dying. Education has definitely played a great role in how we care for them now.

Bobette's views were similar:

I was scared, very scared, because when I just came out of nursing school, they were put on one side of the wards. Back then the whole stigma was stronger than it is now. I think the knowledge and experience that I have gained over the years have caused me to look at the situation different. You tend to care for the patient with the virus or disease much better because you're more educated and you're more trained. You have the porters or the other female attendants, persons who were not medically trained but when they are educated, that also make caring for them easier. But before, if you call a porter or an attendant to take the person to

X-ray, they would wear gloves; want to wear a mask, and anything else they could find. But with the campaigning going on, and the education of all the staff around you, they now know that if they touch that person they will not get infected, or contract the disease. It makes caring for them much easier.

Lovely Merci recalled:

I have been a nurse for 19 years, when I came out of nursing school as a new nurse I was a bit scared and somewhat reluctant in caring for them, but that has changed totally. Increasing your knowledge and understanding of the disease can help you in the handling the condition more and more.

Even with less than five years of nursing experience, and the epidemic of HIV/AIDS sweeping the country, some of the participants still communicated that education and knowledge were still effective in helping to decrease the stigma in their views. Mary shared:

Even with only two plus years of nursing experience and the fact that HIV and AIDS is known in Jamaica, and in nursing school it is now a part of our curriculum, just getting into it you are bit apprehensive initially. I think dealing with something new and especially the stigma that is associated with it in the society. But the more experience you get and the more you interact and learn about the disease and use universal precautions and all of that, you get more comfortable as you provide nursing care to them. So by the time I was a full pledge RN, the transition that occurred was cemented so to speak.

With just three years of nursing experience, Tinker Bell confirmed that when you have knowledge and education, you are more willing to care for the patients. She explained her transition during nursing school:

Well, just leaving nursing school was not bad. It was a transition during nursing school, first year hands-off, second-year a little bit less afraid, but as I go along and got into learning about the disease and how it is transmitted, I became less worried. Third year, I was all right; by graduation, they were like any other patient.

Reflecting on their experiences as nurses, the participants felt that their increased knowledge and education had a significant impact in the transition role. These participants felt that it positively affected how they care for the population. Lovely Merci summed up their feelings: “As we have gotten more education, we have become more comfortable caring for these patients. We are quite comfortable now caring for them just like any other patient.”

### **Powerlessness and Anger**

Another related theme that emerged from the data through multiple readings was powerlessness. Powerlessness is defined as the perception that an individual's action will not significantly affect an outcome and he or she has a perceived lack of control over current situation or immediate happening (Miller-Keane Encyclopedia and Dictionary of Medicine, 2003). Feelings of powerlessness have been described in relation to serious diseases and suffering and can produce strong feelings, such as anger and guilt (Kylma, 2005). Within the concept of powerlessness is anger, which is defined as a strong, uncomfortable emotional response to a provocation that is unwanted and incongruent to

one's values, rights, or beliefs (Thomas, 2009). Anger is rationally justifiable according to Thomas (2009), as nurses see something that is wrong and needs to be corrected, and they feel they have no control over the situation, thus producing the emotion of anger. The participants' sense of anger was not so much associated with negative feelings that they may have harbored towards patients, but rather the feeling of powerlessness due to the inability to change patient situations.

Circumstances that contribute to the participants' feeling of powerlessness are very compelling in the narratives. Participants revealed how frustrating it was and how they became angry when patients were very nonchalant about their diagnosis and their lifestyle. Joy shared her story with much emotion:

There are some days where I have challenges with patients who are just resistant, and I get frustrated because you go through education sessions with them. For instance, you have a newly diagnosed patient, you do your post-test counseling, and all the steps they need to follow, and granted it is a transition from being diagnosed and going on to acceptance. There are some persons who are very aggressive; if that's the word, yes. For example, the other day I had a client who was diagnosed a few years ago but has defaulted with this treatment, so we're trying to get him back into treatment and his whole attitude is "hurry up with what you are doing, cause I want to go to my yard, me want to go eat, cause me no eat from morning." Is like he is rushing you, because you are trying to gauge what he understands of the condition, and where he is at in terms of acceptance, and see if there is a need, or to see if he is at that stage mentally for us to initiate treatment along with his clinical symptoms. But he was just so, as I said so aggressive,

resistant, and I had to stop and said to myself count to 10, count to 10. I was angry; I got angry, but the good thing is that I did not show it physically. I had to stop the interview process with him and call for the adherence counselor to come see him. I ask the counselor to speak to Mr. “So & So” because I was not getting through to him. And after that the man attitude was just the same, no change. He was just awful.

Likewise, Bobette revealed her emotional encounter with a patient:

I am upset most times. No, literally angry. I’m just very upset to know that there is help and they are not getting it. Are they just rebelling, some people still have the idea that “I catch it from somebody, so I have to give it back somebody.” So it’s very sad. I am upset. A lady came in the other day, she came in for attempted suicide because she found that she had this virus and I was saying to her “Why did you want to kill yourself”, and she was saying she’s hurt because this person gave it to her and she was being faithful to the person. I said to her, but life goes on, I know it is a disease, but you can live with it. You can be treated; you cannot be cured, but you can be treated. So she said if she can’t kill herself, she just have to give it to somebody else, that is how angry she was. That does not make sense. It was like I could not get through to her.

Powerlessness and anger related to lack of disclosure by patients with the disease or virus is another common factor that produces the feelings that they cannot do anything, according to the participants. They are aware that they cannot disclose the patient’s condition to their family members or significant others. Words such as cruelty,

wickedness, and unforgiveness permeated the narratives as the participants recall some of these moments. Ms. McKenzie recalled:

To be honest, sometimes I feel I like that person is very cruel, but you try not showing it, you have to maintain your professionalism. But in your mind, you're saying this person is a wicked man or woman, especially when the partners and they are so attentive, they bathe them take care for them, and do everything. And imagine you can't say anything because of patient confidentiality; we don't want to breach their confidence. So you don't express it openly, while to myself, I am saying this is a wicked person. How can they do this?

Desert Rose shared a similar story:

I might be a little bit angry when I find somebody not sharing or disclosing what is wrong with them to their family or significant other. But I always ask myself, why they are doing something like that? And if you question them, you talk to them; it goes back to the fact of how some people deal with certain issues differently. This may be a fight or flight for them, and in some situation, they may say "I have to deal with it, and disclose to my partner and let them know so they can get tested." But some persons, they chose not to disclose it and feel like somebody gave it to me, so I am going to give it to as much persons as I can give. It makes you angry. Yes, because they know that they have the virus and are still participating in unprotected sex. Can you imagine a husband or wife who is positive and is going back home to sleep with their partner and don't tell them? Do you think you can forgive somebody for something like that? That is hard. That is hard.

Deary expressed her feelings of powerlessness:

Some of them may have family support, especially if they are truly loved you will see family taking care of them, and you respect them for letting family know their condition. But you have some of them that no matter how much the family take care of them, they don't tell their family. It is like a secret that they take to their grave. Those are the ones that are hardened, even when it comes down to the last stage, the family will come around them and see them. You are the nurse you cannot tell them you have to maintain a level of confidentiality. I know it is their business, but somehow I think it is irresponsible.

Mishy shared a similar story:

It's very hard, difficult to care for them, because you know they probably can go anytime now. What really bothers me is when some person doesn't want to tell their family or loved ones. The point that is really bothering me, and I don't agree with AIDS, but I don't agree with it. You are going home; you're going home to that relative to take care of you, because you cannot help yourself. In the hospital you try to encourage them to tell their relatives, at least let one person in the household know. Maybe the person is going to take care of you. They are "like no nurse, I can't tell anybody. I don't want my husband or I don't want my wife to know". This is the part that really bothers me. I don't know how they can be like that. It really hurts. I feel hurt because I'm saying that this is a HIV positive wife, the husband doesn't know, and you cannot say anything, because of the confidentiality. One day, this patient came in, and her test came back positive.



We encouraged her to tell her husband. She said no, and she ended up dying and nobody knew what caused her death.

Another way in which these nurses felt powerlessness and anger is a lack of compliance by patients who were diagnosed with the virus or disease in taking their medication and practicing safe sex. Encountering these patients brought frustration for the participants as described by Nurse Beans:

Wow, I see these patients who are diagnosed, and they know they have to take their medication to help them get better and stay alive. Yet still, they go to the clinic and get the medication and still they won't take it. Because the medications are free, that is my problem. So you see them over and over, until eventually they are in the end stage, because if you care for them one time you pretty much know them each time they come into the hospital. You look at them. I said this person doesn't care. And then when it boils down to the nitty-gritty, this is it and this is the time, they say if I had known.

Ms. Miller recalled her encounter with a noncompliant patient:

The ARV medications are free here on the island, and you see so many of them not taking advantage of it. Yes, you get angry, I don't know why but the medication is there. Nobody's stopping them from getting it. It is free, so the first question I asked is why, why they are not getting help. Then, it is never a good reason. Then, that's when you feel the anger more than ever. You have to scold the person and then some people still don't care. They go home and when they come back their medications have finish quite a long time and when you ask them why they did not refill their prescription they can give you no good reason.

Because the medication is free. You feel angry, really angry at them, and you wonder to yourself, what I can do. We know that they want to have a normal life and we encourage it, but they can still be sexually active carefully. But some persons are not using protection because they still come here pregnant many of the young women. Sometimes, the child is likely for a different father each time. You shake your head and said my God, how can I help this person?

Duck shared her story but from a different perspective:

Now, sometimes I work in the accident and emergency department and I see patients who come in for other complications. Then upon examination and asking what medications they take you realize that they're HIV-positive. Looking at them, you would never know that they're HIV-positive. They are the picture of health, especially the men good specimen of men. But when you ask them if they're practicing safe sex, they hiss their teeth and reply "me can't use them rubber thing, it is not the same." They'll tell you I'm going to die anyway so let me enjoy the little time I have left. You try and tell as an individual you should not believe in a promiscuous life; you should be using your condoms, having one sexual partner; but still that person is adamant and go on just having unprotected sex. That is the part that tears your heart apart because you know more people will be infected by this disease because of this one person.

The participants shared their feelings of powerlessness and anger when caring for patients living with the HIV virus or AIDS in Jamaica. Expressing their concerns, many of the nurses experienced a sense of futility caring for these patients, as they are aware that no cure is available for HIV/AIDS. The major concern for the nurses as they shared

their story was the feeling that they could not do anything when patients are noncompliant. Ms. Miller summarized the feelings of being powerlessness in the situation of the other participants:

Persons are just determined, saying somebody gave it to them so they are going to give it to other people. Unfortunately, it is the gift that keeps on giving. What can we do, it hurts, and oh it hurts so much.

### **Compassioness**

Compassioness is the final theme expressed by the participants as they described their experiences caring for patients with HIV/AIDS in the various stages of the disease process. Synonymous with empathy in this current study, compassioness is defined as the acknowledgement of another individual suffering and accompanied by an expression or a desire to ease or end that suffering (van der Cingel, 2009). Halpern (2003) describes empathy as the ability to understand the thoughts and emotions of another person, or in other words, imagining how it feels to be in another person's situation. Helping their patients move beyond feelings of negativity and hopelessness by displaying compassion allowed the participants to acknowledge their feelings. Empathy is an essential component of a caring relationship and especially critical to the provision of quality nursing care. Genuine and heartfelt feelings are expressed by the nurses throughout the narratives. Mary shared her feelings:

Throughout the continuum of the disease you have patients that come to the hospital. They may be newly diagnosed in the hospital setting, and when they develop like secondary infections or disorders that are opportunistic you may see them often. You are empathetic because you know that the end is near so to say.

So you try to make the patient as comfortable as possible, and try to give them as much care until that time come. The persons are having various emotions at this time, and so you have to provide psychological and emotional support according to what the patient is displaying.

Ms. McKenzie expressed her feelings of empathy:

I feel very sad. I am just wondering oh my God, what this person is dealing with. And I can just imagine myself, I know how I would be feeling, the whole mental state. When I see them come in the sympathetic side may want to come out, but the empathetic side always comes out. Because I said oh my God, I wonder how she's doing, how is this person handling it. I see the mothers who have just delivered their baby, especially if it's newly diagnosed. I tend to go to the person very regularly to check to see how she's feeling and to let her know that I am there if she needs to talk to anyone.

Duck expressed similar feelings:

I try to be empathetic towards them and try to be there until the end as much as possible. You want this person to have a peaceful death. So I try to be there, sometimes just sitting not really say anything, but just being there. If they want to vent you just listen, some grieve in a different way, and sometimes they're just quiet. So it is best just to sit and be there for them. Sometimes, no family is around, which makes it harder for them. So as nurses, they look to you.

Caring for the different types of population with the disease in Jamaica, the participants revealed to the researcher that their feelings do not change. However, caring

for the children population, the participants shared intense feelings of sadness, heartbreak, and an overwhelming need to protect them, as shared by Deary:

Oh my God, oh my God, the children. It breaks your heart because they are very innocent. To see children end up with HIV and AIDS. It is very sad. You just want to wrap them up in your arms and protect them.

Joy voiced her sadness:

They suffer you know, they go through a lot and it is not their fault. So sometimes you cry, you don't know what to do, especially when they are at the point where you know that there is not much you can do, you just care for them and make them as comfortable as possible, but it really is draining, emotionally draining.

The sadness and heartbreak continued for Ms. Miller:

It is very heartbreaking. I went to a camp recently and there was a little girl there. She was born with HIV, and you know you want to stop her from doing anything. I just want to watch her. I was being very overprotective; you don't want anything to happen to them. Then, when they get sick your heart just breaks a little more as the disease destroy their little body. That could be my child. It makes you want to cry each day, but you put on a brave face, encourage and support them and their family till the end.

Bobette painfully shared her encounter with a young patient:

Caring for children with the disease hurts you to the core, because they don't really understand what is happening. They keep asking why I am sick. Most times they are recurrent admissions and they really don't understand what is

happening to them. I have met a young woman she was about 10 and she was very knowledgeable and I was saying to her. You have been sick for a while now; you're missing school you need to go to school and play with your friends. And she said, I won't tell them that I have AIDS. I will just tell them that I have a cold, and I was in the hospital. Sometimes I ask God, why the children, and sometimes I think He answers and remind me that I am here to care and make a difference in their lives.

Feelings of much sadness were voiced by Tinker Bell:

It is just pity, pity, pity, just a lot of pity? You tend to want to care more; it is like you want to be that mother figure in the sense. It's like you know, they have the disease and they cannot go through life like that. Some of them, you know is going to get the respiratory infections, respiratory distress and all those things coming into their lives. So you just want to look out for them, because if somebody has a cold you want to first isolate them, because you don't want any further harm to come to them. It breaks your heart, but you just have to do more nursing when it comes to them. Just have to give them that extra care

Caring for the children was not the only population that brought feelings of empathy to the participants. Each participant discussed how being a homosexual and having HIV or AIDS brings strong, negative stigmas and feelings in the Jamaican society. But all participants consistently expressed feeling emotional and sad when caring for this population, even though they may not support their sexual orientation as recalled by EV:

I know they say Jamaicans are homophobic, or the Pastor say we don't like sin, but when it is the patient that is affected, it's not the lifestyle that the person led, that lead to the type of care. No, you look at that the patient needs at that particular time, and care for them. It doesn't matter what the patient is, or whether I'm homophobic or not, the patient needs to be cared for and that is what I have to do. Then you have to teach in the same time, protection, prevention and how to care for them self as an individual.

Similar comments were conveyed by Deary:

As nurses you cannot show how you really feel. So in yourself, you are hurt, but you cannot show it. But as a person, I feel really bad, because it is their lifestyles that may have cause this to happen. But you can't change people's lifestyle; you just have to educate them. You pass no judgment against them. As a nurse you feel as if your mission is not completed unless you have made a difference, and you know shortly their life is going to be gone. So as a nurse you feel sad, but you put those thoughts aside and support them to the end. That is our goal in nursing, to care, no matter who your patient is.

Dessert expressed her views:

Sometimes they are open and say yes they are homosexual, while certain behavior may suggests that they are; but you know I always say some persons are homophobic, but I don't get into what people do behind closed doors, it is just their business. So I just have to respect the person for whom they are. They maybe homosexuals, yes, but sometimes they can be the most wonderful person

you may find, and the ultimate goal is to show them that you understand and care for them as they linger and suffer.

Describing their feelings when caring for the patients, some of the nurses shared how their religious beliefs helped them display empathetic feelings. Motivated by their spirituality, the participants expressed empathy through their touch and words of encouragement. Lovely Merci shared:

Before I start taking care of them, I make sure I have what I need. Because I have to do it, I choose to do it from my heart. And actually, let me tell you, I know Jesus, and I think that makes a difference. So I look at my patients and I treat them because of Jesus. Even though I get frustrated, but I use that in comforting myself when I'm caring for them. Jesus died for me, you understand, so I just have to do what I have to do for them. You touch them and make them feel that you care, not scorning them because of their illness.

Mary described how her religion buffers the care she provides:

Having Christ within makes a whole lot of difference when you encounter these patients. In nursing you have to be as objective as possible; you might not agree with the person's actions, but you have the obligation to care for them. Love overrides the negative feelings, and you look at them as if they were your own family member. Remember, this could happen to anyone of us. If the person has any religious views, I sometimes sing a hymn or a song they know to make them feel some comfort in their last days.

Through rich descriptive and emotional stories, the participants shared their feelings of empathy as they provided care to the different patient population infected with



HIV or AIDS. Empathy was displayed in various ways, from tears of sadness, a gentle touch, to singing songs of comfort. Many of the participants stated that “empathy” was the one word that would sum up their experience when caring for these patients. Ms. McKenzie shared the final words:

I always pictured myself being in this condition and how I would want to be treated with what I would be going through. Try to imagine what that person is going through and how it feels. Sometimes they put on a face to say that I’m okay, smiling and everything, but you know, they are dying inside. So try to picture yourself in their condition and approach them in that manner.

The themes that emerged from the study of the lived experience of Jamaican nurses caring for patients with HIV/AIDS in Jamaica, through rich descriptive narratives, represented the meaning the participants found in their experiences. Identifying their fears associated with the disease and how they overcame them with education provided a positive outcome even in a negative situation. Emotional and passionate accounts of their experiences provided a forum for the researcher to truly become engaged and gain a deeper understanding and the true meaning of their experiences.

The aim of this phenomenological inquiry was to describe the lived experience of Jamaican nurses who have cared for patients with HIV/AIDS in Jamaica. The purpose was to give the nurses a forum to articulate their experiences through narrative stories in an effort to reveal the true essences of their experiences. Max van Manen’s (1990) phenomenological method of inquiry and analysis was used to facilitate the discovery process of this study and allowed the researcher to gain a deeper understanding of what it was like to care for this patient population in Jamaica.

### **Chapter Summary**

This chapter discussed the significant findings of the phenomenological inquiry of the lived experiences of Jamaican nurses who have cared for patients with HIV/AIDS in Jamaica. Demographic representation of the participants was discussed in aggregate, with individual descriptions of each participant in the study. Related themes that emerged from thoughts, feelings, and descriptions of the participants' experiences with the phenomena were presented, as revealed through the narratives. The descriptions were developed from the nurses' experiences and provided the researcher with a clear and concise view into their experiences. The overarching themes that summarized the shared personal stories of the participants were presented, allowing the researcher to gain a deeper understanding of the experience. The outcome of this inquiry enabled the researcher to capture the essences of the phenomenon by uncovering the major themes of fear of infectiveness, transitioness, powerlessness and anger, and compassioness. The meaning of the study will be discussed in Chapter Five.

## **CHAPTER FIVE**

### **DISCUSSION AND CONCLUSION OF THE INQUIRY**

The purpose of this study was to explore the lived experience of Jamaican nurses who have cared for patients with HIV/AIDS in Jamaica to gain an in-depth understanding of the meaning of caring for this population. Qualitative phenomenological research seeks to unfold meanings as they are lived, revealing the true essences of the phenomenon as it is experienced. Understanding this phenomenon of caring for patients with HIV/AIDS in Jamaica can ultimately produce positive outcomes both for patients and nurses.

van Manen's (1990) method for hermeneutic phenomenology was used to explore the rich descriptive data to produce textual interpretation of the phenomenon to reveal the essences. Hermeneutics phenomenology plays a role in postmodern philosophy and seeks to arrive at an agreement or consensus as to what the text means (Aylesworth, 2005). Phenomenology seeks to identify, describe, and maintain the subjective experiences of the participants; therefore, the themes that emerged are the interpretation solely of the researcher and are thus open to discussions or different interpretations. An interpretive analysis of the themes that emerged from the study will be detailed and correlated with a discussion of the relationship between the findings of the study and the theory of meaning.

#### **Exploration of the Meaning of the Study**

This study was a phenomenological qualitative research endeavor to describe the lived experience of Jamaican nurses who have cared for patients with HIV/AIDS in Jamaica. At the heart of every phenomenological research endeavor is a deep

questioning of an experience, a personal interest, and a strong need to discover significant information regarding this population's experience with the phenomena. The rationale for the study was supported by the lack of significant nursing literature describing the lived experience of Jamaican nurses caring for patient with HIV/AIDS in Jamaica.

With the intent of answering this phenomenological question "What is the lived experience of Jamaican nurses caring for patients with HIV/AIDS in Jamaica?" the researcher engaged in various activities to discern the meaning and essence of the phenomena as experienced by the participants. As the rich descriptive narratives were collected, activities of journaling and expressions of meaning through the literature, film, and music were employed to search for the essence of this phenomenon. Listening to the voices of the participants as they shared their stories and viewing the phenomenon through their eyes presented a clear understanding of the phenomenon to the researcher. The compelling stories and intense descriptions of their experiences caring for patients with this disease and the challenges they face propelled a need to search for the essence and meaning within their experiences. As the nurses described their experience, they identified their call to nursing as their life purpose.

### **Interpretive Analysis of the Findings**

#### **Fear of Infectiveness**

The strong stigma and discrimination surrounding the illness of HIV/AIDS has a profound effect on the emotional well-being of those who come in contact with individuals who has the disease. Fear of infectiveness represents the initial, emotional impact these nurses felt during their encounter with patients who are diagnosed with HIV/AIDS. Feelings of anxiety, apprehension, and fear of contracting the disease

permeated the participants' stories within this theme. Participants described what it was like caring for patients with this disease and fearing for their lives within the realm of the nursing duties. This theme "fear of infectiveness" emerged as the participants revealed their emotional reactions and personal feelings towards the devastation that this disease produces.

The participants shared that there is often an amplified notion of threat fueled by stereotypes, which inevitably leads to negative attitudes and stigmatization when an individual comes into contact with people living with HIV/AIDS. The anxiety felt by health care workers when caring for this population and the associated fear has been recognized in numerous studies. Fear of infectiveness remains a concern among nurses involved in caring for HIV/AIDS patients. In a similar study conducted by Mullins (2009), the researcher reported similar findings regarding the fear of infectiveness among West Virginia nurses caring for patients with HIV/AIDS. Even though the nurses would provide compassionate care, an overall sense of anxiety associated with the fear of contracting HIV/AIDS remained one of the biggest concerns for the nurses. Duck revealed this with her comments: "You know it is your duty to care for them, but this is really one disease I don't want to catch. I make sure I have all my universal precautions in place before I take care of them." Ms. McKenzie also felt that the fear of contagion is at the forefront of nurses' mind when providing care to patients with HIV/AIDS.

Gurung and Sangchart (2008) also reported similar findings in their study conducted in Bhutan and concluded that although HIV/AIDS has been around for over four decades, the fear of infectiveness remains the number one concern for nurses. They asserted that although nurses may show positive attitudes when caring for patients with

HIV/AIDS, the fear of the disease still remains. This is consistent with the feelings of Lovely Merci, a study participant, as she shared emotionality: “I have been doing this for a long time, I am quite comfortable caring for them, but, I am still afraid of catching this disease.”

With a fear of contracting HIV/AIDS as a result of accidental exposure, the participants reported examining their previous steps when they are exposed in the caring process. This thought was expressed by Deary: “If I got a needle stick from a HIV patient, I start to wonder, did I have my gloves on, and did I do everything right to protect myself?” The researcher found a similar conclusion in a study by Smit (2005), conducted in South Africa. A qualitative approach was used to interview 35 nurses who worked in a public hospital to ascertain their perceptions of caring for patients with HIV/AIDS. The findings concluded that fear of infectiveness was closely related to the risk of accidental exposure for the nurses. The common thread among the nurses was the need to affirm that they had protected themselves when caring for patients. Loewenbrück (2000) indicated that the fear experienced by nurses is normally far greater than the actual risk of infection. The following verses illustrate the sentiments of the participants,

“The Fear of Fear”

Fear is not what I am afraid of.  
 True, it is a frightful thing to fear;  
 But the fear of fearing fear is overwhelming  
 Especially when its form becomes sheer...

I fear not death nor do I fear life,  
 But I fear the fear of both as my peers;  
 If I could release one fear from my fears  
 It would be the fear of fearing these fears

(Samah, 2007)

Despite the fact that the epidemic of HIV/AIDS has been around for over three decades, the participants still felt that fear of contracting the disease remains a great challenge for the nursing profession. These findings were consistent in a study conducted by Hall (2011) examining the challenges HIV/AIDS poses to nurses in their work environment. The researcher concluded in his findings that being infected with the HIV virus was a major concern for nursing in the course of their professional duties. Similarly, the participants in this study struggled to suppress their fears, while providing care for patients with HIV/AIDS.

### **Transitioness**

Transitioness is another related theme that emerged as the Jamaican nurses described their experiences caring for patients with HIV/AIDS in Jamaica. Moving from novice to an experienced nurse with an increase in knowledge and education, these participants shared that their perceptions change when they encounter patients with HIV/AIDS. Participants described their experience at the beginning of the nursing career when they first encountered patients with HIV/AIDS. They shared how hesitant they were to touch the patients or deliver appropriate care; however, they emphasized that with an increase in knowledge and experience about HIV/AIDS, a transition process took place in their nursing career.

This finding is supported in other studies that examine how an increase in nurses' experience and knowledge changes their perception when caring for patients with HIV/AIDS. Walusimbi and Okonsky (2004) conducted a study in Uganda to assess knowledge and attitude of nurses caring for HIV patients in that country. The researchers' findings supported this current study, as they concluded that lack of

knowledge and experience in nurses caring for patients with HIV/AIDS can affect the nurses' behavior towards the patients. A similar study conducted by Wang, Simoni, and Paterson (2007) of nurses in Taiwan found that nurses with higher level of education and increased knowledge of HIV/AIDS had a more positive attitude towards patient with the disease. According to the participants in this study, the process of transition that is evident with an increase in education and knowledge is one that is necessary for nurses as they encounter patients with HIV/AIDS.

Transition is further supported in a study conducted by Taher and Abdelhai (2011) in Egypt. A pre-and post-educational intervention was used to assess the knowledge, perception, and attitudes of experienced nurses and nursing students towards HIV/AIDS patients. The authors concluded that the nurses with experience and knowledge were more prepared to care for the vulnerable patients and had fewer negative attitudes towards them. However, nursing students were more willing to care for the patient with HIV/AIDS, after they were exposed to the educational intervention. The findings in this study supports the argument that an increase in knowledge and experience can help decrease the negative perceptions and attitudes that surround caring for patients with HIV/AIDS.

Lack of knowledge and experience can impede the way patients are treated with HIV/AIDS, according to the participants in the study. Universally, the participants shared that without knowledge and experience, many nurses will not care for these patients. In order to decrease the fear and transition to a peaceful place of caring for these patients, the participants strongly emphasize that knowledge and experience is the key. Mary shared their universal thoughts:



The more experience you get and the more you interact and learn about the disease and use universal precautions and all of that, you get more comfortable as you provide nursing care to them. This helps the transition to become cemented so to speak.

### **Powerlessness and Anger**

The participants in this study expressed their emotions of powerlessness and anger within their experience of caring for patients with HIV/AIDS in Jamaica. Powerlessness and anger is another related theme that emerged from the descriptive narratives of the nurses as they describe their experiences caring for patients with HIV/AIDS in Jamaica. This emotion of anger was not associated with any negative feelings that the participants harbored against the patients, but rather a feeling of powerlessness in changing their views, beliefs, or actions towards the disease. The nurses' descriptions included "frustration," "patient was just awful, not listening to me," and "It was like I could not get through to her." Kyla (2005) indicated that serious diseases and suffering can produce strong feelings, such as anger and guilt, and are significantly related to feelings of powerlessness. For the nurses in this study, powerlessness and anger consistently overshadowed their experiences when caring for patients with HIV/AIDS. Ms. Miller reflects on her perspective: "You shake your head and say my God, how can I help this person?"

The findings of this current research, which revealed the emotions of powerlessness and anger when caring for patients with HIV/AIDS, are consistent with those of Smit (2005). This author described the perception of nurses in a public hospital in South Africa caring for patients with HIV/AIDS. A qualitative approach was used to

collect in-depth interviews from 35 nurses about their experience caring for patients with HIV/AIDS. The findings of the study determined that nurses felt very helpless and powerless when dealing with patients with this disease because of the incurability and a sense of futility while caring for these terminally ill patients.

The researcher also found a similar pattern in a qualitative study by Fournier, Kipp, Mill, and Walusimbi (2007), assessing nursing care of AIDS patients in Uganda. In-depth interviews were conducted with six nurses who were primary caregivers for this patient population, which resulted in two major themes that emerged from the study: challenges to caring and coping with challenges as they care for these patients. Within the theme of coping with challenges, the authors concluded in their findings that one of the most significant subthemes was a feeling of helplessness and powerlessness by the nurses. These emotions were expressed by the nurses as they felt that no matter what services they provided for the patients, there was still little that they could do to alleviate the devastation of the disease towards these patients. The complexity and challenges the Jamaican nurses face when caring for this population was exemplified by study participant Duck, as she struggled to cope with the acceptance that patients are refusing to seek treatment when treatment is available. She shook her head in dismay: "Can you imagine that we have free medications here and people don't want to take it to help them? Then they go and infect others; that is just wrong."

Addressing nursing attitudes and feelings when caring for people with HIV/AIDS, Breeault and Polifroni's (1992) research findings paralleled those of this current research. A non-experimental qualitative study was conducted with a convenience sample of 16 nurses who worked in three Connecticut hospitals. The themes that emerged after data

analysis were fear, anger, sympathy, self enhancement, and helplessness. The theme of helplessness is synonymous with powerlessness in this current research. The authors concluded in their findings that helplessness was an expression of powerlessness related to providing care to patients with AIDS. These feelings were related to the noncompliance of these patients especially those who continue to engage in high-risk behaviors, even though they were known to be HIV-positive. These findings were consistent within the narratives of several participants in the current study who encountered patients who were noncompliant with medication adherence and participation in safe sex.

The emotions of powerlessness and anger described by the nurses as they encounter patients with HIV/AIDS in Jamaica remain a burden within the challenges of caring for this vulnerable population. The participants in the study consistently voiced in their narratives words such as “what can I do to help this person?”, “can I change how he thinks about this disease to make him seek treatment?”, or “how can I get through to them so that they see they are hurting others when they pass on this disease?”

### **Compassioness**

Compassion is the foundation of nursing practice and represents a commitment to acknowledge and respond to those who are suffering around us. Compassioness is the final theme that emerged from the rich, descriptive narratives of the participants. Described as an intrinsic link to caring in nursing, compassion acknowledges patients’ suffering and the desire to end or ease it (Harrowing, 2011). Sabo (2006) believed that nurses who exhibit compassion will not only respond with feelings at the time of the patients suffering but will also care for the patients in an ongoing way. Halpern (2003)

describes empathy as the ability to understand the thoughts and emotions of another person, or in other words, imagine how it feels to be in another person's situation, which is synonymous with empathy in this current study. Throughout the narratives, the nurses described feelings of sadness, providing comfort in the final days of those dying, and feeling that they have made a difference to patient.

Similar findings of compassion were found in a study conducted by Harrowing (2011) among Ugandan nurses who cared for patients with HIV/AIDS. The author concluded that nurses who practice with compassion were more motivated to provide care to the affected population. One of the themes that emerged out of that study was "a call to serve," an inspiration for the nurses entering the nursing profession. This finding is consistent with the words of Lovely Merci who shared:

I love nursing; you have to enjoy what you do. That is what makes a difference when you care for these patients, and see the devastation in their eyes when everyone has left and they look to you the nurse for help. You just can't turn your back against them when the end is so difficult for them.

Empathetic feelings were not only shown to patients but included the families of those suffering who were aware of their diagnosis. Smit (2005) in assessing the perceptions of nurses in a public hospital in South Africa found that nurses displayed feelings of empathy towards family members of patients who are afflicted with the disease or virus. The nurses in the study contended that compassion and empathy should include the family as they are also suffering along with the patient through the stages of the disease. In this current study, families of children suffering from the disease need the

most support, according to the nurses. They shared through tears how they comforted mothers who have lost their only child to this disease. Mishy emphasized these findings:

I put myself in the place of that mother whose teenager daughter or son is dying.

I have teenager children, so I know how it feels. You put aside any negative views of how they caught the disease and just wrap your arms around them. We are humans who have become nurses, so we have to feel for them.

The following poem by Celes (2010) represents the duty of our profession:

“World Nurses Day, 2010”

Let love of money never interfere  
With sacrificial service for mankind,  
In times of ailments, distress, agony,  
In noble profession on earth – Nursing.

Let duty to the suffering patients stay  
Paramount all life, mitigating pain;  
Let selflessness prevail in loving care  
Of brethren moribund, in throes of death.

Let love of profession fill the hearts  
Those follow Florence Nightingale’s footsteps;  
Let God reward thee amply for thy work  
In saving lives and curing diseases.

May thy noble profession remain so!  
Let ethics not be ignored any day;  
Let loving care of human beings make  
The earth a paradise to some extent!

“May God bless all nurses on this most wonderful Day!”

Even though HIV/AIDS remains incurable, and projected negative feelings are present in many health care settings, Hodgson (2006) discovered in his mini-ethnography study that within the culture of caring for people with HIV/AIDS, a strong empathetic approach is taken by the nurses. Over a 14-month period, he observed and interviewed

31 nurses in the United Kingdom who worked on a unit dedicated to caring for this population of patients. He discovered that nurses developed a caring relationship with the patients over a period of time as negative feelings dissipate and empathy becomes pronounced as they watch the patients slowly deteriorate. This finding is congruent with the finding of this current study as nurses voiced sadness and moments of shedding tears as they watch patients who they have become close with lose their battle. With tears in her eyes, Deary recounted an experience:

I had a patient who told she was a virgin when she got married, and her husband gave it to her. Several of us cared for her during each admission for some related condition, until she could no longer be cared for at home. We bathed her, combed her hair, prayed with her and we would take turns holding her hands, because nobody came to see her. We showed her we cared about her, until she took her last breath; this is what nursing is all about.

As they care for a vulnerable population within the realms of compassion and empathy, nurses are reminded of how devastating this disease can be. A poem by Christine Patterson (2003), titled “The End of Time” symbolizes their feelings:

There are no more birds too sing,  
There are no more bells too ring.  
Time has stopped because of the mistake of war;  
It is too late to bring it back like it was before.

So many laid on the Earth's ground,  
Finally there is peace and it's a lonely sound.  
We the Poet's, wrote the warnings that were too be,  
But the blind did not listen, they refused to see.

The sadness is in the hearts of the wise,  
But now it is too late, time has stopped and we all had to die.  
As many souls slowly go to the heavens above,  
The fools that started this war never knew the gift of love.

We are paying a price that never should have happened this way,  
If only we would have thought, there would be another day.  
Now all that is left is a cloud,  
With the tears of despair, the cries are so loud.

The water is now darkened with blood,  
The lands are layered with bodies and bones of a war's flood.  
I can't do anything except stand here and shake my head,  
Because the world we once knew is now dead.

### **Theory of Meaning**

The meaning of life without a doubt is one of the most challenging and yet one of the most fundamental questions the mind can consider. Human beings continue their quest to make sense out of life as they see, hear, and experience it. Understanding and interpreting life's meaning in our everyday existence continues to be an integral aspect of human life. According to Fabry (1991), "A person's life offers meaning in every moment and in every situation" (p. 130). The theory of meaning (Starck, 2008) seeks to uncover meaning and purpose in life, regardless of the circumstances. This theory is based on the work of Viktor E. Frankl (1984) and was originally developed to treat individuals with psychiatric or psychological disorders but "has been expanded to assist human beings cope with everyday stresses of life and catastrophic life-changing events" (Starck, 2008, p. 85).

The foundation for this theory of meaning is embedded in generalized statements of truths according to Frankl (1984), statements that are represented by three principles that support the underpinnings of his theory. In the first principle, Frankl (1984) believed that "A person's search for meaning is the primary motivation of life" (p. 121). He further contended that the meaning of the experience is unique and specific for that

individual and can only be fulfilled by the person. The perception of this principle is that in every life experience, there is some meaning and purpose.

The second principle in Frankl's (1961) theory suggests that "a person is free to be responsible and is responsible for the realization of the meaning of life, the logos of existence" (p. 9). The implication of this principle is that each individual is responsible to find true meaning in his or her experiences of life and has the freedom to choose what position he or she will take when he or she encounters challenging situations of suffering.

The third principle suggests that "A person may find meaning in life, even when confronted with a hopeless situation, when facing the fate that cannot be changed" (p. 135). Fabry (1991) implied that the objective is to find meaning in life regardless of the situation, when coping with an unchangeable fate or situation. Finding meaning in life through suffering in whatever situation an individual may find themselves in can ultimately bring satisfaction and healing, revealing his or her purpose in life.

The findings of this current research have led the researcher to a connection between the lived experiences of Jamaican nurses caring for patients with HIV/AIDS in Jamaica and Starck's theory of meaning. The related themes of fear of infectiveness, transitioness, powerlessness and anger, and compassioness are parallel to the major concepts of this theory.

### **Concepts of Theory**

The major concepts of Starck's (2008) theory of meaning, from the works of Frankl (1984), are life purpose, freedom to choose, and human suffering. The conception of this theory originated with the need to help individuals who are experiencing inevitable suffering find ways in which to cope as they search for meaning in their lives.



The focus of theory is individuals discovering meaning when facing life challenges or experiences. Starck (2008) implied that finding meaning is a journey towards achieving life's purpose, and ultimately it is the responsibility of the individual to choose which pathway he or she will take, despite unchangeable suffering. According to Frankl (1984):

The way in which a man accepts his fate and all the suffering it entails, the way in which he takes up his cross, gives him ample opportunity even under the most difficult circumstances to add a deeper meaning to his life. (p. 76)

The concepts of the theory and the relationship among them are depicted in Figure 7.

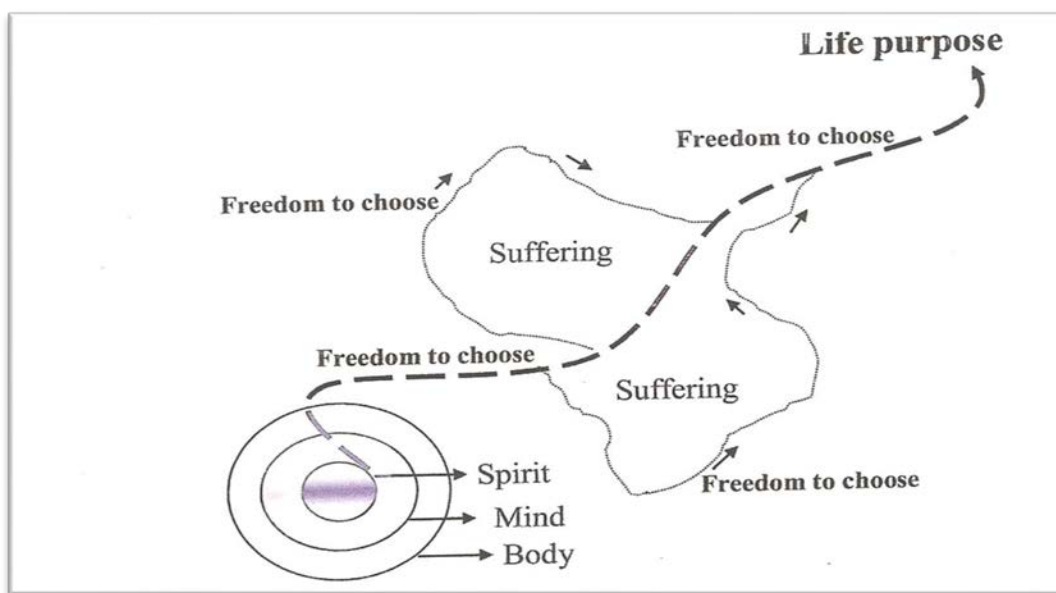


Figure 7. Theory of Meaning (Starck, 2008).

### **Life Purpose**

The central concept of the theory of meaning is life purpose. Starck (2008) described this concept as a representation of an individual's existence and purpose in life. The concept of life purpose seeks to bring satisfaction to an individual seeking his or her place in the world. Discovering life's purpose is a means to unearth one's calling or

work to which one can become dedicated. The undertone of this concept of life purpose is making a contribution and leaving the world a better place.

Frankl (1984) maintained that in discovering meaning, a person can also discover his or her life's purpose. He specified that individuals can find meaning in three different ways to an to uncover their life purpose: by working and giving back without thinking of yourself, by experiencing the world through something and others, and by choosing an attitude of acceptance towards our fate, no matter how unchangeable the situation is.

Caring for patient with HIV/AIDS in Jamaica, which seems as an unchangeable event some of the participants in this research sought to accomplish their individual life purpose, regardless of the challenges they may face. Confronted by the stigma and discrimination that surrounds this disease, the participants have found ways to fulfill their purpose. The transition that occurred through an increase in knowledge and experience provided the avenue through which the participants cared for these patients, ultimately gaining a sense of purpose for which they were called. Many of the participants reported that once they gained knowledge of how the disease is transmitted and how to properly care for patients using universal precautions, their attitudes and perceptions were no longer negative.

With an advanced degree as a nurse practitioner, Joy reported that she felt that her calling is to care for this vulnerable population no matter how difficult it may seem. She took pleasure in educating the patients with HIV/AIDS that she encounters, making sure they understand their disease process and how to better take care of themselves. Passing on the education regarding HIV/AIDS to others is the fulfillment for Mrs. Miller and Ms.

McKenzie in the maternity ward, as they see this as a way of giving back to others. Some of the other participants simply held the hands of those that were dying from this devastating disease, knowing that they would not contract the disease, feeling that somehow they had made a difference to someone else. Making the difference in someone else's life regardless of the unchangeable situation was a way for the nurses in this study to find meaning in their experiences and ultimately their life purpose.

### **Freedom to Choose**

The second concept of the theory of meaning is the freedom to choose. Starck (2008) describes it as “the process of selecting among options over which one has control” (p. 91). Frankl (1984) emphasized that when we are confronted with unalterable destiny, a unique opportunity is presented to choose one's attitude how we will react to the situation. This is the freedom that an individual has to choose how they will control the unchangeable situation. Humans have the potential within themselves how they will behave, and the manifestation depends on their decision, not necessarily on the condition. Frankl (1984) believed that individuals have the freedom to rise above their suffering and find meaning in their lives regardless of the unchangeable circumstances. Fabry (1991) further asked the question: What can we do that will benefit someone else?

The concept of freedom to choose supports the theme of empathy that emerged in the study. The nurses caring for patients with HIV/AIDS in Jamaica expressed thoughts and emotions of sadness and heartbreak, imagining how it feels to be in the person's situation. They struggled with the emotions of sadness as they watched the devastating effect of the disease take the lives of their patients. Many expressed giving words of

comfort, praying, and singing in order to provide psychological and emotional support to both patients and families. Seeing new mothers just deliver a newborn baby and then be shattered by the news of being HIV positive, the nurses embrace the patients, provide a shoulder to lean on, wipe the tears, and ultimately provide words of encouragement.

The participants felt they had made a decision to enter the nursing field, knowing that one day they would encounter patients with HIV/AIDS, and the decision to care for these patients is something they would do all over again. The participants recalled the voices of family members expressing concern regarding the population that they care for; however, their attitudes were, I made nursing my calling, and therefore, I made the choice to care. These research participants essentially saw that caring empathetically gave them a choice in how they face the situation of caring for patients with HIV/AIDS. Frankl (1984) said it best: “.... everything can be taken from a man but one thing: the last of the human freedoms—to choose one’s attitude in any given set of circumstances, to choose one’s own way” (p. 104).

### **Human Suffering**

Human suffering is the third concept of theory of meaning. Considered to be an unavoidable phenomenon in the human experience, suffering is viewed as a subjective experience that is unique to the individual only and swings on the pendulum of simple transitory discomfort to extreme anguish and despair. Frankl (1984) believes that the meaning of suffering holds the deepest possible meaning in the human experience and can only be described as a subjective experience. He emphasizes that the search for meaning in an individual’s unique suffering can be a very lonely one and is considered to be a threat to self and wholeness as the individual knows it.

The concept of human suffering supports the theme of fear of infectiveness. The fear of contracting HIV/AIDS when caring for patients causes a surmountable amount of suffering for the nurses, as the negative perception of having this disease is in the forefront of their mind. Many of the participants expressed their reaction when they come into contact with contaminated blood and fearing for their lives and the suffering they would endure. These experiences caused extreme anguish and despair as their life's flash before them when they encounter these situations. Nurse Beans recalled it best: "My God, my God, what would I do, how would I tell my family. Could I endure the suffering that comes with this disease?" Other participants who work in the labor and delivery ward view their suffering experience as retracing their steps, making sure they had used every precautionary measure when a break in universal techniques is recognized during the care of a patient with HIV/AIDS.

Another theme in this current research that is supported by the concept of human suffering is powerlessness and anger experienced by the nurses when they care for patients with HIV/AIDS in Jamaica. Within the concept of human suffering, this theme of anger and powerlessness brings some transitory discomfort to the nurses during the caring process. This discomfort brings emotional suffering to the nurses as they experience patients who are non-compliant in their care regime. As a result, the nurses felt that their actions will not have any significant outcome. Joy had to stop and count to 10, as she encountered a patient who refuses to give up a promiscuous lifestyle although he was HIV positive. Other participants recalled emotions of feeling upset as they watch patients die without disclosing their illness to their family who may be infected. Experiencing human suffering, whether through the fear of infectiveness or the emotional

suffering that occurs as a result of being powerless and angry, each nurse sought to find meaning in her experience.

### **Relationship of Theory to this Study**

The theory of meaning provided a framework to achieve a deeper and more authentic understanding of the lived experience of Jamaican nurses caring for patients with HIV/AIDS in Jamaica. Underpinning this phenomenon is the themes of fear of infectiveness, transitioness, powerlessness, and compassioness. The initial reaction for the nurses when caring for patients with HIV/AIDS in Jamaica was one of fear. Associated with strong stigma and discrimination, contracting this disease would be challenging for the nurses. As a result of increased knowledge and experience, a transition process occurred in the nurses were no longer afraid of caring for these patients. However, encountering patients who were noncompliant in various aspects produced emotions of powerlessness and anger. Nurses felt that in many situations, they could not change the perception of the patients. Ultimately, recognizing their purpose and calling in the profession of nursing, with compassion, the nurses chose to provide care to a diverse population.

### **Implications/Significance of the Study for Nursing Knowledge**

Multiple studies from qualitative and quantitative perspectives have addressed the experiences of nursing caring for patients with HIV/AIDS; however, the experiences of Jamaican nurses have not been addressed, leaving a gap in the literature. Understanding the effects of caring for patients with HIV/AIDS has implications for the nursing profession, which encounters this vulnerable population. The findings that emerged from this study could potentially be used to advance the body of knowledge in nursing.

### **Implications for Nursing Education**

As the epidemic of HIV/AIDS continues to impact the island of Jamaica and the experiences of the nurses who provide care to the affected population, the findings of this study clearly illustrated that additional education of this disease and its effect is needed to provide quality care. The fear of infectiveness and the suffering of nurses as they care for this population necessitate the need for nursing education to address the psychological and emotional stress that is associated with caring for this population. National and international organizations that offer certifications or continuing education could also incorporate information from this study to increase knowledge and enhance patient outcomes.

A deeper understanding of the life world as experienced by Jamaican nurses caring for patients with HIV/AIDS in Jamaica resulted from this phenomenological investigation. Through the narratives from the nurses and expressions of their feelings with this experience, a deeper appreciation of the Jamaican perception of HIV/AIDS emerged. Understanding and acknowledging the perceptions could have direct implications on nursing education in Jamaica. Reform of educational curriculum in schools of nursing can be revised to incorporate how these perceptions affect the nursing profession. Information from this study can be utilized in planning lectures, workshops, and seminars and be further disseminated into nursing practice.

The findings of the study also indicated the fundamental need to comprehend the culture of Jamaica and the meanings placed upon caring for patients with HIV/AIDS. Formal nursing education or in-services is necessary to understand the sensitivity of

Jamaican culture and reaction to this disease. Culturally sensitive curriculums can help to develop culturally sensitive nurses. As the population that is affected by HIV/AIDS increases on this island, the nursing profession needs to evolve in order to meet its needs. Thus, nursing interventions regarding caring for patients with HIV/AIDS could be identified, producing less stigmas and discrimination.

### **Implications for Nursing Practice**

The epidemic of HIV/AIDS remains a constant threat to the nursing profession, and as a result, nurses are faced with the challenges that surround this disease. The findings of this study indicate that nurses are burdened with emotional stress and face components of human suffering caring for this vulnerable population. Caring is the foundation on which nursing was built, and the caring interaction between nurses and their patients allows for open expressions of feelings during this time. The increased understanding of their experiences and the meanings could be applied to the clinical settings, such as hospitals and community clinics in Jamaica, in order to incorporate support measures to the nurses who continue to provide quality patient care, in spite of the adversities.

Health care professionals such as nurses are viewed as the backbone in times of crisis; however, as the profession of nursing evolves to meet the needs of this population, we should not forget the needs of our nurses. Implementing structured support groups can provide an environment where nurses are able to share their experiences, express their feelings and daily challenges with others. The knowledge gained from this study could assist in bridging the gap between the stigma and discrimination of this disease and



how nursing practice is implemented, by nurses being ethically responsible and advocating for their patients' best interests.

### **Implications for Nursing Research**

Evidence-based research continues to be the building blocks for the nursing profession, and this study provided a small view into the meaning of nurses' experience caring for patients with HIV/AIDS. Hence, there is a great need for more investigations to identify meaningful insights of this phenomenon within another population. These investigative approaches should not be limited to just exploratory research but should be addressed from both quantitative and qualitative perspective to fully grasp the effects of this phenomenon within a population. Nursing research helps to provide effective practices, which can be applied within the nursing profession. This study highlighted the need for further extensive studies of HIV/AIDS and how nurses in other Caribbean islands are affected. Replication of this study in other areas could potentially produce rich data to substantiate the need for changes in caring for patients with HIV/AIDS.

### **Implications for Health/Public Policy**

Despite the impact of HIV/AIDS in Jamaica, the findings of this study revealed that there are several implications towards health/public policy. There is a tremendous need to address the lack of understanding within Jamaica regarding the impact of this disease on individuals and the country as a whole. The participants shared that treatment for HIV/AIDS, such as antiretroviral medication, is provided by clinics in Jamaica. However, the percentage of infected individuals who take advantage of this privilege remains very small.

The need to educate the public is tremendous, and nurses should be influential in petitioning the Ministry of Health in Jamaica to develop programs that address preventative and treatment strategies for the society. Nurses in Jamaica practice under the Jamaica Council of Nursing, a branch from the Ministry of Health. This organization could assist in providing necessary policies to encourage patient education in all health care facilities. These programs could further educate their common surroundings including their community, such as schools, churches, and both private and public organizations regarding the transmission of this disease and how individuals can protect themselves.

As the disease and its related complications impact this small island, the participants revealed the act of deliberate transmission by individuals causing a vicious cycle within communities. Public policies regarding this deliberate act of transmission are greatly needed to help decrease the percentage of infected individuals on this island. These policies should mandate that such individuals be held accountable within the court of law.

### **Strength and Limitations of the Study**

The purpose of this study was to explore the lived experiences of Jamaican nurses caring for patient with HIV/AIDS in Jamaica, to gain an understanding of the meaning of this experience. This study allowed the nurses to voice their perceptions, fears, and challenges caring for this population. The strength of the study was it helped to provide insight into the experiences of caring for this population and some identifiable knowledge in addressing the concerns of these nurses.

This study was conducted in Jamaica and presented several identifiable limitations for the researcher. The first limitation is the strong stigma and discrimination surrounding the disease in the Jamaica, which presented some resistance in the recruitment of participants from the hospital. In addition, several of the potential participants worked the night shift and would only commit to a short 15-minute interview, limiting the pool of potential participants for the researcher.

Another limitation of the study is that the 14 participants worked at the same hospital on the island, therefore limiting the ability to generalize the findings of this study on the island. However, within the qualitative perspective, such as phenomenology, a small sample size can produce rich data about the phenomenon and is not intended to be generalized within the population. This exploratory research consisted of 14 participants who were all female, which produce a limitation in the characteristics of the research participants.

### **Recommendations for Future Study**

To fully comprehend and gain a deeper understanding of the lived experiences of nurses who have cared for patients with HIV/AIDS, there is a need for more qualitative studies. The central core of qualitative phenomenological research of the lived experience is to reveal the essence or meaning that is associated with the experience. The lack of qualitative research that examines the lived experiences of Jamaican nurses caring for patient with HIV/AIDS supports the exploration of this study and has partially bridged the gap in existing knowledge of this phenomenon of interest.

Future study of this phenomenon should include HIV/AIDS intervention programs targeting both health care personnel and communities. This study could

determine individual's perceptions of the disease and help in the development of prevention strategies. Examining the meanings that are placed on this phenomenon of interest by a diverse population of nurses, can produce significant findings to support the body of nursing including nurses from other Caribbean islands. The island of Jamaica is diverse in its culture, which could affect how patients are treated on the island. Examining the nursing profession according to the inherent culture of this island could produce significant information that could be utilized in adjusting strategies to meet the needs of the population. The continuation of the HIV/AIDS epidemic around the world and new methods of treating this disease requires investigation in order to develop strategies and knowledge to assist nurses in following their call to duty.

### **Conclusions and Summary**

Caring for patients with HIV/AIDS on the island of Jamaica continues to be a challenge for nurses as the epidemic continues to affect patients of all ages. The focus of this phenomenological study was to explore the lived experience of Jamaican nurses caring for patients with HIV/AIDS on the island and gain a deeper understanding of the meaning of their experience. This chapter discussed the findings of the inquiry and the meaning of the experiences as described by the participants.

With the support from participants eager to share their story, the purpose of this phenomenological study was accomplished. The rich, narrative descriptions of the study participants' experience with the phenomena revealed the themes of fear of contagion, transition with knowledge, anger and powerlessness, and empathy in caring. These themes brought out the essence and meaning of the experiences of the participants.

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**APPENDICES**

**APPENDIX A****IRB FORM**

OFFICE OF THE PROVOST  
INSTITUTIONAL REVIEW BOARD

Research with Human Subjects  
Protocol Review

Date: August 16, 2012

Protocol Number: 120816  
Title: The Lived Experience of Jamaican Nurses Caring for Patients with Human Immunodeficiency Virus or Acquired Immune Deficiency Syndrome in Jamaica

Meeting Date: August 15, 2012

Researcher Name: Blondel Martin  
Address: [REDACTED]

Dear Ms. Martin:

Barry University Institutional Review Board (IRB) reviewed the above-referenced research protocol prior to its regularly scheduled meeting on August 15, 2012. It is the IRB's judgment that the rights and welfare of the individuals who may be asked to participate in this study will be respected; that the proposed research, including the process of obtaining informed consent, will be conducted in a manner consistent with requirements and that the potential benefits to participants and to others warrant the risks participants may choose to incur. You may therefore proceed with data collection. Enclosed is the stamped Consent Cover letter indicating that your protocol has been reviewed and approved by the IRB. Please use this form when collecting your data.

As principal investigator of this protocol, it is your responsibility to make sure that this study is conducted as approved by the IRB. Any modifications to the protocol or consent form, initiated by you or by the sponsor, will require prior approval, which you may request by completing a protocol modification form.

It is a condition of this approval that you report promptly to the IRB any serious, unanticipated adverse events experienced by participants in the course of this research, whether or not they are directly related to the study protocol. These adverse events include, but may not be limited to, any experience that is fatal or immediately life-threatening, is permanently disabling, requires (or prolongs) inpatient hospitalization, or is a congenital anomaly cancer or overdose.

The approval granted expires on September 30, 2013. Should you wish to maintain this protocol in an active status beyond that date, you will need to provide the IRB with and IRB Application for Continuing Review (Progress Report) summarizing study results to date. The IRB will request a progress report from you approximately three months before the anniversary date of your current approval.

If you have questions about these procedures, or need any additional assistance from the IRB, please call the IRB point of contact, Mrs. Barbara Cook at [REDACTED] or send an e-mail to [REDACTED]. Finally, please review your professional liability insurance to make sure your coverage includes the activities in this study.

Sincerely,



Linda Bacheller, Psy.D., J.D.  
Chair, Institutional Review Board  
Barry University



Cc: Dr. Jessie Colin

\*\*\*\*\*  
Note: The investigator will be solely responsible and strictly accountable for any deviation from or failure to follow the research protocol as approved and will hold Barry University harmless from all claims against it arising from said deviation or failure.

## APPENDIX B

### PERMISSION LETTER

Approved by Barry University IRB a

Date: AUG 16 2012

Signature a

*Smile Barrella, Esq., JD*

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#### Permission Letter

July 9, 2012

To: Administrative Board

My name is Blondel O. Martin, MSN/ED. RN. I am a doctoral student at Barry University in Miami, Florida in the dissertation phase of my study. My research project is entitled "*The Lived Experience of Jamaican Nurses Caring for Patients with Human Immunodeficiency (HIV) or Acquired Immune Deficiency Syndrome (AIDS) in Jamaica*". The information obtained from this research will be useful in the field of nursing, by giving the Jamaican nurses with this experience a medium for their voice to be heard.

I am hereby requesting permission to place a recruitment flyer in your health care organization for nurses to participate in this study. I would like to place flyers in the following places: lobby of hospital, nurses' stations, and nurses' lounges. Your cooperation would greatly be appreciated. Should further information about the study be needed, please e-mail me at [REDACTED]. Thank you very much in advance for your help and cooperation.

---

Blondel Martin, MSN/Ed. RN  
Barry University  
Doctoral Student





July 23, 2012

Ms. Blondel Martin, MSN/ED,RN  
Barry University  
Miami  
Florida

Re: Permission Letter

Dear Ms. Marlin

I have received your letter of request to conduct your research project at the [redacted]  
[redacted]

Permission is granted for you to place your flyer in the facility.

It is anticipated that the Nurses will participate in the study.

Yours truly

*Paulett Long-Carr*  
Paulett Long-Carr  
Director of Nursing Services

PLC\skgj

## APPENDIX C

### INFORMED CONSENT FORM

Approved by Barry University IRB ■

Date: AUG 16 2012

Signature: *Andre Barcelon, PhD, JD*

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## APPENDIX B

### BARRY UNIVERSITY INFORMED CONSENT FORM

You are asked to volunteer in a research study. The title of the study is: The Lived Experience of Jamaican Nurses Caring for Patients with Human Immunodeficiency Virus (HIV) or Acquired Immune Deficiency Syndrome (AIDS) in Jamaica. The research is being conducted by Blondel Martin, MSN/Ed, a doctoral student at Barry University; she is seeking information that will be useful in the field of nursing. The purpose of this research is to understand the experiences of registered nurses who have cared for patients with HIV/AIDS in Jamaica. The maximum number of participants will be 25. To volunteer in this study, you must be a registered nurse, speak English, and have over one year of nursing experience.

If you decide to participate in this research, you will be asked to participate in two interviews. The first is approximately 1 hour long, audio-taped face to face interview. The second is to verify transcripts, and answer any questions. Your consent is strictly voluntary and should you decline to participate or withdraw during the study, there will be no adverse effects to you, or your health care. There are no risks by participating in this study. As a participant, you have the right to refuse to answer a question, ask that the tape recording stop, or withdraw from the study. If you withdraw none of the information will be used in the study. Although there are no direct benefits to you, your participation will help in our understanding of the registered nurses experiences caring for this population. As a token of appreciation upon completing the interviews, you will receive US\$10.00

As a research participant, information you provide will be held in confidence to the extent permitted by law. You will be asked to choose a pseudonym for the interview to maintain confidentiality. Any published results of the research will refer to group averages only and no names will be used in the study. Data will be kept in a locked file in the researcher's home office. Audio-tapes of the interview will be destroyed once you confirm authenticity in the second interview. Your signed consent form will be kept separate from the data. All data will be destroyed after five years.

If you have any questions or concerns regarding the study or your participation in the study, you may contact Blondel Martin at [REDACTED] the Institutional Review Board point of contact, Barbara Cook, at [REDACTED] or Dissertation Chair, Jessie Colin, at [REDACTED]. If you are satisfied with the information provided and are willing to participate in this research, please signify your consent by signing this consent form.

#### **Voluntary Consent**

I acknowledge that I have been informed of the nature and purposes of this experiment by Blondel Martin, and that I have read and understand the information presented above, and that I have received a copy of this form for my records. I give my voluntary consent to participate in this experiment.

<i>Signature of Participant</i>	<i>Date</i>	<i>Researcher</i>	<i>Date</i>

(Witness signature is required only if research involves pregnant women, children, other vulnerable populations, or if more than minimal risk is present.)

## APPENDIX D

## RECRUITMENT FLYER



## **CARING FOR HIV/AIDS PATIENTS**

**Are you a Registered Nurse?**

**Do you have over one year nursing experience**

**Have you taken care of HIV/AIDS PATIENTS?**

**Would you like to share your experience?**

If you answered yes to the questions above, you may qualify to participate in a research study. This research study involves sharing your experience of caring for patients diagnosed with HIV/AIDS in two interviews with a nurse researcher. The interviews will be conducted face-to-face.

The purpose of this research is to explore what it is like to care for patients with AIDS/HIV. This study will be conducted by a registered nurse, Blondel Martin, in partial fulfillment of requirements for the PhD in Nursing from Barry University, Miami Shores, Florida.

A token of \$US 10.00 will be given to the first 25 accepted participants in appreciation for their time. For more information, please contact

**Blondel Martin, MSN/Ed. RN at:**



Institutional Review Board  
Barbara Cook



Dissertation Chair  
Dr. Jessie Colin



**Participation is voluntary and all information will be held in strictest confidence**

**APPENDIX E**  
**INTERVIEW PROTOCOL**

Date: \_\_\_\_\_ Time: \_\_\_\_\_

Researcher: Blondel Martin, MSN/Ed, RN

Pseudonym Name: \_\_\_\_\_

Contact Number: \_\_\_\_\_ Email: \_\_\_\_\_

1. Describe research project.
  - Purpose of the study.
  - Risks and benefits of the study.
  - Time commitment.
2. Obtain informed consent.
3. Assure confidentiality and obtain pseudonym.
4. Ensure participants that they:
  - May choose to stop the interview and withdraw from the study at any time.
  - May refuse to answer any specific question or questions
  - May ask that tape recorder be turned off at any time
  - May request to take a break at any time.
5. Request permission to begin interview and recording of audio-tape recording.
6. Conduct interview.
7. Ask if there is anything else participant would like to discuss.
8. Obtain demographic questionnaire.
9. Conclude interview.
  - Thank interviewee and give token of \$US 10.00
  - Repeat assurances of confidentiality.
  - Request for a follow-up meeting and confirm contact information for scheduling.
  - Offer researcher availability by phone or email if questions arise.
  - Ensure that all communication with the researcher will be through a secure, confidential, and password-protected email account, and phone number to be used exclusively for this study.
10. Post Interview:
  - Label audiotape with participant pseudonym.
  - Complete researcher notes and reflection.
  - Begin transcription of taped interviews.

**APPENDIX F**  
**DEMOGRAPHIC QUESTIONNAIRE**

**Pseudonym Name** \_\_\_\_\_

**Date:** \_\_\_\_\_ **Time:** \_\_\_\_\_

**Age:**

- 20 – 29,
- 30 – 39,
- 40 – 49,
- 50 – 59,
- 60 and over

**Race:**

- White
- Black
- Hispanic
- Caribbean

**Marital Status:** \_\_\_\_ Single \_\_\_\_ Married \_\_\_\_ Widowed \_\_\_\_ Divorced

**Employment Status:** \_\_\_\_ Fulltime \_\_\_\_ Part time

**Highest level of education that you have completed:**

- Elementary School
- Middle/Junior High School
- High School
- Some College/Technical School
- College
- Professional/Graduate School

**How long have you been caring for HIV/AIDS patients?** \_\_\_\_\_ years

**How long have you been a nurse?** \_\_\_\_\_ years

## APPENDIX G

### INTERVIEW QUESTIONS AND PROMPTS

1. Primary Question:

*“Tell me what it is like caring for HIV/AIDS patients here in Jamaica”*

2. Prompts:

- What is your mental image of AIDS?
- How would you describe AIDS?
- What feelings come to mind when caring for these patients?
- Does HIV/AIDS have any meaning in your life?
- What population have you cared for (heterosexual, homosexual, or children)?
- Did the care you provided changed based upon the patient population?
- Can you give me one word that described your experience?
- Is there anything else you want to add?

## CURRICULUM VITAE

**BLONDEL MARTIN, MSN/Ed, RN**

<b>EDUCATION</b>	<b>DEGREE</b>	<b>DATE</b>	<b>MAJOR</b>
Barry University	Doctor of Philosophy	Present	Nursing
University of Phoenix	Master of Science/ Health Care Education	2008	Nursing
University of Phoenix	Bachelor of Science	2006	Nursing
Broward College	Associate of Science	1996	Nursing

### **PROFESSIONAL LICENSURE**

Florida 1996  
District of Columbia 2001

### **PROFESSIONAL EXPERIENCE**

<b>Position</b>	<b>Organization</b>	<b>Dates</b>
Adjunct Professor	Palm Beach State College, Lake Worth, Fl.	2001-Present
Registered Nurse	Boca Raton Community Hospital, Boca Raton, Fl	2006-Present
Registered Nurse	North Ridge Medical Center, Fort Lauderdale, FL	2003-2006
Registered Nurse	Washington Hospital Center, Washington, DC.	2001-2003
Registered Nurse	Providence Hospital, Washington, DC.	2001-2003
Registered Nurse	North Broward Hospital District, Fort Laud., FL	1999-2000
Registered Nurse	Florida Medical Center, Oakland Park, FL	1996-2000

### **SCHOLARLY ACTIVITIES**

#### **Dissertation**

Present Student Researcher - *The Lived Experience of Jamaican Nurses Caring for Patients with Human Immunodeficiency Virus Or Acquired Immune Deficiency Syndrome in Jamaica: A Phenomenology Study.*

**INSTRUCTIONAL ACTIVITIES****Teaching Responsibilities**

<b>Course Number</b>	<b>Course Title</b>	<b>Content Focus</b>	<b>Theory/Clinical</b>
NUR1023L	Nursing I	Fundamentals of Nursing	Clinical
NUR 1213L	Nursing II	Medical/Surgical Nursing	Clinical

**MEMBERSHIPS IN PROFESSIONAL ORGANIZATIONS**

Florida League for Nursing	2010
Sigma Theta Tau International	2008