The Lived Experience of Indian Women with HIV/AIDS in South Africa: A Phenomenological Inquiry

Ronica Subramoney[1]

Abstract

Background: South Africa is a multi-ethnic country that has been hardest hit by the HIV/AIDS epidemic. A steady increase in HIV/AIDS infection rates among the Indian population in Kwa-Zulu Natal (KZN) has been noted because of their failure to accept HIV/AIDS as a threat. HIV/AIDS clearly affects all race groups; however, there is a lack of research on Indian women with HIV/AIDS in KZN despite their vulnerability to the disease. This phenomenological research aimed to better understand the essence of the experience of living with HIV/AIDS. **Purpose:** The purpose of this qualitative phenomenological study wasto explore the lived experience of Indian women living in KZN with HIV/AIDS. This research aimed to give Indian women a voice to express their individual experience living with the disease, to provide an inductive description of the lived experience, and to gain understanding of the essence of the experience of living with HIV/AIDS. Philosophical Underpinning: Guided by the phenomenological perspective of Max van Manen. Methods: A purposive sample of Indian women from Kwa-Zulu Natal, South Africa with HIV/AIDS was selected to explore the overarching question: What is the lived experience of living with HIV/AIDS? Data collection occurred from hour-long semi-structured interviews that were tape-recorded, transcribed for verification, and member checked. Data analysis included describing, interpreting, and textual writing as guided by van Manen. **Results:** Therelated themes of themes of struggling, isolating, supporting, and hoping emerged as a total representation of the Indian's women's liveswith HIV/AIDS. **Conclusions:** This research study exposed the depth of the challenges confronting the Indian women with HIV/AIDS. A significant dimension of this experience of living with HIV/AIDS was the search for meaning, which the women were compelled to address in order to move forward in their respective lives.

Chapter One

The human immunodeficiency virus (HIV) declared war on the human race. No one knows for sure the exact date, or time of attack, but it was quiet and unassuming until the causalities began to surface. At first, the Centers for Disease Control and Prevention (CDC) did not realize what it had stumbled upon, but it was concerned about of the increased request for Pentamidine. This drug was used for the treatment ofa severely immuno-compromised condition called Pneumocyctiscarinii pneumonia (PCP). There was a very low incidence of such conditions in the United States (US) until then, and because Pentamidinewas rarely used, the CDC controlled the distribution of the drug. The increased requests for thismedication did cause alarm, but the CDC had not yet realized the enormity of the disease it had just discovered. The CDC, expressed concern about the troubling trend of young homosexual men diagnosed with severe immuno-deficiency diseases, and because very little was known about the disease that appeared to affect onlyhomosexuals, the CDC termed it "Gay-Related- Immunodeficiency" (GRID) and inadvertently stigmatized the disease forever (CDC, 2011).

---

[1] Presented in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy in Nursing, Barry University

HIV infections are caused bya retrovirus that enters the human body through exposure to infected blood, during sexual activity with an infected individual, by sharing needles, from mother-to-child transmissions, and through needle stick injuries. The HIV virus attacks the immune system, which normally protects a person from germs that could make him or her sick (Avert, 2011). Once HIV is in a person's system, it lowers the number of healthy immune cells (CD4 cells) or Helper T cells that a person has to fight the germs. Thus, the human body cannot fight off viruses, bacteria, and fungi that cause diseases. Therefore, when the CD4 cells drops below 200, this makes the person very susceptible to opportunistic infections, such as PCP, Kaposi's sarcoma, or wasting syndrome. The development of these opportunistic infections is known as Acquired Immune Deficiency Syndrome (AIDS). Put simply, the infection caused by the virus is known as HIV, but AIDS is the later stages of an HIV infection. The rate of AIDS differs among the infected but appears to be related to access and adherence to medical care (National Institute of Allergy and Infectious Diseases [NIAID], 2010a). HIV/AIDS was once considered the disease of people who indulged in high-risk behaviors, but sadly, the demographic face of HIV/AIDS has changed. Today, more women are infected with HIV/AIDSthan men, and heterosexual sex is the most common source of infection. Women are the vulnerable gender and have been affected since the beginning of the HIV epidemic. The female gender is at a higher risk in a patriarchal culture and developing countries that favor men over women with education or jobs (World Health Organization [WHO], 2012a).Indian women residing in Kwa-Zulu Natal (KZN), South Africa face the same risk factors that have made the female gender so vulnerable to HIV/AIDS. This study explored the lived experience of the minority Indian women in KZN, to gain an understanding of the essence of their experience with HIV/AIDS. A qualitative approach was suitable because not much is known about this phenomenon. The philosophical framework ofhermeneutic phenomenology was used to guide this study.

Background of the Study

HIV/AIDS was first recognized in 1981, yet more than 30 years later, success in curbing this disease has remained a challenge. Statistical data from 2010 that was published in the UNAIDS Global Report in 2011 indicated that more than 34 million people around the world are infected with HIV/AIDS, and about 2.7 million were infected with HIV/AIDS in 2010. Despite the vast knowledge base, and theextensive research about HIV/AIDS, 7,500 people are still infected daily (The Joint United Nations program on HIV/AIDS [UNAIDS], 2010). This disease continues to be a problem of astronomic proportions that has crossed borders very easily with the ease of international travel. There is simply no cure for this devastating disease that has affected millions worldwide. HIV/AIDS infections have resulted inincreased mortality rates, high infection rates, and imbalances in the population because the most productive are dying young. Thus, the economic growth of developing countries has been stunted, thereforecontinuing the cycle of poverty and illness. Developed countries also face the havoc of this stigmatized disease, but they have the resources to provide adequate care as compared to developing countries. Simply put, this disease is a death sentence in developing countries and a life sentence in developed countries (Tiamson, 2002).

Thus, HIV/AIDS is a global threat that cannot be ignored because of the persistence of new cases despite the knowledge of the modes of transmission, methods of prevention, and resources available. To date, 60 million people have been infected globally, and the epidemic has claimed almost 30 millionlives. A plethora of research has been conducted on AIDS, resulting in increased knowledge of the modes of transmission, methods of prevention, and the development of several treatment options. However, HIV/AIDS remains one of the world's leading infectious killers, claiming about 30 millionlives since 1981 (Avert, 2011). The demographic face of HIV/AIDSprevalencehas changed, and women are currently the most vulnerable population in the world today, making up more than 50% of those infected with HIV (UNAIDS, 2010). The attitude to living with HIV/AIDS is changing, depending on the region of the world in which a person lives. Developed countries offer easy access to medical care, availability of antiretroviral drugs, and availability of psychological care. These countries are beginning to view HIV/AIDS as a chronic condition (Beaudin&Chambre, 1996).However, in developing countries, HIV/AIDS is still considered an acute condition because of the contributing factors that have maintained HIV/AIDS as an epidemic in these areas of the world. These contributing factors include poor access to medical care, fear, shame because of stigmatization, and lack of social support resulting in isolation of people who share their status (Scandlyn, 2000) A great divide continues to exist in the world today between developed and developing countries in their approach to HIV/AIDS. This disease has single-handedly reduced countries' development and productivity because the young are the most high-risk group. Thus, the gap between developed and developing countries in their approach to this disease and economic status has widened (Kaiser Family Foundation, 2011).One possible reason for the persistence of this disease is the reluctance of people to seek help early because of the stigma of AIDS.

HIV/AIDS was primarily stigmatized when it first arose because it was initially diagnosed as a gay man's cancer. However, this stigmatization has failed to disappear even when it has been proven that HIV/AIDS can infect anyone after exposure. HIV/AIDS has devastated families in every country, class, economic status, and social standing and has become a global epidemic (Flowers et al., 2006; Bunting, 1996).

HIV/AIDS in the United States

In the U.S., more than 1.2 million people are infected with HIV/AIDS (Kaiser Family Foundation, 2012a). However, the HIV/AIDS epidemic has had a disproportionate impact on certain populations, such as ethnic minorities, gay, bisexual men, and women. HIV/AIDS have been reported in every state but are mostly concentrated in large metropolitan areas. The disparity of HIV/AIDS epidemic in Black Americans has widened over time. The Black population accounts for most of the new HIV/AIDS infections, and deaths compared to any other race group in the U.S. The Black population represents 12% of the population but 44% of people living with HIV/AIDS. Black women account for 64% of new HIV/AIDS infections, most of which occurred through heterosexual transmission. Most of the women infected with HIV/AIDS have low-income and are uninsured, and have difficulty accessing quality care in addition to balancing family responsibility. Thus, HIV/AIDS is a definite cause for concern in the Black community, specifically for the Black women, and the goal for HIV/AIDS treatment is to reduce the disparity in the U.S. (Kaiser Family Foundation, 2012b).

HIV/AIDS in Africa

Sub-Saharan Africa represents 12% of the world's population but is home to 67% of people living with HIV and 70% of AIDS-related deaths. The adult HIV/AIDS prevalence rate was 5.2%, and was the highest of any region of the world. UNAIDS (2010) have estimated that 75% of all women with HIV/AIDS live in Africa. The young people are most at risk, and the young women most vulnerable. These statistics are frightening and troublesome as the impact of HIV/AIDS will alter the structure of the population pyramid very severely. This epidemic poses a severe challenge for the continent already fighting poverty and has already altered the structure of many nations (Kaiser Family Foundation, 2012c).

HIV/AIDS in South Africa

South Africa is at the southern tip of Africa. The country is divided into nine provinces and is a multi-ethnic nation with diverse cultures and languages. The Black ancestry is further divided among a variety of ethnic groups speaking several languages, making up nine of the 11 languages that have official status. South Africa is considered the most developed and economically stable country on the African continent, yet HIV/AIDS is a threat to the future of the country. The South African government adopted apartheid rule in 1948 (Downing, 2004).Black South Africans were forbidden from marrying Whites (1949), assigned to specific residential zones (1950), required to carry a passbook called a "dompas" (Blacks only) at all times (1952), and compelled to use separate public facilities even when permitted to work in white areas (1953). Figure 1 is one of the many signs that clearly demonstrated the apartheid policy. The apartheid system involved exclusion, oppression, and maltreatment of Blacks (Kon & Lackman, 2008).South Africa is a country of 49 million people with a racial makeup of 79% African or Black, 10% white, 8.8% Colored, and 1.6% Indian(Statistics South Africa, 2010).Although South Africa became a democratic country in 1992, people still see themselves in these four categories.

Figure 1: Sign used during the apartheid era in South Africa. (Source: Bing Images, 2012).

South Africa has been hardest hit by the AIDS epidemic compared to any other country in the world. The Joint United Nations program on HIV/AIDS (UNAIDS) Global Report estimated that 5.6 million people were living with HIV/AIDS in South Africa, a 17.8% prevalence among those aged 15-49 and that 1 in 3 women aged 25-29 were living with HIV/AIDS (UNAIDS, 2010). The South African HIV/AIDS epidemic has been described as an "African-type" AIDS epidemic characterized by the following: The primary mode of infection is heterosexual; the number of HIV-infected women exceeds the number of HIV-infected men; HIV/AIDS is the primary cause of death; and HIV seroprevalence rates exceed all human plausibility of heterosexual HIV transmission. To understand how South Africa became the country with the most number of infected people in the world, a person would have to understand the political struggle of South Africa. In fact, South Africa's quest for racial equality ran parallel to the emergence of the HIV/AIDS epidemic in South Africa (Kon & Lackman, 2008).The first HIV/AIDS case in South Africa was diagnosed in 1982, in a White homosexual flight attendant. Little attention was given to this disease as South Africa was focused on ending racial segregation caused by the apartheid system. Thus, the main focus was on the political unrest in South Africa, and minimal attention was paid to the HIV/AIDS epidemic.

HIV/AIDS thrived among the gay population in the 1980s but soon spread to the heterosexual population. By 1991, HIV/AIDS infection among the heterosexual population equaled those of the homosexual population, but the new government was very slow to respond to this epidemic. South Africa had just ended the brutal apartheid regime, and the newly elected Democratic Party came into power favoring housing and jobs over HIV/AIDS prevention (Gow, 2009). Therefore, little attention or thought was given to these preventive programs. The government made poor economic choices about raising HIV/AIDS awareness. It chose to produce a costly play (Sarafina) that did little to improve HIV awareness (Phila Legislative update, 1996; Department of Health: Republic of South Africa, 1995). The politicians were making decisions about permitting drug trials, and the government also downplayed the importance of retroviral drugs that had proved to be effective in reducing transmission and infection rates (Kaida, 2011).

Some public voices even attributed HIV spread to socioeconomic and lifestyle choices (Mamaila & Brand, 2000). Thus, the history of HIV/AIDS in South Africa is the most controversial of any country. The complaints of inactivity, interference, and conflict among the government, AIDS organizations, and scientists have created an epidemic of mammoth proportions (Colvin & Robins, 2009). The result of the counterproductive activities has resulted in South Africa leading the world with the largest number of people infected with HIV/AIDS. Apartheid ended in the early 1990s, but a new apartheid in HIV/AIDS management emerged, as great disparities in the prevalence of HIV/AIDS continue to exist. KZN, a predominantly Black area, has the largest HIV/AIDS prevalence rate in South Africa (39.1%). The Indian population that resides in KZN is the largest outside India, and while Indians make up 2.6 % of the 49 million South Africans, they represent 1.6% of new HIV-positive people (Statistics South Africa, 2010). HIV/AIDS prevention was initially aimed at the White and Black population only, but recent infection trends have indicated that HIV/AIDS has crossed the racial barriers as evidenced by the presence of the disease in all race groups. Thus, the need for culturally appropriate care is essential in this battle against HIV/AIDS infection. The rate of infection, the prevalence, and death rates of HIV/AIDS are frightening statistics for the South African people and the world. Clearly, South Africa has not addressed their issues with HIV/AIDS adequately. Three decades later and HIV/AIDS has dominated the world as the number one threat. The suffering, devastation, and economic losses from this disease are astronomical. The health care gap between the developing and developed countries continues to grow, and the impact on the minority racial groups widens (UNAIDS, 2010).

The UNAIDS Global Report indicated that HIV prevalence among females in South Africa is highest between 25-29 years, and women with HIV/AIDS outnumber the men.HIV/AIDS remains a global problem because of the multitude of issues, such as stigma, gender inequalities, and the deep impact on the infrastructure of countries that supports the need for investigating this phenomenon (UNAIDS, 2010).Although HIV/AIDS does not discriminate, societal norms do, and a disparity does exist in infection and prevalence rates between the genders. Women make up more than 50% of the people infected with HIV/AIDS, and majority of these women live in sub-Saharan Africa. The literature review revealed that women's infection rate is unacceptably high because of the unique impact on women because of societal roles and gender-specific issues(Dageid & Ducker, 2008; Mugambi, 2006).The physical differences between the genders have contributed to women's susceptibility to heterosexual infection (Rhatigan, 1996). Stigmatization has allowed HIV/AIDS to dominate the world with terror. The United Nations Secretary-General, Ki-Moon (2008) once stated: Stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world. Second, disparities among populations groups and genders have contributed to the increasing HIV/AIDS statistics in South Africa and the world. Women have since become the most at-risk group, especially in Africa where the infection rate is higher in women than men (Gow, 2009). Although several research studies have been conducted on various ethnic groups, the literature revealed that there is limited research conducted on Indian women with HIV/AIDS in South Africa. Third, 2011 marked three decades that HIV/AIDS has dominated the world as the number one global health threat. The suffering, devastation, and economic losses from this disease are astronomical (Coovadia & Hadingham, 2005). The health care gap between the developing and developed countries continues to grow, and the impact on the minority racial groups widens. Although research has been extensive and exhaustive, studies show HIV/AIDS thrive in conservative cultures because people fail to get help (Parker, 2002).

Statement of the Problem

A steady increase in new HIV/AIDS infection rates among the Indian population in South Africa has been noted. The Indians in South Africa did not see HIV/AIDS as a threat to them, as HIV/AIDS awareness and prevention programs were primarily aimed at the Black and White population. This has resulted in the Indian population's failure to identify or accept HIV/AIDS as a threat. However, the increased infection rates prove otherwise. There is a lack in the literature of research studies that have been conducted on Indian women with HIV/AIDS in KZN. Therefore, because little is known about this phenomenon, a phenomenological approach is recommended to understand the lived experience of Indian women with HIV/AIDS (Creswell, 2007). Several studies have revealed that women are a vulnerable group because of their disproportion to HIV infection, their societal roles, and biological vulnerability (Kon & Lackan, 2008). Little research has been conducted on Indian women with HIV/AIDS in South Africa. While Indians only make up 2.6 % of the population, they represent 1.6% of all new HIV-positive people. Statistics reveal that HIV/AIDS is currently evident in all race groups. Unfortunately, the minority Indian population did not perceive HIV/AIDS as a threat to them, nor did they embrace HIV/AIDS prevention aggressively. The Indian population's failure to accept HIV/AIDS as a threat has resulted in increased in new infection rates among them. The paucity of literature concerning this ethnic group is evident in the literature review. "This epidemic unfortunately remains an epidemic of women" (United Nations News Service, 2010).In Sub-Saharan Africa, women are most commonly infected through heterosexual contact. Women are two times more likely to be infected from a partner through unprotected sex as compared to women infecting men. The anatomical differences expose a larger surface area to HIV, increasing a women's risk for infection. Women cannot negotiate sexual demands, such as condom use, and are often victims of sexual violence. Additionally, stigma and gender inequality, such as inequalities within the family, violence against women, and economic instability, have had a significant impact on women. These factors are helping to drive HIV/AIDS in South Africa's traditionally conservative Indian communities (Jewkes, Dunkle, Nduna, & Shai, 2010). Thus, women in Africa and South Africa in particular are disproportionately infected.

Purpose of the Study

The purpose of this qualitative phenomenological study was to explore the lived experience of Indian women living in KZN with HIV/AIDS. This research aimed to give Indian women a voice to express their individual experience living with the disease, to provide an inductive description of the lived experience, and to gain understanding of the essence of the experience of living with HIV/AIDS.

Research Question

The guiding research question of this study was: What is the lived experience of women with HIV/AIDS living in South Africa?

Philosophical Underpinnings

Qualitative Research

Qualitative research is aimed at understanding a phenomenon, or exploring attitudes. However, a great divide exists between qualitative and quantitative research because of the lack of generalizability. Despite the lack of support, qualitative research does provide crucial information about the "why" of a phenomenon as compared to the "how" in quantitative research. This information has opened doors for nursing researchers to understand the experience of people as they live it and provide key information to individualized, holistic care of patients (Creswell, 2007). The manner of approach to a qualitative study is determined by the researcher's worldview that is a set of beliefs or assumptions that will provide guidance for the study. The philosophical assumptions are ontological, axiological, epistemological, and methodological. The researcher adopts a view on each assumption, and this in turn has practical implications to guide the research. The ontological assumption perspective is that reality is subjective and has multiple meanings. The researcher can use the individual's own words to describe his or her perspective. This correlates with the axiological assumption, which is the role of values in a study, and researchers have to be aware that data collected contains values important to the participant (Flick, 2009).

Phenomenology

This studyused phenomenology because the researcher was interested in studying the lived experience. Patton (2002) defined phenomenology as"...one that focused on descriptions of what people experience and how it is that they experience what they experience" (p. 71). Van Manen (1990) stated that phenomenological inquiries are descriptive, interpretive, and self-reflective into the "world as world" (p. 72). Phenomenology has been described as a philosophy and a method. Phenomenology is over 100 years old and was founded by Edmund Husserl (1859-1938), who was a German philosopher. Husserl is considered to be the father of phenomenology, and he developed phenomenology to establish psychology as a science. Husserl introduced phenomenology during the mid-1890s, and he believed in the "essence" of the experience. Husserl believed that realities are pure phenomena from which all studies must begin, and he believed in bracketing. Husserl was a student of Franz Brentano. Brentano (1838-1917) was an Austrian, who is credited as the first person to develop the basic approach of phenomenology. He wrote extensively about consciousness, was concerned about the distinction between the "mental and nonmental," and discussed the tem intentionality or the internal experience of being conscious of something (Munhall, 2010). Although Brentano first wrote about phenomenology, it was Husserl who propelled phenomenology forward together with his student Martin Heidegger (1889-1976). They explored the "lived world" and focused on "essences." Martin Heidegger believed that interpreting of meanings is influenced by cultures, history, and worldviews. He introduced the concept of "Dasein or Being there." The phenomenology of Heidegger was further enhanced by the works of Jean-Paul Sartre (1905-1980) and Maurice Merleau-Ponty (1908-1961). Merleau-Pontybelieved that individuals are interrelated with their world (Munhall, 2010).

Phenomenology continued to spread throughout the 20th century through the works of Van Kaam, Giorgi, Parse, and later Max van Manen (Creswell, 2007, p. 58). Several fields have used phenomenology to understand their sciences better, such as social sciences, health sciences, psychology, education, and even nursing (Koch, 1995).Phenomenology bridges the gap between what really exists (metaphysics) and epistemology or the manner in which knowledge is gained (Creswell, 2007). The participants provide the input, but it is the researcher tasks to interpret the responses of the subject accurately. The two main types of phenomenology are descriptive or interpretative. Descriptive phenomenology is based on Husserl's approach and uses epoche or bracketing as the ability to suspend one's judgment, or philosophical belief, and examine phenomena in the original setting with no judgments. Martin Heidegger differed from Husserl, and his phenomenology is interpretative.

He believed that people developed from their experience, background, and the world they lived in and that they could not separate themselves from their world. Heidegger's phenomenology is an interpretative approach (Koch, 1995). Van Manen's human science approach is based on the combination of phenomenology and hermeneutics. According to van Manen, hermeneutics edifies the personal insight. He believed that everything becomes richer with understanding.   He followed Heiderggerian phenomenology and used interpretative hermeneutics so that the researcher could obtain deep, descriptive data, and give meaning to the experience. Van Manen accomplished this by overlapping description, interpretation, and language activities to describe what it means to be in the world (Figure 2).
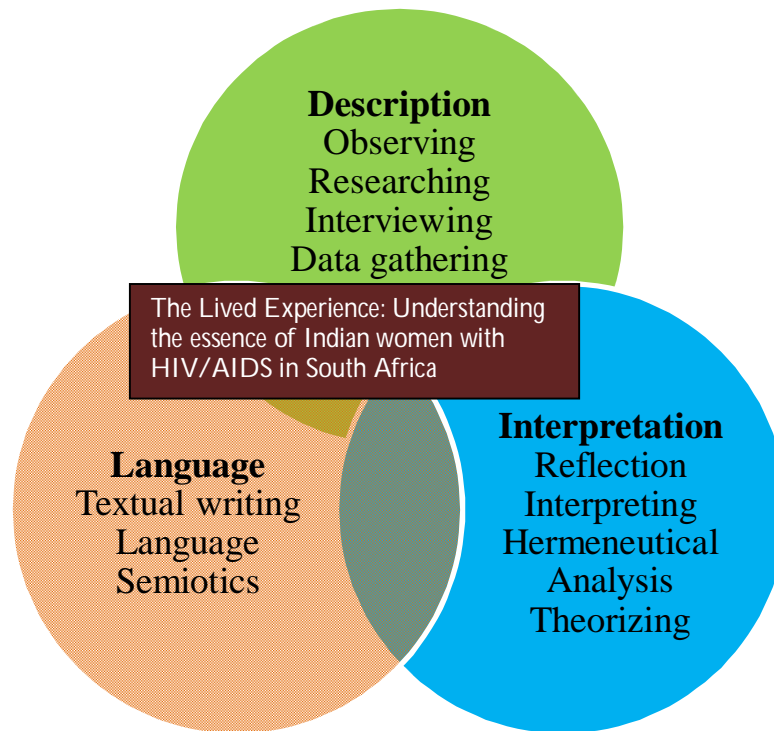

Figure 2.Phenomenological approach. (Subramoney, 2012). Adapted from van Manen (1990, p. 2-8).

Van Manen (1990) advocated for six activities for the conduction of a hermeneutic phenomenological research study. These six activities provide a framework for reflecting and interpreting the phenomena. In activity one, the researcher is committed to a phenomenon to make sense of it. Phenomenological research starts in the "life world" such as lived space, lived body, lived time, and lived relationality. In phenomenology, lived space maybe interpreted as a sense of belonging or it can be objective and measurable, and lived body represents the fact that one is always represented in the world. Lived time addresses the past, present, and future that affect a person's perception. Lived relationally refers to how individuals maintain relationships in the space they share. These are unique to each person, and according to van Manen, all experience can be seen as temporal in nature. The second activity focuses on investigating the lived experience that can be achieved by researching lived experiences in the life world. This aspect of van Manen's method is supported by Heidegger's concepts of being in the world and Dasein. This means that instead of researcher's conceptualizing what it would be like, he or she can seek to understand this experience from someone who lived it. Thus, the researcher has to investigate the lived experience as compared to learning about it. The third activity is about reflecting on essential themes and can be achieved by the researcher's reflection on what made the experience significant. Van Manen(1989) stated that essential themes are not "objects or generalizations … but themes are the stars that make up the universe of meaning we live through" (p. 90). The fourth activity is writing and rewriting to "bring into words" something thoughtful about the experience. Thus, the transcribed interview becomes the texts that the hermeneutical analysis will be conducted upon. It is during this stage that significant themes are detected.

Activity five is about maintaining a strong relation to the phenomenon. The researcher should not allow false data to compromise the research. This step draws upon the concept of the hermeneutic circle that in order to obtain the essence, the researcher has to understand the interconnectedness of themes to the individual interview and that of the whole and determine if the interpretation fits the context of a specific section, in addition to the overall data collected. The sixth activity involves putting it altogether. The themes identified will lead to the essence, which according to van Manen (1990), "makes a thing what it is" (p.177). However, even van Manen (1990) acknowledged that a theme does not fully capture an experience: "…a thematic phrase does not do justice to the fullness of the life of a phenomenon…only serves to point at, to allude to, or hint at the main significance" (p. 92-93). The researcher chose a phenomenological approach because phenomenology allows a participant to describe an experience as it is lived and thus adequately capture the lived experience of the participant in a study (van Manen, 1990). Phenomenology is trying to understand the experience, not seeking to explain a phenomenon, and is one of many qualitative approaches that seek to understand the lived experience. Phenomenology seeks clarification, gains valuable knowledge about an individual's experience, and is defined by Husserl as setting aside previous thoughts, breaking down mental barriers to see exactly "what stands before us" (Husserl, 1931, p. 43). When researchers use the hermeneutic phenomenology of van Manen, they seek to uncover the meanings in everyday existence that are "the fulfillment of our human nature: to become more fully who we are" (van Manen, 1990, p. 10). This method is appropriate based on the research question to understand the lived experience of Indian women in South Africa with HIV/AIDS.

Significance of the Study

The phenomenon of interest was Indian women with HIV/AIDS. They are a particularly vulnerable group because of their conservative culture and subservient social roles. HIV/AIDS among the Indian women are at an endemic stage in KZN and therefore need to be addressed. Little research has been conducted on Indian women with HIV/AIDS in South Africa. Addressing the needs of this population is crucial to South Africa's goal of reducing new HIV/AIDS infection outbreaks.

Significance to Nurse Education

South Africa ended the apartheid regime in the 1990s. However, the citizens still see themselves and others by the four race groups they were divided into during the apartheid era. They have come a long way from that oppression, but it is difficult to say that all South Africans are equal when the citizens themselves view each other by their race. South Africa has a multiethnic society, with several cultural differences among the Black ethnic groups as well as within the four race groups. Thus, cultures do influence the health care needs of individuals in the various cultural groups. To reduce discrimination in the health care field, a cultural competence course may need to be included in the nursing curriculum. Cultural competence theories provide guidelines for nurse educators on how to best disseminate cultural information. Leininger's transcultural theory includes studies of the similarities and differences among and within cultures. She postulated that culturally based care was essential to any individual's health (Leininger, 1978). This is essential in the South African health care provider's approach to Indian women with HIV/AIDS in KZN. Leininger believed that respect for patient culture is crucial to success of any health care regime. The outcome of this study may identify the need for curriculum changes in nursing programs to aid students in becoming more grounded in cultural competency issues.

Significance to Nursing Practice

Health care in South Africa is often provided by nurses who have different cultural backgrounds and who once regarded other race groups with mistrust. This research is significant to nursing practice in the cultural context. Cultural competency is crucial to understand the community to provide effective care. An Indian's woman lack of interest in her health can be perceived as a "do not care' attitude, but health care providers may need to approach this from a cultural perspective. When they look at the HIV/AIDS diagnosis in the cultural context, the shame, stigma, and guilt have placed an enormous burden on the shoulders of these women. This conservative society is very judgmental, and the stigma of this disease can ostracize the woman and her family. Most women cannot discuss their HIV status and would rather suffer in silence than seek help. Understanding the culture may help the nurses be to connect with these women. Showing the women understanding and caring about their plight may make them more accepting of treatment options, rather than being judgmental, which will drive them away (Palattiyil&Chakrabarti, 2008; Costello, 2012). However, cooperation with any medical regime requires a certain amount of buy-in from the people. Buy-in can be achieved only when there is understanding of the culture of the people being treated.

Cultural awareness and sensitivity may make treatment options more accepting. Thus, addressing the cultural needs of each group could ensure greater acceptance by the people.

Significance to Research

The Indian population that resides in KZN is the largest outside India. Little research has been conducted on this population group. Addressing the needs of this large group is crucial to South Africa's success in reducing HIV/AIDS infection rates. Ignoring a minority population can result in catastrophic results, such as the rampant increase in HIV/AIDS among this conservative society. Research may aid in understanding the lived experience of the women and interventions that can help to improve a more active role in the health care.

Significance to Health/Public Policy

The South African government has been criticized for its inadequate addressing of the HIV/AIDS epidemic. However, it has since made slow but more positive changes to its approach. The success of this country's HIV/AIDS program depends on equitable access to care, provision of the required treatment required, and counselors to encourage compliance.   The South African government has been more responsive in offering anti-retroviral medication, testing, and increasing HIV/AIDS awareness. However, the South African government needs to realize that HIV/AIDS prevention is not a "one cap fit all" approach. South Africa is more than just a "four-race group" country. There are several ethnic groups, and all want to be recognized. This is depicted in their choice of an official language. South Africa has 13 official languages excluding the dialect of the Indian population. Culture plays an important role in this country. Therefore, this research may highlight the importance of a culturally based HIV/AIDS prevention plan and the need for a unified approach to eradicate or minimize stigmatization.   Thus, the recommendation of this research may be the provision of culturally acceptable care and the need to address all ethnic groups to ensure greater compliance.

Scope and Limitations of the Study

This study was conducted on Indian women with HIV/AIDS residing in KZN, South Africa. The sample was purposeful. Participants had to volunteer to share their story. This research aimed to give Indian women a voice to express their individual experience, provide an inductive description of the lived experience, and gain understanding of the motivating factors and barriers to seeking treatment. The potential limitations were the shyness of this conservative population that may not divulge total details for fear of being judged by the researcher. The participants may have told the researcher what they think she wants to hear. The study was conducted in South Africa.   The destination may have been a limitation as the researcher's time in South Africa was limited.   The researcher needed to ensure that the data was transcribed correctly and have any queries answered during the second interview while she was in South Africa. The researcher was a novice, and maintaining rigor, and trust worthiness needed to be reinforced. Additional limitations may yet be identified.

Chapter Summary

Chapter one provided an introduction to this study. It presented the background and significance of the study and discussed the purpose and research question. The purpose of this study was to explore the lived experience of Indian women living in KZN with HIV/AIDS. This research aimed to give Indian women a voice to express their individual experience, provide an inductive description of the lived experience, and gain understanding of the motivating factors and barriers to seeking treatment. A qualitative study using the phenomenological approach of Max van Manen was used to fully describe the experience of living with HIV as perceived by these women.

Chapter Two

Review of the Literature

The purpose of a literature review in a qualitative study is to assist the researcher to focus on what was done and the discoveries of that research and highlight the gaps. Thus, a literature review places the topic in context. This review reduces the recurrences of repeated research on the same topic and sample because research is aimed at finding new knowledge or "filling in the gaps" (Wood & Ross-Kerr, 2011). The purpose of this study was to obtain a deeper understanding or the essence of the lived experience of Indian women in South Africa with HIV/AIDS.

Therefore, a synthesis of the literature is crucial to provide a comprehensive reflection of the topic, thereby identifying patterns or gaps. This chapter will begin by presenting the historical background of the disease. Research from 1981 will be reviewed to provide a detailed path of HIV/AIDS from diagnosis to the use of medication to treat HIV/AIDS. This will provide knowledge to understand the concept of HIV/AIDS as a global problem and as an epidemic to women specifically those living in sub-Saharan Africa. Based on the review, the concepts HIV/AIDS, and women, HIV/AIDS, effects on family, emotional, and social well-being, and HIV/AIDS, stigma and chronicity will be grouped to address the purpose. A summary of the studies will end the chapter followed by a brief critiques of the gaps in the literature. A literature search was conducted on Indian women with HIV/AIDS across all disciplines. The researcher used books and the ProQuest search engine provided by Barry University's online library. The following databases were accessed: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Dissertation Abstracts, EBSCOhost, Medline, ProQuest, PubMed, OVID, and Science Direct. Key words used were HIV, AIDS, women, lived experiences, phenomenology, Indian women, and South Africa. Citations were limited to English and literature published since 1981 to gain insight of HIV/AIDS from its earliest stages. Several research studies were reviewed in which the experience of HIV/AIDS was explored. The literature review led to three areas (HIV/AIDS and women, HIV/AIDS and family, psychological, and psychosocial effects, and HIV/AIDS, stigma, and chronicity) that will be addressed. Synthesis of the literature reveals what is known and not known about a phenomenon. The chapter will begin with the historical context.

Historical Context

No one knew exactly what caused HIV/AIDS, but research has since attributed it to the chimpanzee in West Africa as the source of HIV infection in humans. Researchers believed that these chimpanzees had the simian immunodeficiency virus (SIV) that was transmitted to humans when they either hunted the chimpanzees for meat or came into contact with their blood. An assumption is that missionary workers from Haiti working in African countries carried the disease back to Haiti and then to whichever country they migrated to (Vatanoglu& Ataman, 2011). Retrospective studies have indicated that people may have died of AIDS as early as 1959. Jonathan Mann was the head of the World Health Organization's Global AIDS Program in 1986 (Gallo, 2006). He was an early advocate in the fight against HIV/AIDS, and he provided a simple, yet appropriate outline of the history of AIDS (see Figure 3).
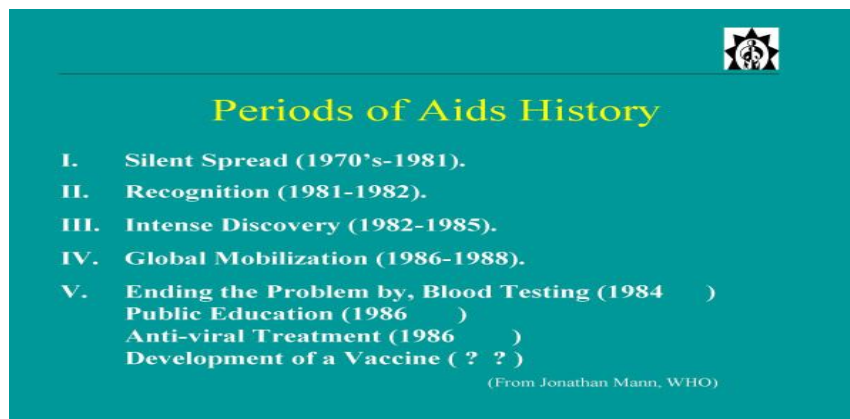

Periods of Aids History

I.   Silent Spread (1970's-1981).
II.   Recognition (1981-1982).
III. Intense Discovery (1982-1985).
IV.   Global Mobilization (1986-1988).
V.   Ending the Problem by, Blood Testing (1984   )
      Public Education (1986   )
      Anti-viral Treatment (1986   )
      Development of a Vaccine (? ?)
                                          (From Jonathan Mann, WHO)

Figure 3. The five periods of AIDS history as modified after Jonathan Mann. (Source: Gallo, 2006).

The disease process was unusual for supposedly healthy young men, and the increasing death rates from immunodeficiency were causing alarm. No one knew what was causing this infectious, deadly disease, or how to prevent it from spreading. The CDC called it the gay cancer or gay-related immune deficiency (GRID) because at first, it appeared to only affect gay men. Soon after, the CDC received reports of severe immune deficiency occurring in hemophiliacs, people who had received blood transfusions, intravenous drug users, and their sexual partners both male and female, children, and Haitian immigrants. The CDC re-termed the disease AIDS in 1982 (National Institute of Health, 2011), but unfortunately, the disease was already stigmatized. Stage three (1982-1985) described the intense research era that followed. HIV/AIDS captured the attention of the world because it became clear that HIV/AIDS did not, and does not, discriminate, and anyone who is exposed can be infected.

Infections occurred heterosexually along main highways from truck drivers to prostitutes in Central Africa, in well-educated gay men, in the artistic community (such as actor Rock Hudson), babies, and Haitian immigrants who were not homosexual or drug users (Weiss, 2008). HIV/AIDS posed a risk to everyone regardless of ethnicity, social standings, age, and gender. This human vulnerability did fuel a massive onslaught of scientific inquiry to determine cause and prevention of HIV/AIDS. The mode of transmission was identified as contact with infected blood, or sexual fluids, intravenous drug users sharing needles, and mother-to-child transmission either during pregnancy, and even breastfeeding. When the Helper T cell (CD4) count fell below 200 per micro liter, individuals were likely to have personality changes, dementia, wasting away, vulnerability to certain cancers, pneumonia, and certain death (Fauci, 2008). In fact, everyone inflicted with HIV/AIDS in the early 1980 was essentially on death row. Death was inevitable, depending on how quickly the person developed AIDS. The race for a vaccine was on. In 1983, French scientists from Pasteur Institute under the leadership of Luc Montagnier published an article in *Science*, identifying the retrovirus HIV as a cause of AIDS. In 1984, there was a publication by Dr. Robert Gallo and his team at the National Institute of Health in Maryland that also identified HIV. These findings resulted in a controversy of who exactly discovered HIV. Soon after the virus was discovered, a blood test to diagnose patients and to screen blood supply was developed. However, the blood bank was slow to respond to HIV screening of blood products. This resulted in 50%, or more than 10,000 of the hemophiliac population being infected from contaminated plasma by 1985. Thereafter, it was mandated that all blood products be screened for HIV (Fauci, 2008).

Stage four saw the introduction of the retroviral drug (AZT) for HIV treatment in 1987. Researchers were very optimistic, and AZT, at first, held great promise. The first World AIDS Day was held on December 1, 1988. The purpose was to raise funds, increasing awareness, fighting prejudice, and improving education to curb this disease (CDC, 2011). Unfortunately, eight million people were living with this HIV/AIDS worldwide by 1990, and HIV became resistant to AZT. This was a sobering moment because the scientists realized that they did not have a quick solution as anticipated, and the focus changed to increasing awareness of HIV/AIDS (Kaiser Family Foundation, 2011). Stage five saw each country adopt its own HIV prevention programs in the early 1990s. This global problem led to the development of The Joint United Nations Program on AIDS (UNAIDS). The primary aim was to assist countries to reduce their infection rates. A new class of anti-retroviral was introduced toward the end of 1995. The use of the highly active antiretroviral therapy (HAART) in combination with older drugs led to increased optimism as the prognosis of the HIV-infected patients improved (Vatanoglu & Ataman, 2011). Since the 2000s, the world has realized that this disease has proved to be a monster. This disease cannot be curbed by treatment alone. The rate of new infections outnumbers the number of people on treatment. Unless a vaccine is developed that can cure HIV/AIDS, issues with medication adherence or accessibility of drugs remain will allow HIV/AIDS to persist in society. Therefore, a global approach is needed to combat this disease. Every country has to start at the grassroots level. Countries need to focus on their people, address their culture, and focus the prevention and HIV awareness accordingly (Schwartlander, 2006).The first concept identified was HIV/AIDS and women that will be discussed in the next paragraph.

HIV/AIDS and Women

Women were excluded in the first decade of HIV/AIDS research. Clinical trials were conducted on White middle-class men and excluded women and minorities despite evidence that the disease was seen in other race groups and resulted in increased deaths of minority women from AIDS. Investigators defended their stand by limiting research to subject homogeneity and the "do no harm" ethic, thereby excluding women of childbearing age from clinical trials. Although women and men suffer the same diseases, they affect women differently. The National Institute of Allergy and Infectious Diseases (NIAID) began funding research studies on women and HIV around the world. Sadly, this research on women only began in 1993, which means that countless women died without the benefit of treatment (NIAID, 2010b). "This epidemic unfortunately remains an epidemic of women," according to Michel Sidibe, Executive Director of UNAIDS (United Nations News Service, 2010). Sarkar et al.(2008) conducted a quantitative, community-based, cross-sectional study among brothel-based sex workers in Eastern India and West Bengal. They wanted to understand sex-trafficking, violence, negotiating skills, and HIV infection in and among sex workers. Five-hundred-and-eighty sex workers from the brothels responded to a pretested questionnaire that was admitted to the subjects to study the sociodemographics and factors affecting sex workers. Blood for HIV testing was also collected using an unlinked anonymous method to study their HIV status.

Data was entered into the computer using the EPI Info software. Univariate and multivariate analysis were conducted to discover the association between risk factors and HIV. Results of the study revealed that thesero prevalence of HIV was higher among Nepalese (43%) than among Bangladeshis (7%) and Indians (9%). One in every four sex workers (24%) had joined the profession by being trafficked. Violence at the beginning of this profession was more among the trafficked victims, including those sold by their family members (57%) compared to those who joined the profession voluntarily (15%). The condom negotiation rate with the most recent two clients was 38%. Therefore, by multivariate analysis, HIV was significantly associated with sexual violence (odds ratio=2.3; 95% confidence interval 1.2-4.5). The study documented that the trafficked victims faced violence, including sexual violence, to a greater magnitude, and sexual violence was associated with acquiring HIV in them. There is a need for an in-depth study to understand the problem of trafficking and its consequences (Sarkar, 2008). In addition, a quantitative study by Dunkle et al., (2004) sought to assess gender-based violence as a risk factor for HIV, after adjustment of women's own high-risk behaviors. The cross-sectional study was conducted on 1,366 women attending four antenatal care centers in Soweto and South Africa. The field workers who were trained in gender-based violence and HIV administered the World Health Organization violence against women instrument that assessed lifetime experience of physical and sexual violence from a male partner. Data was double entered into the EpiInfo and SAS for analysis. They looked for association among the following variables: sociodemographic, HIV, violence, and risky behavior. They used multi-variate logistic-regression models to determine associations between violence and HIV after adjustment for risky behaviors by the women. After adjustment for age, current relationship, women's risky behavior, and intimate partner violence (odds ratio 1.48, 95% CI 1.15-1.89), the high levels of male control in a woman's current relationship as measured by the Sexual Relationship Power Scale (1.52, 1.13-2.04) were associated with seropositivity. The discoveries were that women with violent or controlling men were at increased risk for HIV infection. They postulated that abusive men are more likely to have HIV and impose risky behaviors on their partners (Dunkle et al., 2004).

Then, van Staden and Badenhorst (2009) conducted a literature review on gender and cultural factors associated with HIV/AIDS among university students in the South African context. The purpose of the literature was to review South African literature on students' sexual practices and high-risk behaviors to identify themes and trends so that new direction maybe identified on students and HIV prevention. They sought to:

1. Explore the gender and cultural factors on South African students' sexual behavior.
2. Provide evidence that cultural and gender stereotypes exist among SA students.
3. Discuss factors influencing gender and sexual behaviors.

First, they found that it was important to understand sexual behavior in its cultural context: The risk factors were identified as multiple partners, big age gaps (sugar daddies and mommies), not using condoms consistently, presence of sexually transmitted diseases, excessive alcohol use, and not knowing either their own or partners' HIV status. Second, male, and female roles are shaped by society, culture, family, communities, and individual decisions. There were sufficient research studies that indicated that gender inequality affects females negatively in ways that include submissiveness, sexual subordination, obedience, and willingness. Third, male dominance versus female submissiveness, age of first sexual encounter, gender-based violence (intimate partner violence, domestic violence, child sexual abuse, and rape), circumcision, and financial status were all crucial factors that predisposed young South Africans to HIV/AIDS infection. There was no sample or psychometrics reported as it was a literature review (van Staden, 2009). The previous year, Badenhorst, van Staden, and Coetsee (2008) conducted a quantitative, descriptive study on students at the University of the Free State (UFS) to investigate the sexual campus culture of students by focusing on gender and culture as patterns of high-risk behavior. The sample consisted of 396 participants; 211were female and 185 were male. The participants (61%) associated themselves with a western culture and 39% with an African culture. The data was collected by a questionnaire survey. The survey was developed after a review of South African and international literature and was designed to measure students' knowledge, attitudes, and self-reported behavior related to sexual activity and possible HIV risk of infection. A pilot study on the questionnaire was conducted, and the sample understood the questionnaire well. The reliability of the tool was validated by the coefficient of (a = 0.70). Chi square tests ($x2$) of statistical significance were used to determine relationships between variables. They found that students from an African culture view a strong relationship with HIV and homosexuality ($x2 = 26.796$, df=4, p=0.000) and that HIV/AIDS is strongly associated with African students ($x2=30.772$, df=4, p=0.000).

The data showed that even if students were knowledgeable, their sexual practice (number of partners) (x2=18.677, df=4, p=0.001), and risk-taking (gifts in exchange for sex) (x2=14.857, df=2, p=0.001) remained unchanged. HIV infections occur most commonly in 15-24-year-olds, and if the universities cannot provide academically trained workers, the economy of South Africa will be affected (Badenhorstet al., 2008). Additionally, Fawzi et al.(2010) conducted a quantitative study to estimate the prevalence of HIV among women in rural Haiti and identify economic risk factors for HIV in this population. The sample consisted of 935 women who had accessed healthcare from June 1999 to December 2002, but they had to be recruited to participate. The analysis was based on the data from a case controlled study of sexually transmitted diseases (STD) in rural Haiti. Nine hundred and eleven were HIV negative, and 31 were HIV positive. In multivariate analyses, partner occupation was associated with HIV infection in women, with mechanic (OR 9.0, 95% CI 1.8-45) and market vendor (OR 4.2, 95% CI 1.6-11) reflecting the strongest partner occupational risk factors. Partner's occupation as a farmer reduced the risk of infection in women by 60% (95% CI 0.14-1.1). Factors indicating low socioeconomic status (SES), such as food insecurity (OR 2.0, 95% CI 0.75-5.6) and using charcoal for cooking (OR 1.7, 95% CI 0.72-3.8) suggested an association with HIV infection. The findings were that gender inequalities exist in Haiti and that a women's economic security is dependent upon her partner's income. Although there were correlations between poverty and HIV infection, women whose partners had more secure occupations were at a higher risk for HIV infections. Programs that provide access to education and economic opportunities for women may have long-term implications for HIV infection (Fawzi et al., 2010).

The final study in this concept was by Rose, House, and Stepleman(2010), who conducted a quantitative study to understand the links among intimate partner violence (IPV), post-traumatic stress disorder symptoms (PTSD), medication adherence, and HIV-related outcomes in African American women with HIV/AIDS. The sample consisted of 40 women from Georgia and South Carolina who participated in the survey. The questionnaires measured interpersonal violence victimization, traumatic stress symptoms, frequency of medical visits, medication adherence, and functional impairment. IPV is related to HIV viral load (r=.44, p <0.01) CD4 count (r=-.40, p=<0.05), medication adherence (r=-0.38, p=0.05), and IPV was not related to quality of life. Bivariate correlations identified a significant correlation between education and viral load (p=-0.47, p<.01). PTSD symptoms mediate the relationships between IPV and HIV-related outcomes. PTSD was significantly correlated with IPV (r=0.40, p=<0.05). However, the researcher could not prove that PTSD affected HIV outcomes. Medication adherence predicted viral load. Women with IPV had worse HIV-related health as indicated by reduced CD4 counts, post-traumatic symptoms were related to IPV, and quality of life. The need for clinical interventions to address IPV was indicated. In most parts of the world, women are not free to negotiate on safe sex or condom use or refuse sex. Most societies are patriarchal, so discussions about abstinence or faithfulness are impossible in these cultures (National Institute of Allergy and Infectious Diseases (NIAID), 2010b, & UNAIDS, 2009). In developing countries, financial dependence on the men is enhanced by the women's lack of employment opportunities and education. Thus, the sex trade provides women with the only option to earn money to support themselves and their children. Many women face sexual, physical, or the threat of violence in their relationships and the sex trade business, thereby exposing them to riskier behaviors involuntarily (Sarkar et al., 2008).

Most of the studies have identified the risk factors that contribute to women's susceptibility to HIV/AIDS clearly, and the research findings are consistent. However, despite several consistent research data, women in developing countries are still not empowered to equip themselves with equal educational and employment opportunities, and South Africa is no exception. Until the governments of each country recognize these threats to women and implement change to empower them, women will continue to be at a greater risk for infections. The literature review revealed two gaps. First, there are limited data or research studies on Indian women in South Africa who have HIV/AIDS, and none of the studies addressed how to empower these vulnerable women. This study seeks to understand the lived experience of these women living with HIV/AIDS and to identify possible factors that promote empowerment.

HIV/AIDS, Family, Psychological, and Social Effects

HIV has proved to be a debilitating disease that has had an enormous impact on families. For the first 15 years since HIV/AIDS was diagnosed, this disease was a death sentence to all who acquired it.

Families just watched helplessly as their loved ones died and were forced to deal with bereavement. However, with the onset of treatment, families are plagued with the psychological, physical, and social impacts on the family. In addition, role changes, financial instability, and altered family relationships have had far-reaching consequences for both the individual and family. Sadly, families with low socio-economic status are the most affected. Today, there are more women than men who are living with HIV/AIDS, especially in the developing countries. Although the women are infected with HIV/AIDS, they still bear the additional burden of caring for others in the family who has HIV, providing childcare and coping with social isolation and financial loss if they become widowed or divorced. HIV/AIDS affects the individual, family, and community. Thus, the increased stress and concern can lead to many psychological problems. Psychological issues can range from anger, depression, and hopelessness to physical changes in the brain from the disease process that can diminish the functional capacity of a person (Avert, 2011). The women are caregivers regardless of their health status. They are often blamed for contracting AIDS even if they were infected by their husbands, and they are shunned by society. In addition, women face violent abuse when their HIV status is discovered and increased reproductive illnesses. They are more likely to postpone health care because of their illness or lack of access to health care services. This vicious cycle places the women caregivers in an extremely difficult position as they try to weigh the effects of this disease on their family versus seeking medical help. Most often the women choose to neglect themselves for the benefit of the family, yet eventually the family suffers from the loss of the primary caregiver. Thus, an infection with HIV/AIDS has a profound effect on the individual, family, and community.

The first study reviewed was by Kaida et al.(2011), who conducted a quantitative study in 2011 to determine if the intention to have children varied according to HIV status and use of highly active antiretroviral therapy (HAART) among women in Soweto. They used survey data from 674 women. Logistic regression models examined the association between HIV status, HAART use, and intention to have children. Overall, 44% of women reported intent to have children, with significant variation by HIV status: 31% of HAART users, 29% of HAART-naive women, and 68% of HIV-negative women (P<.001). TheHIV-positive women were nearly 60% less likely to report childbearing intentions compared with HIV-negative women (for HAART users, adjusted odds ratio [AOR] =0.40; 95% confidence interval [CI] =0.23, 0.69; for HAART-naive women, AOR=0.35; 95% CI=0.21, 0.60). The majority of HIV-infected women are young adults, who are in their prime reproductive age. Therefore, HIV prevention, HAART, and mother-to-child prevention must be provided to support the rights of all women to achieve her reproductive goals. Next, Tuck, McCain, and Elswick(2008) conducted their quantitative study to examine the role of spirituality and psychosocial factors in people living with HIV/AIDS. This was a descriptive, correlational study. The purpose of the study was to determine whether spirituality would be positively related to quality of life and social support or inversely related to illness and stress. The sample size was 52. The men who volunteered had to be able to complete the six-month follow-up. Spirituality was measured in terms of spiritual perspective, well-being, and health. The spiritual perspective scale (SpS), the spiritual well-being scale (SWBS), and the spiritual health inventory (SHI) were used.

Correlational analysis were used to examine the nature of relationships among spirituality and the psychosocial factors of perceived stress, uncertainty, psychological distress, social support, coping strategies, and quality of life. Moderately high spirituality scores were reported (SpS mean=5·08, SD=0·84, range=1·9–6; SWBS mean=91, SD=16·2, range = 42–117; SHI mean=113, SD=14·2, range = 79–147). The discoveries were that quality of life was positively related to social support and functional well-being but negatively related to stress, uncertainty, and psychological distress. Social support was positively related to effective coping strategies. The hypothesized relationship among spirituality, and psychosocial measures were supported. The implication of this study is that HIV/AIDS is a deadly disease that causes turmoil in those inflicted. Spirituality plays an important role in the complete well-being of patients inflicted with HIV/AIDS (Tuck et al., 2001). Then, Trevino et al.(2007)quantitative study investigated the relationships between positive religious coping and spiritual anger versus biological, psychosocial, social, and spiritual well-being in participants with HIV. This quantitative study hypothesized that positive religious copings will correlate with positive psychosocial, physiological, and social outcomes, and that positive religious strategies will result in physical well-being, but spiritual struggle will result in a decline in well-being. The sample was recruited from four large medical centers and consisted of 429 participants. The average age was 43.3, and the sample was equally divided between White and African American. Questionnaires were administered initially and repeated at 12-18 months. Descriptive studies were conducted to determine the mean, standard deviations, and proportions.

Analyses were conducted on 16 outcome measures, and post-hoc was measured to assist in interpreting significant regression co-efficients. The study revealed that religious coping was associated with positive outcomes (B=0.12, p < 0.05), and negative outcomes were associated with spiritual struggle (B=0.12, p = 0.01). The implications of this study for nursing are to assess religious coping as it is crucial to the well-being of the patient (Trevino et al., 2007). In addition, Knoedel, Zimmer, Kim, and Puch (2007) explored the economic and social effects in a quantitative approach of parents who have had to care for their adult children infected with HIV/AIDS. This study was based on survey data and was focused on 1,127 parents in Cambodia to explore economic and social effects on parents in the worst hit HIV country on the Asian continent. Their discoveries were that parents in Cambodia played a key role when their children were ill, sharing their home and food and paying for their medical expenses. The multivariate analysis indicated that this practice had affected the financial well-being of the parents negatively because of their advanced age. Surprisingly, there was little stigma associated with the children's death from HIV/AIDS. The Cambodian community was more sympathetic to the parents for the loss of a child. Thus, caring for an HIV/AIDS-infected loved one can lead to family role reversals, such as a change in the breadwinner, poor communication, lack of support, family breakdowns, and a strain on family resources. No clear psychometrics was reported (Knoedel et al., 2007). In comparison to Knoedel et al., Palattiyiland Chakrabarti (2008) conducted a quantitative research to explore coping strategies of families with HIV/AIDS family members in Scotland and Kerala, India. Their purpose was to focus on the family's ability to cope with the stress of HIV/AIDS care. Purposive sampling resulted in 23 participants (mostly wives) from Kerala and five (mostly parents) from Scotland volunteering. They used a modified questionnaire of the ways of coping scale. The researchers added questions to make it more appropriate for the HIV/AIDS family, which resulted in 85 questions. They used yes or no options as participants were not familiar with the Likert scale. The results were compared using the Mann-Whitney U test, and the results were statically significant (U=8.00, p = 0.003). This showed that the families in Scotland used a larger number of coping mechanisms as compared to the families in Kerala. However, because of the small sample size from Scotland, the results may not reflect the complete picture. This study revealed a clear contrast faced by caregivers in the developed and developing world. Scotland had easily available antiretroviral treatment, easily accessible medical care, and support groups that made circumstances favorable for the family. Even though both participants faced stigmatization, caregivers in Kerala had to deal with the limited access to medical care and poverty. The people in Kerala were ostracized, isolated, and subjected to verbal abuse. Thus, many chose to hide their disease or that of their loved one for fear of shame. This had placed a heavy burden on caregivers and families in Kerala.

The final study reviewed for this concept, Brincks, Feaster, and Mitrani (2010) conducted a quantitative study that looked at African American women with HIV/AIDS in South Florida to investigate a stress and coping process together with their families. Two hundred and fourteen HIV-positive women participated together with 294 family members. The purpose of the study was an analysis of a cross-sectional data from a longitudinal, randomized clinical trial testing the efficacy of psychological intervention on stress reduction and increasing family support. The researchers used the Brief Symptom Inventory to measure psychological distress. It was a 53-question inventory that allowed the participants to rate their level of distress on nine dimensions such as depression, anxiety, and anger. There were significant differences between families in the relationship between coping and distress (t = 0.00002, SE = 0.0000003, p<.001), and between stress and distress, controlling for coping (t = 0.00003, SE = 0.0000001, p<.001). There were no significant differences between families in the relationship between stress (X) and coping (M) (t = 0.001, SE = 0.009, p = .910).At the individual level, this analysis demonstrated a positive and significant relationship between avoidance coping and psychological distress (β = 0.027, SE = 0.003, p<.001), and a positive and significant relationship between stress and psychological distress (β = 0.017, SE = 0.003, p<.001). The relationship between stress and avoidance coping was also positive and significant (β = 0.179, SE = 0.056, p = .001).The results supported the need to address both the HIV/AIDS-infected woman and her family's capabilities for coping. These research supported prior research that living with HIV/AIDS does present multiple challenges to the women and her family and that minority groups affected by HIV/AIDS have their physical and social stresses compounded by finances, housing, discrimination, and crime. The study revealed that African American women's role was deeply interwoven into their families and highlights the importance of family in the lives of HIV/AIDS people (Brincks et al., 2010). The effects of HIV/AIDS are a traumatic experience that has far-reaching consequences. The research clearly depicts the emotional and social toll on individuals affected.

However, there is a gap in research that depicts how HIV/AIDS affect Indian women in South Africa. This study sought to understand the lived experience of these women. The final concept of HIV/AIDS, stigma, and chronicity will be discussed in the next paragraph.

HIV/AIDS, Stigma, and Chronicity

First, Galvan, Davis, Banks, and Bing (2008) conducted a quantitative research to examine the relationship between perceived social support and perceived HIV stigma among 283 HIV-positive African Americans. They divided stigma into two types (perceived and enacted). Perceived stigma can be real or imagined fear of society's attitudes and enacted stigma is the discrimination directed to individuals who do not meet society's view of normality. The three sources of perceived social support were family, friends, and a special person. Bivariate and multivariate regressions were used to determine the variables predicting perceived HIV stigma. The participants were found to have a wide variety of opinions concerning perceived HIV stigma. Of the three different sources of perceived social support, only perceived social support from friends was found to be related to perceived HIV stigma when controlling for the presence of other relevant factors. Multidimensional Scale of Perceived Social Support revealed the following: for perceived support from a special person, 18.7 (8.48 SD), for perceived support from family members, 19.2 (7.13 SD), and for perceived support from friends, 20.0 (6.27 SD).High perceived social support from friends was associated with less perceived HIV stigma. The recommendations were that information about the beneficial effects of perceived social support from friends and other factors can help to provide guidance to those working to decrease the negative impact of HIV stigma among HIV-positive African Americans. Thus, it is important for health care workers to acknowledge the benefits of social support to a successful medical regimen.

Then,Makoae et al. (2008) conducted research on coping with the stigma of HIV/AIDS in five African countries (Lesotho, Malawi, South Africa, Swaziland, and Tanzania). This descriptive, qualitative research design was used to explore the experience of HIV-related stigma of people living with HIV (PLWH) and nurses in 2004. Forty-three focus groups were conducted with 251 participants. The purpose of the study was to explore coping strategies of people who experienced HIV-related stigma. A grounded theory approach was used to explore the experiences of stigma. The sample size was equally divided among the five countries. The discussion was guided by two questions: How do people you know refer to people living with HIV/AIDS? Can you share an example of stigma directed to the person with HIV/AIDS, their family, or nurse? A transcript from each country was chosen to determine sub-themes using the open coding technique. Coping strategies used by nurses as well as coping strategies they observed as used by HIV-infected patients were coded. Seventeen different self-care strategies were identified: restructuring, seeing oneself as okay, letting go, turning to God, hoping, changing behavior, keeping oneself active, using humor, joining a support or social group, disclosing one's HIV status, speaking to others with same problem, getting counseling, helping others to cope with the illness, educating others, learning from others, acquiring knowledge, and understanding about the disease, and getting help from others. Rationalizing was the highest recorded strategy. The research revealed that in these African countries, coping is self-taught and marginally helpful in managing stigma. The nurses and health care workers need a greater understanding of the challenges the HIV/AIDS patient and family members endure (Makoae et al., 2008).

In addition, Rahangdale et al. (2010) conducted a qualitative study on 14 women to explore the role of HIV-associated stigma as a barrier to access treatment designed to prevent maternal-to-child transmission (PPTCT) in India. They used a theoretical framework developed by Steward to understand the roots and effects of HIV-related stigma. They conducted open-ended interviews and role play in focus groups, and they modified a tool by the World Health Organization that was used to study adolescent sexual and reproductive behavior. Barriers identified from this study were health care workers, society, family, and themselves. In India, HIV-related stigma or fear of HIV transmission through personal contact and moral judgment is rooted in cultural traditions, social structures, and government institutions, which, in turn, influence the agents of stigma who are health care workers, community members, family, and self. Health care workers displayed poor quality care during HIV testing and antenatal/care associated with PPTCT services. The women experienced refusal for treatment, abusive behavior, moral judgment, and lack of confidentiality by staff. Society displayed stigma from the denial of personal contact, hospitality, and physical removal from one's own community. Participants described this fear of personal contact and treatment like an outcast in their community. In India, a woman's family (her parents, her husband, and his family) are an integral component of a woman's support system to ensure her physical, emotional, and financial well-being. However, because of the lack of confidentiality practices, family members were frequently the first to be informed by providers of a woman's HIV test results, thus making a woman vulnerable immediately after testing.

Family stigma was evidenced by moral judgment by family members who associated HIV infection with immoral behavior and lead families to react negatively. The interview revealed that stigma from self was evidenced by moral judgment of oneself for not fulfilling traditional gender roles of wife and mother, judgment about the women's character and fidelity, and inability to care for their own children properly. Ultimately, the stigma, whether it was enacted (interpersonal experience of stigma), felt normative (an individual's awareness or anticipation of stigma), and internalized (an individual's acceptance of stigma as valid), served as a barrier to these women. Therefore, they avoided seeking treatment for fear of discrimination. Recommendations were to incorporate interventions to reduce institutional and interpersonal stigmatization of pregnant women. Next, Varni, Miller, McCuin, and Solomon (2012) conducted a quantitative study to determine if the consequences of stigma-related stressors on psychological well-being would depend on how people cope with the stress of HIV/AIDS stigma. A sample of 200 participants completed a self-report measure of enacted stigma and felt stigma, a measure of how they coped with HIV/AIDS stigma, and measures of depression, anxiety, and self-esteem. Their discoveries were increases in felt stigma (concerns with public attitudes, negative self-image, and disclosure) together with how participants reported coping with stigma (by disengaging from or engaging with the stigma stressor) predicted self-reported depression, anxiety, and self-esteem. Scores on the concerns with public attitudes subscale were higher than scores on the enacted stigma subscale (t (199) = 4.30, $p \leq .001$, r = .30) and the negative self-image subscale (t (199) = 8.42, $p \leq .001$, r = .58). Enacted stigma subscale scores were higher than negative self-image subscale scores (t (199) = 2.80, $p \leq .01$, r = .20). These results indicated that participants reported more experiences with felt stigma (particularly disclosure concerns and concerns with public attitudes) than enacted stigma.

Increases in felt stigma were associated with increases in anxiety and depression among participants who reported relatively high levels of disengagement coping compared to participants who reported relatively low levels of disengagement coping. Increases in felt stigma were associated with decreased self-esteem. The depression and anxiety scores were strongly positively correlated with one another (r (200) = .85, $p \leq .01$) and were both negatively correlated with self-esteem scores (r (200) = −.57 and −.48, $p \leq .01$ for depression and anxiety, respectively). The data also suggested that increases in enacted stigma predicted increases in anxiety but not depression. Therefore, health care professionals working with people who are HIV positive should consider how their clients cope with HIV/AIDS stigma and consider tailoring current therapies to address the relationship between stigma, coping, and psychological well-being (Varni et al., 2012) Chronic illness is defined as a persistent, permanent illness. The infected person's health deteriorates, leading to physical changes in the body, poor quality of life, and eventual death. HIV as a chronic disease is applicable only in the developed countries where antiretroviral treatment, easily accessible medical care, and support groups are provided and available for use. HIV/AIDS still represent an acute illness that ultimately will result in their death to the majority of people living with HIV/AIDS in the developing countries. The Western world has more resources to provide effective HIV/AIDS care, and the infected face less stigmatization from health care personnel. The responsibility for successful treatment is dependent upon the infected person's ability to ensure that he or she obtains the treatment needed. This is not the case in developing countries as the lack of resources and adequate supply of basic needs make this disease a threat (UNAIDS, 2010)

The first study reviewed was by Swendeman, Ingram, and Rotheram-Borus (2009), who conducted an integrative review on chronic disease self-management to identify factors common across chronic diseases, highlight HIV-specific challenges, and review recent developments in self-management interventions for people living with HIV.A literature review using "chronic illness," "chronic disease," and "self-management" combined with specific chronic diseases, such as arthritis, asthma, diabetes, COPD, and HIV/AIDS, was searched on Medline, PsycInfo, Science Direct, and Web of Science. Article reference lists and the websites of government health departments, the WHO, and disease-specific organizations were also searched. The selected articles synthesized the literature on self-management, described program implementation, or addressed health policy issues regarding self-management programs. The authors reviewed each abstract to eliminate articles that were not relevant. An integrated framework of common elements or tasks in chronic disease self-management is presented that outlines 14 elements in three broad categories: physical health, psychological functioning, and social relationships. Common elements for physical health include: a framework for understanding illness and wellness; health-promoting behaviors; treatment adherence; self-monitoring of physical status; accessing appropriate treatment and services; and preventing transmission.

Elements related to psychological functioning include: self-efficacy and empowerment; cognitive skills; reducing negative emotional states; and managing identity shifts. Social relationship elements include: collaborative relationships with healthcare providers; social support; disclosure and stigma management; and positive social and family relationships. Their findings revealed that HIV management had similarities to other chronic conditions, such as lifelong changes in physical, psychological, social, and medication regimen. Their integrative review revealed that there is a global need to improve self-management services for HIV as it is cost-effective but also provides easily accessible health care service. However, they found challenges, such as provider capacity, and the stigma associated with an HIV-identified service that reduced compliance. The researchers believed that if HIV was treated as a chronic condition and managed as such, this will reduce discrimination. There was no sample size or psychometrics reported as this was an integrative literature review. Next, Russell and Seeley (2010) conducted a two-phase qualitative research study on 70 participants in rural Uganda using the grounded theory approach. The purpose was to analyze the productive activities of people living with HIV following their uptake of antiretroviral therapy (ART). Their thematic analysis was not focused on the economic effects of ART for individuals and their households, but on how the participant "transitioned" to living with HIV as a chronic condition. Transition is referred to as a person incorporating a long-term illness, treatment regimen, and thus the effects of transition into his or her life. This transition is achieved by people taking action and making changes in different aspects of their lives including reflective and spiritual endeavors. The themes from prior to ART use were loss and disruption (unexplained illness and death of a child or partner), a growing fear of HIV, and anxiety about the future. Themes of adjustment struggles included: Loss of meaning to life: giving up hope (especially, when bed-ridden for long time); disruption and disorder: inability to work, to continue parenting, and impoverishment. Loss of control over decisions: Increasing dependence on others for food and care; prejudice: labeled "already dead," the break-down of relationships, isolation or "social death." However, despite the profound disruption of HIV, a new chance of life on ART motivated a transformation in the purpose and activities of some participants that were evidenced by their "quests" to regain control, create order, and feel "normal" again. Poverty and vulnerability hindered the transition process (Russell& Seeley, 2010).

Therefore, the researchers postulate that meaningful economic and social lives are essential if people will incorporate HIV as a long-term chronic condition into their lives and adhere to treatment. Support is needed for these participants to adjust to their HIV status and to ensure the success of antiretroviral therapy. The stress of living with HIV is not different from any other chronic condition, except that there is a clear need for more mental health support. The scarcity of these services, combined with the cultural barriers to seeking mental health services, provides a challenge in accepting this disease as chronic problem. Addressing HIV/AIDS as a chronic disease does not alter the crisis mode that patients are placed in when first diagnosed. However, when the crisis has subsided, the people have to readjust their lives to get back to normal. Living with a chronic condition means that life is unpredictable and that their health status will vary depending upon the symptoms. This can be challenging and frustrating and can result in mood swings ranging from depression to anger. Therefore, it is imperative as health care workers to address the holistic needs of the patient and not merely the physical. The stigma of HIV/AIDS has negative repercussions for both the person and his family. The infected person fears disclosure because of the repercussions, such as shunned by his friends, exclusion by family from social events, loss of employment, and loss of relationships. The fears of these consequences drive people's decisions not to seek treatment or support as they risk losing their "lives." A plethora of research exists on HIV/AIDS since 1981. This disease is predominantly a disease of the developing countries. Research has shown that stigmatization and poverty are major factors for lack of treatment. HIV/AIDS has an impact physiologically and psychologically, and there is a need for social support to ensure compliance with treatment. This study attempted to understand and explain the lived experience of women with HIV/AIDS in South Africa.

Experiential Context

Experiential context is the description of the researcher's prior connection, experience, values, and feelings about the study. My personal opinion is that the experiential context is valid in any research to ensure that the researchers are vested in their research. Van Manen, (1990) stated that the phenomenon should be of interest to the researcher. The purpose of the experiential context is for the researcher to reflect on his or her experience of the study and allow his or her biases and prejudices to be voiced and discussed so that effective bracketing can occur (Munhall, 2010). I am of Eastern Indian descent but was born in KZN, South Africa. My personal experience of HIV/AIDS was the death of a close friend who did not seek treatment at 36 years old. When I tried to rationalize to my friend the importance of getting help, I was told "this is not America; this is South Africa. No one wants to touch you or be your friend anymore. I would rather die than let anyone know what I have."

The disease is shrouded in secrecy in the very conservative Indian community, as HIV/AIDS is a highly stigmatized disease associated with loose morals. The women are condoned regardless of the source of their infection. Ironically, the attitude to treatment options only, seems so tragic to me, yet I can understand it because I know the culture. This is, unfortunately, a lose-lose situation. Qualitative researchers have a high risk of bias because of proximity to the study. Therefore, reflexivity is an important component of qualitative inquiry. Munhall (2010) defined reflexivity as an ongoing reflection, or process by which researchers recognize the circularity of the relationship of the researchers to the data. Reflexivity involves constant attention to the researcher's perspective, background, and influence on the research process and the effect this has on the researcher. Reflexivity is a process of awareness by the researcher. Reflexivity increases researcher accountability to all stakeholders. Creating awareness is an open and honest approach to conducting research. Researchers must be reflexive in the topics they wish to investigate so that they account for the personal and professional meanings their topics have for them, but reflexivity can occur at any time in the research process, such as during data collection and analysis. Researchers can be reflexive by writing thoughts, experiences, emotions, biases, and later reflecting upon these, or talking to others about them, thus adding to the integrity of the research. Qualitative researchers are considered the "instrument" and spend hours in the field obtaining data. They are aware of their role in the interpretation and meaning of data. Therefore, to avoid bias, researchers should start a reflexive journal. This journal requires that the researcher makes regular entries during the research process. The entries should include methodological decisions and the reasons for them, the logistics of the study, and reflection upon what is happening in terms of one's own values and interests. Reflexivity provides awareness of how a researcher developed particular understandings (Munhall, 2010). The purpose of my study makes reflexivity a prominent thread throughout because of my role as researcher and the role of empathy.

Epoche allows qualitative researchers to be aware of their prejudices and views regarding a phenomenon. Reflexive journaling permits bracketing; thus, researchers set aside any preconceived ideas and allow themselves to listen with a clear mind to hear what the participant has to say (Munhall, 2010). Phenomenology allows the collection of extensive data that can create bias or assumptions. Thus, bracketing is essential because it allows the researcher to bracket out the world and presuppositions to identify the data in pure form. For this study, I relied on continual self-reflection by verbalizing, journaling, and audio recording thoughts after an interview has ended. I actively listened and asked open-ended questions to gain in-depth knowledge. I clarified ambiguous answers to ensure that I was not making assumptions for the participants. Thus, reflexive journaling provides a venue for the participant's perspective to be revealed, thus increasing the dependability and authenticity of the findings. Audio-taping the interview limited any non-verbal reactions by the researcher that influenced responses to the inquiry. Put simply, bracketing is a temporary shelving of the researcher's assumptions that are later visited to gain understanding.

Chapter Summary

This chapter reviewed the literature on HIV/AIDS since1981. The history of HIV/AIDS was presented along with an experiential track. The literature review revealed that HIV/AIDS has a major psychological, physical, and social impact on the individual and family. The prevalence of HIV/AIDS is facilitated by stigmatization that prevents individuals from seeking treatment early for fear of social repercussions. HIV/AIDS is a chronic condition in developed countries and an acute disease in developing countries. This disease has proved to be voracious in its spread globally and has caused havoc in its path. HIV/AIDS to human beings is like an act of nature (tornado, hurricane, and earthquake) to the world. The aftermath and destruction are overwhelming. Indian women inflicted with HIV/AIDS in South Africa are victims of their conservative culture. Their fear, shame, and stigmatization are not clearly understood because of the lack of research conducted on this population group. They need a voice as their experiences are unique both culturally and individually. This obvious gap in literature can lead to neglect of the needs of a whole population group. Understanding the culture and experiences of these women will equip health care providers to be more effective in their treatment of these women.

Chapter Three

Methodology

This chapter will contain a discussion of the research methodology and offer a brief description of qualitative paradigms, a detailed explanation of the method of inquiry, data collection and processing, analysis of data, ethical considerations, and chapter summary. The purpose of this study wasto explores the lived experience of Indian women with HIV/AIDS in South Africa. This experience can be captured by interviews, observations, journals, art, and creative writing (Creswell, 2007). The hermeneutic phenomenology of van Manen was used to identify and describe the meaning of the lived experiences of the women with HIV/AIDS in South Africa.

Research Design

A research design provides the framework for a study. However, the vast number of choices in methods and methodology, combined with the philosophical underpinnings can be a daunting experience for a novice researcher. Crotty (1998) stated that the deciding factor is always the purpose of the research (p. 2), and therefore, the design of the research was based on the topic and a paradigm. A paradigm is defined as a systematic set of beliefs, and their accompanying methods, which provide a nature of reality (Lincoln & Guba, 1985). The paradigm or worldview is a set of beliefs that provides a framework for the researcher to work. The two distinct types of research are quantitative and qualitative research. Quantitative research is associated with positivism. The positivist paradigm focuses on the scientific method and is associated with generalizability. The epistemological assumptions are that knowledge is objective and generated deductively from a hypothesis. However, while quantitative research always answers the "what," it fails to address the why (Munhall, 2010). Post positivism was developed in response to the positivist approach. Interpretivisim is associated with an individual's ability to construct meaning. Qualitative researchers postulate that research cannot be seen objectively from the outside. It must be observed from the inside through the experience of the people (Crotty, 1998). Simply put, the purpose of qualitative research is to increase understanding, explain a phenomenon, or discover meaning. The ontological assumptions are that reality is subjective because it is based on individual experiences, and people make their own meaning of the event. The events are not generalized, and they can be multiple interpretations on one event. The researchers are interested in meaning or how people make sense of their environment. The epistemological assumptions are that knowledge is gained inductively from a personal experience. Although qualitative research is subjective as the researcher is the primary instrument, objectivity is maintained by bracketing and the data analysis process (Creswell, 2007).

The major characteristics of qualitative research are that qualitative research occurs in the natural or real-world setting, the emergent design permits flexibility, and the sample has to be purposeful. Data collections involve the collection of detailed in-depth interviews on a person's experience that generate extensive data, and the researcher is heavily involved in the data collection process. Although the researchers have to practice bracketing, they have to ensure that they are empathic by displaying respect, awareness, and responsiveness. The data analysis process involves capturing the details of individual cases first, discovers themes, patterns, and interrelationships, and looks at whole phenomenon under study. The qualitative researcher has to ensure that the study is credible and trustworthy (Creswell, 1998). There are several approaches in qualitative research. However, the qualitative approach chosen is generally dependent upon the purpose and the research question. This study was concerned with the essence or meaning of an experience of South African Indian women with HIV/AIDS. Thus, a phenomenological approach was warranted for this research as phenomenology is concerned with understanding phenomena. The concept of phenomenology is to examine how individuals describe things or experiences through their senses and what these may mean to them. The researcher looks for the inner meaning of the experience of these individuals. The participants in a qualitative research provide the majority of the input, but it is the researcher's task to interpret the responses of the subject accurately. Phenomenology bridges the gap between what really exists (metaphysics) and epistemology, which is the manner in which we gain knowledge (Creswell, 2007).

Phenomenology

Phenomenology is rooted in the discipline of philosophy. It is both a philosophy and method and was proliferated in the first half of the 20th century by Edmund Husserl, Martin Heidegger, Maurice Jean-Paul Sartre, and Maurice Merleau-Ponty. However, it has been postulated that phenomenology has been practiced for many centuries without a name as evidenced by:

       a) Buddhist philosophers reflecting on states of consciousness through meditation

       b) Descartes, Hume, and Kant who characterized states of perception, thought, and imagination

      c) Brentano who classified varieties of mental phenomena and William James who appraised kinds of mental activity in the stream of consciousness (Creswell, 2007).

In the early phase, Brentano was credited with writing about phenomenology as a method and was the first to discuss the term "intentionality." His concept of phenomena would inform Husserl's discipline of phenomenology eventually (Creswell, 2007).   Husserl, Heidegger, Sartre, and Merleau-Ponty are considered the four classical phenomenologist's, and they practiced distinguishable methods: Husserl and Merleau-Ponty spoke of pure description of lived experience, and Heidegger spoke of hermeneutics and the art of interpretation in context. These four phenomenologist's' contributions to phenomenology can be divided into German and French contribution. The German contribution originated with Edmund Husserl (1859-1938). He was a German mathematician and is considered the father of phenomenology. It was only when Husserl adopted phenomenology as a term for his new science that phenomenology finally came into its own. Husserl defined phenomenology as "the science of the essence of consciousness," focusing on the trait of intentionality, approached explicitly "in the first person" (Husserl, 1931, p. 33). Husserl's interpretation of phenomenology was the nature of knowing (how the world is constituted) and focuses on experienced through conscious acts. He believed that "we can only know what we experience," and thus his phenomenology focused on the study of a phenomenon as experienced through consciousness. He viewed consciousness as the relationship between a person and the world. His original descriptive phenomenology deepened into the development of transcendental phenomenology.

During this stage, the concepts of essence ("ideal or true meaning of something"), intuiting (accurate interpretation of what is meant in the description of a phenomena), and phenomenological reduction (return to original awareness of a phenomenon) were introduced. Noemaand noesis are also central to phenomenology. Noema is that which is experienced, and noesis is the way in which it is experienced. Both terms refer to meanings. The aim is to look and look again and reflecting to obtain a complete description. Husserl presented phenomenology with a transcendental turn that involved his discovery of the method of epoché.   Husserl proposed practicing phenomenology by "bracketing" the question of the existence of the natural world around us.   Bracketing is separating the phenomenon from the researcher's own beliefs. This can be achieved by the researcher holding back preconceived ideas, beliefs to uncover the essence of the experience. Epoche or bracketing was also practiced to maintain the researcher's neutrality. Therefore, researchers guided by Husserl's philosophy have to bracket their presuppositions. Transcendental phenomenology concentrates on describing the experiences of the participants rather than the researcher's interpretations (Munhall, 2010). Husserl's student Martin Heidegger (1889-1976) had his own ideas about phenomenology, which he revealed after succeeding Husserl. In *Being and Time* (1962), Heidegger described his version of phenomenology. For Heidegger, our activities are always "in the world," our being is being-in-the-world, so we do not study our activities by bracketing the world; rather, we interpret our activities and the meaning things have for us by looking to our contextual relations to things in the world. Heidegger approached phenomenology as the art or practice of "letting things show themselves" or as interpreting phenomena of our everyday "being in the world."Heidegger used this term to emphasize the temporary, relational basis of our daily lives as opposed to being separate and non-relational. Heidegger is known for introducing the concept of being and time. He focused on "what does it mean to be" to understand a phenomena (Heidegger, 1962). Thus, he differed from Husserl in his approach and focused on hermeneutical phenomenology that reflects on the lived experiences of the participants and results are interpreted by the researcher and are accepting of the "constructivist and interpretive view of human consciousness" (Creswell, 2007). Hermeneutic phenomenology does not set aside biases but sees them as essential to the interpretive process (van Manen, 1990). The researchers acknowledge their experience, history, cultures, worldviews, and use their unique perspective to reflect and interpret data (Koch, 1995). Phenomenology uses the concept of the hermeneutic circle during the interpretive phase. This means that the researcher moves in and out of the imaginary circle connecting parts, and the whole goes back and forth, increasing understanding with each dynamic movement. Thus, the hermeneutic circle refers to the knowledge that an understanding of a phenomenon as a whole is determined by reference to an individual part, and understanding of an individual part by reference to the whole. He believed that language exists within perception and is important to one's life-world (Munhall,2010). Simply put, Husserl, and Heidegger differed in their approach of exploring the lived experience.

Husserl looked at understandings beings or phenomena whereas Heidegger focused on Dasein, or the meaning of a human in the world. Heidegger believed that a person's background and culture influences his way of understanding of the world. He is credited with influencing the French contribution to phenomenology. In the 1930s, phenomenology moved from German philosophy into French philosophy. Sartre and Merleau-Ponty led the French contribution to phenomenology. The key concepts during this phase were embodiment and being in the world. Sartre developed his conception of phenomenological ontology in *Being and Nothingness* (1943). For Sartre, phenomenology proceeds by a deliberate reflection on the structure of consciousness. His method was interpretive description of different types of experience in relevant situations. His method starts with the general sense of meaning and ends with the most concrete forms that meanings take. Sartre analyzed two aspects of being in the general sense en-soi (the in-itself) and the pour-soi (the for-itself).Sartre's phenomenology in *Being and Nothingness* became the philosophical foundation for his popular philosophy of existentialism (Sartre, 1956).

In the 1940s,Merleau-Ponty joined with Sartre in developing phenomenology. In *Phenomenology of Perception* (1945),Merleau-Ponty developed a rich variety of phenomenology, emphasizing the role of the body in human experience. Unlike Husserl, Heidegger, and Sartre, Merleau-Ponty looked to experimental psychology. Merleau-Ponty believed that individuals are interrelated with the world, and this allows the individuals to learn about themselves. He stated that "one's body is one's point of view upon the world … Sensation, sexuality, language, and speeches are all expressions of our existence" (Merleau-Ponty, 1962, p. 79) .These four classical phenomenologists had differing opinions about phenomenology. Despite these differences, phenomenology evolved with each philosopher's contribution. Today, there are several approaches to phenomenology that exists. Max van Manen(1990) developed a phenomenological philosophy using elements of both Husserl's and Heidegger's philosophy and merged both hermeneutics and phenomenology. He proposed six activities for conducting this research. As a methodology, this approach is both descriptive and interpretive. Using the hermeneutic phenomenology of van Manen, the researcher will seek to uncover the meanings in everyday existence and that according to vanManen is "the fulfillment of our human nature: to become more fully who we are" (van Manen, 1990). vanManen used interpretative hermeneutics so that the researcher could obtain deep, descriptive data, and give meaning to the experience. These six activities provide a framework for reflecting and interpreting the phenomena (see Figure 4). These researchers will explore the lived experience by following van Manen's six steps:

1. Turning to a phenomenon which seriously interests us and commits us to the world
2. Investigating experience as we live it rather than as we conceptualize it
3. Reflecting on the essential 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

Turning a phenomenon of interest which seriously interest us and commit us to the world: Explore the lived experience of Indian women with HIV/AIDS

Balancing the research context by considering parts and whole: Look for codes and sub themes from individual to entire transcripts to describe the experience of Indian women living with HIV/AIDS

Investigate the experience as we live it rather than as we conceptualize it: In-depth interviews with the women to explore their experience

Becoming fully human: To understand the essence of being an Indian woman with HIV/AIDS in South Africa

Maintaining a strong and oriented pedagogical relation to the phenomenon: Maintain a professional and bracketed relationship to the experience, thereby limiting bias

Reflect on the essential themes which characterize the phenomenon: Analyze the data: read and re- read transcripts, listen to audio-taped recordings of interviews to find meaning that can be grouped into themes

Describe the phenomenon through the art of writing and rewriting: Compile and interpret emerging themes. Expresses the themes through poetry, music or film that reflect the themes

Figure 4.Six research activities. Subramoney, R. (2012). Adapted from van Manen (1997).

Sample and Setting

Sampling enables a researcher to conduct a successful study based on the aims and purpose of the inquiry. Sampling is the process of selecting a small slice of the population that will represent the patterns of the target population accurately. The two major types of sampling are probability and purposive sampling. Qualitative studies favor purposive sampling which will allow the researcher to get rich information and in-depth analysis related to the research question (Flick, 2009). Purposive sampling is appropriate in this study as the small numbers of individuals chosen will be sufficient to explain the human perceptions and problems, and they will have the best knowledge because they are living with the phenomenon. Purposive sampling aided in the snowball effect. The researcher hoped that word of mouth would increase the awareness of the study. The aim of any research is to find something new, and if the sample is too small, the researcher runs the risk of bias, thus affecting the research. A larger sample will provide more perceptions, and the researcher can decide on the size based on saturation. Theoretical saturation occurs when there are no new themes or concepts discovered in subsequent interviews. For this study, a maximum of 20participantswas sought, or until saturation was achieved (Creswell, 2007). All participants met at the place and time that was mutually agreed upon, and an informed consent was signed. The participant was allowed to ask questions to ensure she understood the purpose of the study and her right to withdraw from the study.

The participant was made aware that if she withdrew, none of her data would be used in the analysis. If the participant were too emotionally distressed to continue with the interview, the researcher stopped the interview and provided the participant with a referral to the free clinic that provides counseling. Unless specifically asked to withdraw, information gathered was used. Participants were allowed to select a pseudonym for the purpose of the study.

Access and Recruitment

The researcher contacted all public health clinics in the predominantly Indian communities of KZN and sought permission to access potential participants for the study. Once access was approved, and after IRB approval, the flyers were posted at the sites and given to the staff in the clinics and doctor offices for distribution. Flyers were also posted in all community-associated areas. Access to a major clinic in Chatsworth, a predominantly Indian suburb, was granted (see Appendix G). The contact details of the researcher were provided so that potential participants could call for further verification of the study and confirm if the interested participant meets criteria. Contact information for the researcher was also available to all local community health nurses at the identified clinics.

Inclusion Criteria

Women, who wished to participate in this study must be at least 18 years old, speak English, self-identify as Indian, reside in KZN, self-identify as HIV positive, and be willing to consent and speak about their experience. No limitations were placed on time of diagnosis because the researcher was interested in the lived experience of Indian women with HIV/AIDS. The women's experience living with the disease was the basis of this research rather than the length of time she had the disease. However, someone recently diagnosed may provide a different lived experience as compared to someone who has had a positive HIV/AIDS diagnosis for a longer period.

Exclusion Criteria

Exclusion criteria included men and Indian women who met the criteria but did not reside permanently in KZN.

Ethical Considerations and Protection of Human Subjects

Qualitative research is usually considered harmless because no clinical trials are conducted, but truthfully, no one has rated emotional distress in terms of harmful or not. Therefore, it is untrue to state that qualitative research has no risks. It is the responsibility of the researcher to ensure that no harm will be done. To prevent any untoward reactions from the study, the researcher provided a clear description of the purpose of the study, the role of the participants, and how the information would be disseminated. The participants were reassured that none of the real identities would be revealed. All questions and concerns were addressed prior to signing the informed consent. In this study, the sensitivity of the subject could have caused emotional distress to the participants. Therefore, participants were made aware of this risk prior to the interview process. They were informed that because of this risk, they had the choice to withdraw if they thought they could not carry on. A referral to the free clinic service would be provided upon request (see appendix F). Participants were informed that there was no direct benefit from this study except an opportunity to talk freely about their condition, which could be either a distressing or helpful experience. The researcher explained that this study gave a voice to the difficulties of this population group (Flick, 2009). Participants were given a $10 gift card to show appreciation for their time. In South Africa, the data was stored in a locked cabinet in the home of the researcher. Demographic and consent forms were stored separately from the transcription. The researcher transcribed the interview verbatim. Upon return from South Africa, the transcriptions were stored safely in a locked cabinet, and the consent forms and demographic data were locked in a separate drawer in the home office of the researcher. Data stored in the computer was password protected in both countries. Pseudonyms were used on the transcriptions to protect identities. Peer reviews for member check were performed.

Data Collection Procedure

Upon approval from the Institutional Review Board (IRB) of Barry University; the data collection procedure began. Qualitative data collection involves direct contact with participants individually, in a group setting, or through observation. This method of data collection is very time consuming, thus validating the need for a smaller sample as compared to a quantitative study. Interviews can be very structured, semi-structured, or unstructured. A highly structured interview has limited responses and may hinder the search for in-depth data. Semi-structured data allows for open-ended questions so that all aspects can be addressed. This type of interview allows both the researcher and participant to discuss the phenomenon in great detail.

This allows the researcher to use prompts to encourage further discussion or probes to follow a line of inquiry originated by the participant. Unstructured interviews are simply interviews with no preconceived plan on how to extract the data. Unlike unstructured interviews, in semi-structured interviews, the researcher has an overarching question, prompts that may help the participant along, and the researcher has time to respond to the participant's responses. Qualitative interviews need to be informal and almost conversational. When the participant agreed to the study, a meeting was scheduled at a time and place that convenient for the participant. The research approach method was a semi-structured interview. The location ensured the participant's privacy and was mutually agreed upon. After explaining the purpose, risks, benefits of the study, and the length of the interview, the participants were asked if they had any questions. All questions and concerns were addressed prior to them signing the consent. A demographic questionnaire was completed at the end of the interview. The participant chose a pseudonym for the interview that was not be recorded on the demographic sheet. This protected the confidentiality of the participants. The key for the pseudonym and the demographic data was stored separately. The participants were made aware of their rights:

1. The right to withdraw from the study at any time. If they did withdraw, none of their information would be used.
2. They may have refused to answer any question or have the recording device stopped. If they did, the information would still be used unless they withdrew altogether.
3. The interview lasted approximately one hour, and a second interview for transcript verification was required, which lasted about a half hour. The participants were given a $10 gift card for their time, even if they withdrew.

The interview consisted of semi-structured questions, face-to-face in a quiet location. The researcher used open-ended questions to obtain in-depth information and probing for clarification of meaning. The interviewer requested permission to start the interview and audio-tape the recording to ensure verbatim transcription. Audio taping is preferred over taking notes as it is less distracting; the researcher can focus on what the participant is saying and respond appropriately. The researcher used two audio-tape recorders in case of equipment failure (Flick, 2009). After all the questions were addressed, the researcher asked the participants if there was anything additional they wanted to discuss or mention. The participant's were also advised if they thought of anything else after the interview, they may write it in a journal and give it to the researcher at the follow-up visit. They were also asked to share poems or songs that help to express their lived experience. The researcher thanked them, provided the gift card, and made arrangements for the follow-up interview. Reassurance was reinforced about confidentiality, the availability of the researcher if they need to talk, and that the next interview would not be time consuming. The researcher recorded notes immediately after the interview, regarding body language, verbal, nonverbal cues, and the researcher's own personal reflection of the interview and labeled the audio tape with the pseudonym. The reflection allowed the researcher to bracket personal assumptions and reduce bias. The interview was transcribed, which meant there would be a written version of the interview. Transcription was performed by the researcher. After the interview, transcription, and initial data analysis, the participant was contacted for transcription verification. This interview was short and not recorded, but it was necessary to ensure accuracy. The participant needed to verify that the transcription was exactly what she had said and verify the participant's description of her lived experience (Creswell, 2007). The audio-tape will be destroyed after five years. In addition, the participants were allowed to choose a pseudonym to maintain confidentiality. The researcher will keep all transcripts in a locked file in her home office. The consent form and demographic data will be stored separately and locked. Transcripts, demographic data, and the informed consent will also be destroyed five years after the study.

Interview Questions

Interviews allow the participants to verbalize their thoughts or experience about a phenomenon of interest. Researchers use semi-structured questions to guide the interview and avoid distraction. In qualitative study, the researchers are in close contact with the participant, but they need to maintain a professional relationship. The researchers need to realize that the interview is aimed at learning about the experience and not providing therapy. The interview began with the purpose of the study, the risks and benefits, interview duration, and goal of the study. This study was focused on "What is the lived experience of Indian women with HIV/AIDS in South Africa?" The researcher used open-ended questions to direct the interview and probes to clarify meaning (see Appendix D).

Epoche or bracketing was practiced where the researcher set aside all preconceived ideas to best understand the participant's experience (Moustakas, 1994).

Demographic Data

Demographic data was collected at the end of the interview for the purpose of describing the participants. The information gathered included age, educational background, marital status, children, and occupation. This data helped the researcher identify commonalities that transcended the group.

Data Analysis

Analyzing qualitative data involves summarizing the massive amounts of data collected to present the important features of the interview. Creswell identified six major steps in analyzing data in a phenomenology research study. First, the researcher manages the data by creating and organizing files so that they can be accessed easily for analysis. Second, the researcher reads and reread the transcriptions, making notes in the margins identifying any sub-themes and memoing the data to form baseline codes. Third, the researcher describes the personal experiences through epoche, attempting to identify the core meanings or essence of the phenomena, the concepts, or themes. Bracketing ensures that the researcher's opinions are not incorporated. Fourth, classify data by developing pertinent statements. These statements are grouped according to significance and meaning. The fifth step is the interpreting phase, which is a written description to answer "what happened?" and "how the phenomenon was experienced."As the researcher answers these questions, the essence or core meanings of the experiences will be revealed. Credibility of the transcription with the participants is very important as they can correct any misinformation presented. The sixth step is presenting the discoveries of the study, and this can be done through discussion or a published article. Reading and rereading transcripts are crucial to data analysis in phenomenology to detect emerging themes (Creswell, 2007). The researcher summarized data analysis as follows:

1. Read a transcript completely, and make a brief note in the margin about anything interesting or relevant.
2. Look at the notes in the margin, and list the different types of information found.
3. Create a list of items taken from the text. Categorize each item in a way that it describes what it is about using as many categories as needed at this time.
4. Look at the categories that have been identified from the transcript, and consider if they are linked in any way, thus creating major and minor categories.
5. Compare and contrast major and minor categories as this may be helpful to the researcher to see the big picture, and the researchers may need to change categories to provide a better fit.
6. Color coding categories makes it easier for the researcher to recognize it later. This should be performed on all transcripts.
7. Look again at all extracts from the transcribed interviews that were placed into categories to determine if they fit accordingly. Then, repeat the procedure with the major and minor categories as this may be necessary if any adjustments were made.
8. When all data appear in the correct categories, look at the range of categories to see if any two or more are similar. These may form the major themes of the study.
9. Look at the original transcripts and compare to the themes, major categories, and minor categories. This process of continual analysis involves revisiting the data and categories until the researcher is sure that the themes and categories accurately reflect the data.
10. This process will be ongoing until saturation is reached.

Qualitative data is subjective, interpretative, and holistic. However, by using themes and categories, a researcher can present the findings in a structured way. Quotes should be used to highlight each category and show association with each theme.

Research Rigor

Qualitative researchers justify research rigor by the trustworthiness of the research. Trustworthiness is when the findings reflect the meanings as described by the participants as closely as possible. Trustworthiness is necessary to validate qualitative research in the same manner as quantitative studies. Qualitative researchers are the instruments and can be easily biased; therefore, the aim of trustworthiness in a qualitative inquiry is to support the argument that the inquiry's findings are "worth paying attention to" (Lincoln & Guba, 1985, p. 290). Researchers have to adopt a variety of strategies to maintain trustworthiness such as prolonged engagement, triangulation, peer debriefing, member check, audit trail, and reflexivity.

To ensure authenticity, researchers should include all data in the final report to allow the readers to see the basis upon which conclusions were made and always seek professional feedback. The aim is to seek the authentic understanding of the phenomenon, and this can be achieved by semi-structured interviews using open-ended questions. The researcher ensured that the study was trustworthy based on Lincoln and Guba's criteria of credibility, transferability, dependability, and conformability.

Credibility

Credibility is ensuring that the results are credible or believable and that the interpretations are true. Therefore, researchers have to ensure that their methods are credible and appropriate for the problem to be researched. Credibility can be achieved by prolonged engagement, triangulation, peer debriefing, member check, audit trails, and reflexivity. Prolonged engagement is the time the qualitative researchers spent in the field collecting data, observing, and interviewing to gain in-depth knowledge. Triangulation or "mixed method" research is the combination of several research methods to study one phenomenon. Triangulation is important because when there are different methods, different samples, and different sites in agreement, it lends to a credible study. Peer review is the discussion of the researcher's interpretation with other people. A peer reviewer can play "devil's advocate" and ask questions throughout the process, ensuring that the researcher is addressing any gaps. The data, analysis, interpretations, and conclusions were continuously peer reviewed by members of the dissertation committee who are experts in this field (Creswell, 2007). The audio-taped interviews were not destroyed until member check and transcription verification. Lincoln and Guba (1985) describe member check as the "… most crucial technique for establishing credibility" (p. 314). The researcher ensured that the transcription was validated by the participant. This means that the participants verified that the described experiences were their perceptions and that the transcribed words reflect their individual experience. Audit trails were accurate transcriptions, clear description of analysis process, and interpretation of data. Reflexivity involved self-awareness, reflection by the researcher on her potential bias, and predispositions that may have affected the process and conclusions. The researcher engaged in journaling to bracket any preconceived ideas. Journaling is crucial so that the researcher can document her feelings or thoughts on the choices made throughout the process of analysis. In this study, the researcher met with participants twice in face-to-face meetings. The verification of the transcripts by the participants enhanced credibility.

Dependability

Dependability is the assessment of the data collection and data analysis process. Dependability is described as audit ability or reliability of the study. The researcher can enable this by ensuring accurate documentation by, including all documents in the final report, avoiding spelling errors that will reduce the quality of work, and ensuring that the details of the procedures will be described in detail. This means that the sampling procedure and data collection procedures will be described in detail so that others can read them, evaluate the method, and deem the study useable. Including the notes written during and after the interview will provide a rich description of the interview. Put simply, the audit trail describing the research should be detailed and thorough so that if individuals read the study, they would be able to replicate it.

Confirmability

Confirmability is a measure of how well the study's discoveries are supported by the data collected and reflects the objectivity of the data. Confirmability was established by a paper trail. This means that the researcher's bias should not alter the result. Bracketing is important in this stage, together with maintaining a reflective journal. The researcher set aside any preconceived ideas regarding HIV infection, allowing the researcher to write out her feelings and experiences to separate them from the participants. Reviewing the analyzed data through peer review and member check further minimizes researcher bias. Confirmability can be achieved by linking the words of the participants and with the discoveries (Lincoln &Guba, 1985).

Transferability

Transferability is the degree to which the discoveries of this inquiry can transfer beyond the research project. The researcher can ensure transferability by providing a detailed description of the study from purposive sampling to data analysis to provide a "paper trail," thereby providing opportunities for replication or to determine transferability of results.

Transferability requires detailed, descriptive data in the research report so that others can evaluate the contents, to either make a transfer or form a conclusion.   Therefore, the method, sample selection, inclusion, exclusion criteria, and data collection were clearly described in this study to provide a clear audit trail. The use of experts in the field can enhance the transferability of the research.

Chapter Summary

This chapter dealt with the methods that were applied to this study. The research design is van Manen's method of hermeneutic phenomenology, and the rationale for this approach was discussed. Phenomenology is the lived experience, and the phenomenological inquiry was the framework for the study "the lived experience of Indian women with HIV/AIDS living in South Africa." A purposive sample was used; inclusion and exclusion details as well as recruitment, protection of human rights, ethical considerations, and research rigor were discussed in detail.

Chapter Four

Findings of the Inquiry

This chapter highlights the findings of the phenomenological inquiry into the lives of Indian women with HIV/AIDS residing in Kwa-Zulu Natal, South Africa. A demographic description will be presented in addition to the individual descriptions of the 10 research participants. This study allowed the women to share their life worlds, thoughts, and feelings, thus depicting the essence of the phenomenon. vanManen (1990) stated that "we gather other people's lived experiences because they allow us to become more experienced ourselves" (p. 62). The stories of the participants depicted the meaning of their lived experiences. In addition, the process of data analysis and the thematic representation reflecting these women's lived experience will be provided, as well as the summary of the key findings. The goal of this study was to explore the lived experiences of Indian women living with HIV/AIDS in South Africa. The phenomenological researcher remains open to seeking the deeper nature of lived experience and remembers the day that the nature of any phenomena has been possible because of others (van Manen, 1990). Through the participants' personal thoughts and feelings, the researcher was able to describe, interpret, and illuminate the meaning of Indian female participants in this study with HIV/AIDS in South Africa. Data collection and analysis of this study was guided by van Manen's six activities. Although the aim of phenomenological inquiry is to uncover the meaning of the experience, allowing "each participant to stand alone" is encouraged (Munhall, 2007, p.151). Thus, a brief description of each participant will be provided. This study provided these women with a platform for their voices to be heard, to see the world through their lens, and to uncover the meaning of affliction of disease upon their lives through the personal stories (words and emotions) of someone who had experienced the phenomenon. The aim was "to construct an animating, evocative description of human actions, behaviors, intentions, and experiences as we meet them in the life world" (van Manen, 1997, p. 19).

The researcher employed a phenomenological approach to guide the study to fully describe the experience of an Indian female living with HIV/AIDS in South Africa. Phenomenological inquiries are usually time and labor intensive (Cohen, Manion, & Morrison, 2000;Patton, 2002), but in this study, it was costly as well.The international destination placed constraints on the amount of time available to conduct the research. In addition, the researcher's daily travel time to the clinic as well as time spent to contact participants, schedule interviews, and travel to the mutually agreed upon places of interviews were both expensive and time consuming. Unforeseen circumstances such as locations of interview (participants' homes that were difficult to locate or in unsavory neighborhoods) and unanticipated road construction that made travel time longer. The researcher transcribed all of the interviews immediately for transcript verification and ensured member check because of the researcher's limited stay in South Africa. The researcher spent a total of 25 days collecting data, transcribing, and member checking. The experience was overwhelming for the novice researcher. In hermeneutic phenomenology, there is no absolute method, so this study was guided by Max van Manen's six activities. The emphasis is on the data analysis process to capture the essence of the lived experience by reflecting on the themes identified from the interviews. Phenomenological research allows the researcher to bring out the essence, which is usually obscured as compared to what is seen every day.van Manen(1997) clearly states that there is a distinction between appearance and essence (p. 31.). The intention in the art of writing and rewritings is to highlight the thoughts and feelings of the participants while still focusing on the research question on hand. Although these activities are sequential, the researcher goes back and forth between the activities throughout the research process. The researcher reads and rereads, examines, and re-examines continuously throughout this circular process to transform the lived experience into a textual expression of its essence.

vanManen(1990) stated that it is impossible to learn about a lived experience through any secondhand account (books, journals, or discussions), thus the phenomenon must be investigated. Therefore, semi-structured, in-depth interviews were used because they supported the study and the phenomenological approach. The twofold purpose of interview is to gather narrative text that can deepen understanding of a phenomenon while allowing the participants to tell their stories in their own words, thus promoting comfort, and understanding between the researcher and participant. In addition to tailoring questions, the advantages of a semi-structured interview is that it is flexible, allowing the interviewer to probe new or potential lines of inquiry based on the responses disclosed by the participant.

Demographic Representation

The study included 10 Indian women all of whom were HIV/AIDS positive who lived in Chatsworth, a predominantly Indian community, located just outside Durban in Kwa-Zulu Natal. Nine of the research participants were recruited from the anti-retroviral clinic (ARV) clinic that is affiliated with the hospital that serves the population of Chatsworth and surrounding areas. The hospital is one of the major hospitals in the Durban region and treats 600,000outpatients annually in various clinics such as the ARVclinic. Sample recruitment proved to be a challenging endeavor despite permission from hospital administrators to conduct the research, access to the ARV clinic, permission to approach potential participants as they came to the clinic granted, and the location of the ARV clinic in the predominantly Indian community. On average, one Indian female visited this clinic per day. The participants were very shy, often reluctant to talk and often recanted even if they agreed to do the interview in the clinic. It was a slow process, but nine women eventually participated in the study. One participant was recruited via snowball sampling method, and this participant resided in Phoenix, another predominantly Indian community. The lack of Indian women at the clinic emphasized the "stigma associated with the disease accordingly" stated Doctor J. Bridgkumar, Director of the ARV clinic. He said that the shame causes the women to seek help at far-away clinics for fear of recognition or deny the disease's existence, and it is a tragic situation because "we can help" (personal communication, October 2012). The female participants' ages varied from the 24 to 62, with a mean age of 44.2 years. Their ages at time of diagnosis were from 18 to 57, with a mean age of 39.3 years. The participants reported that they were living with this disease from 6 months to 10 years. Seven participants reported contracting the disease from their husbands and three from their boyfriends (although they were supposed to be in a monogamous relationship). The youngest participant was infected during her first sexual encounter with an older male whom she believed loved her. She was 18 at that time and had just graduated from high school.

Although all the participants' ethnic backgrounds were Indian, eight of the women stated they were of the Christian faith; two were Muslim, but one participant who listed Christianity as her current faith had changed from Muslim to Christian and also currently practiced Hindu customs as well. Their marital statuses were reflected with only one participant currently married, one was divorced, five were widowed, one was separated, and two were single. Four of the participants had adult children, of which two of the participants' adult children totally supported their moms, while the other two of them had some or no support at all regarding their illness. The one with no support had not told her son because she claims he is "fussy," and he is also a drug addict. Three of the participants had no offspring, while the other three had minor children ages 3, 7, and 10, respectively. All of the young children were HIV negative, which was a big relief to the mothers, and the 10-year-old was aware of her mother's illness and was a source of support to her. The seven- and the three-year-old both knew their mothers were ill, but neither knew the details of the illness. Nine of the 10 participants were unemployed, and all relied on some stipend from the government. Three of the participants did admit to seeking employment but had found it to be very difficult. Two of the participants had left work because of complications of the disease and could not return to work when they were healthy to work again. The oldest participant verbalized additional health issues that made employment difficult for her. One participant had a college education and was a substitute teacher; another had finished high school but never worked due to complications with the disease; one never went to school at all; and one only went until sixth grade. The other six participants had the equivalent of some middle school education, but they did not complete middle school. All participants depended on government supplied healthcare (socialized health care), which means attending a state hospital for routine care was time consuming, and the lines were very long. The 10 participants wholeheartedly expressed their experience of living with HIV/AIDS. Their thoughts, feelings, and emotions were presented with great intensity and a sense of deep understanding regarding their lived experiences during the narrative interviews.

The participants found their voices and reflectively shared their memories in an atmosphere of openness and interest by the researcher. Their voices described the intricacies of their journeys, and their lived experiences gathered meaning as the participants described them.

Characteristics of the Participants

Although the participants could choose a pseudonym, two refused, preferring to use their own name; one chose to use her initials, but the other seven did choose a pseudonym. The purpose of the pseudonym was to maintain the confidentiality of the true identity of the participants given the sensitive nature of the phenomenon. They will be described by their respective choices throughout the study. The description of the participants was extracted from the audio-taped and transcribed interview. They were very emotional during their reflection, yet they provided an in-depth insight into lives as Indian women with HIV/AIDS in a conservative culture. The interviews were productive and highlighted their willingness to talk to researcher about a very painful era in their lives. The relationship between the researcher and participant was mutually conducive with the researcher being appreciative of the participants willing to share their story, while the participants appreciated the opportunity to tell their story. The narrative interview provided a myriad of feelings, thoughts, and emotions.

Pamela

Pamela is a 40-year-old Christian, single mom to a 10-year-girl. She attended school until grade six, and was then forced to leave school to care for her ailing mother, which was expected of her as she was the oldest child. She has never been gainfully employed. She stated she was 29 years old when she was diagnosed 2002 and was seven months pregnant. The interview was conducted in a friend's apartment at her request. It provided privacy, and the only occupants at the time of the interview were the researcher, Pamela, and her daughter. Pamela stated she was comfortable talking in the presence of her daughter because her daughter knew everything. She admits that she wanted to commit suicide at that time when she heard about her HIV positive diagnosis. Her neighbor encouraged her to think about her baby as she was in an advanced stage of pregnancy, so she opted to wait until delivery and decided to keep the baby. She stated that she was told that her daughter is HIV negative. Pamela lives at home with her father and her immediate family. Pamela is troubled by social and economic issues, and she does not have much support from her immediate family. She stated she is not in any relationship currently.

SN

SN is a 57-year-old, Christian, recently widowed female who has no children. She has had no formal education, but she spent her adult life working in a factory for many years. She was recently diagnosed just a month ago (August 2012) after the death of her husband. SN allowed the researcher into her home for the interview. She said she had been married for 18 years, and she claimed that her husband was her only sexual partner. She had moved in with her sister because of economic reasons and currently resides with her. Her husband became very ill suddenly and passed away in August 2012. Her affect appeared flat, as if she did not fully realize what had happened to her. Her biggest concern was financial, as this has been the only year that she had not worked, and she was concerned about the effects of HIV/AIDS on her life. She appeared to still be mourning the death of her husband; however, she appeared to have a supportive base in her sister and her niece. Questions about her current relationship status were deemed inappropriate given the recent death of the participant's husband and her obvious current state of despair.

Dolly

Dolly is a 62-year-old Christian widow who has one adult daughter. She has the equivalent of a seventh-grade education, has worked most of her adult life, but had to leave work due to health issues. She was 57-years-old when she was diagnosed HIV positive in 2005.The interview at Dolly's house was time-consuming due to difficulty locating her home because of the geographical area. Dolly mentioned that she discovered her status coincidently when she was hospitalized for an allergic reaction to a penicillin injection. She stated she was on her death bed because she of the allergic reaction, and the doctors did not expect her to live. Her hospital workup revealed that she was HIV positive. She believes that God had a plan for her, and it is because of him she is alive and well today. She said that her daughter and three grandchildren are very supportive of her. She receives a stipend from the government that she lives off, and could not workas she was plagued by several hospitalizations and infections after she was diagnosed as HIV positive that has left her too weak to work. She is not involved in any romantic relationships currently

Sharon1

Sharon1 is a 61-year-old Muslim woman widow who has one adult son who lives with her. She claimed to have the equivalent of sixth-grade schooling and is currently unemployed. She was diagnosedonly in June 2012. The interview was conducted in her apartment. She was married for 26 years, has been widowed for seven years, and has a 26-year-old unemployed, drug addicted son. She has worked for 30 years in a factory but had to leave in 2010 before she was diagnosed with HIV. This was due to symptoms of the HIV infection that left her weak to work, such as a massive weight loss to 40kg (88lbs), excessive rashes, numbness of extremities, and headaches. She appeared to be very positive about her life, giving full credit to the clinic staff for supporting and encouraging her.

Fe

Fe is a troubled 43-year-old Christian divorcee who is a mother of two adult sons. She completed grade 10 schooling and claims to have had an exciting job with the police department but is currently unemployed. Fe found out she had HIV in 1988, when she was 29 years old, and had just had a heart attack from what she describes as all the stress in her life at that time. She was interviewed in the researcher's car, while she waited for her medication from the hospital pharmacy. The waiting period is a minimum of one hour. Fe was married at 16 and had two sons but eventually divorced when she was 22 years old. She stated that she was estranged from her oldest son (his preference), and she currently resides with her youngest son at her parents' home. She claims to have lived with the man who infected her for 12 years but had to leave when he became abusive. Fe has not been able to come to terms with her illness and has been referred to a psychiatrist, but she is non-compliant because she does not like how the psychiatric medication makes her feel. Fe denied any intimate relationships, but she sometimes contradicted her own answers because she says her dad fights with her because of alleged promiscuity.

Melissa

Melissa is a 44-year-old Muslim widow who did not have any children. She stated she attended school until grade 10 and is currently unemployed. She was 42 years old when she was diagnosed in 2010. Her interview was conducted in the car as she waited for her medications because she was afraid to be seen with the researcher for fear of being questioned by 'nosy' people. She was married for 18 years and described herself as a good, faithful Muslim wife. She was gainfully employed until 2009, when she had to stop work because of a persistent outbreak of boils that affected her daily functioning. In 2010, her husband became very ill suddenly but was reluctant to seek medical attention. She eventually forced him to seek medical help, and found out he was HIV positive. He died within two months of her finding out. She goes on to describe that even though she knows how HIV is spread, she feels contagious. She started her ARV medications on October 25, 2010. She has a very close male friend (who is HIV negative) who really cares about her, but she says that they are not intimate.

Cheryl

Cheryl is a 29-year-old Christian, recently separated mom of a three-year-old boy. She is the only participant that had completed high school, obtained a college degree, and is a substitute teacher. Cheryl was diagnosed in 2010 at age 28. She did not want to use a pseudonym, and the interview was conducted in her mom's home where she currently resides. She was married at the time of her diagnosis but is currently separated. Cheryl does not want her disease to be shrouded in secrecy. She said she has nothing to feel ashamed about because she did not do anything to contract this disease. It was passed to her by her husband. Cheryl is the only participant that physically appears to be severely affected by the HIV/AIDS virus. She is extremely emaciated, her body is covered in eczema, and she states that she has had several prolonged hospitalizations, alopecia, and tuberculosis. She said she had a massive weight loss after the birth of her son and got herself tested. She was shocked that she was positive because she says "I never did anything wrong." She later found out that her husband had an affair with a prostitute. She is no longer able to perform her activities of daily living. She said that she wanted to live for her son, to see him go to school, and that she loved him very much. She was grateful that he is HIV negative.

Sharon 2

Sharon2 is a 47-year-old Christian widow who is a mother to three adult children (two girls and a boy). She has a tenth-grade education and is the only participant that has gainful employment. She was diagnosed in 2005, when she was 40 years old, and she had a difficult time accepting her diagnosis.

She was married for 15 years, and her husband was killed in an accident. She says she stumbled upon her diagnosis "accidently;" she had planned to take an insurance policy and was doing the routine preliminary blood work when she was advised to see her medical doctor. She spent 2005 in denial, and refused to accept that she had this disease. She credited the counselor for "staying with me, never giving up," and she said "it is because of her, I am alive today." Sharon's three adult children are very supportive of her, and she currently resides with her son. She said she was infected during a vacation romance, and she "should have known better." She has always maintained her job, and she credits her positive outlook, social support, and keeping busy (working) as reasons that she is doing so well despite HIV. She is not involved in any relationship currently.

Candice

Candice is a 35-year-old Christian woman, the only married participant, and a mom to a seven-year-old boy. She completed the equivalent of grade 10 schooling and is currently unemployed. Candice was 341/2 years old when she diagnosed in February 2011.Her interview took place at her home, on the outskirts of the residential area in a less than reputable area. She stated that she had to go on tuberculosis (TB) treatment for a month starting in February 2011, prior to starting antiretroviral in March 2011 because the TB had damaged her lungs. She still has severe bouts of coughing that last for several minutes, one of which occurred during the interview. Candice said that she knew something was wrong with her before that (2009), and she had several "tests" done to find out the problem, but they were negative but she never tested for HIV until 2011 with the help of a physician from church. She was employed full-time in 2009, but she became sick frequently, and she lost weight, dropping from 64kilograms (140.8lbs) to 48kilograms (105.6lbs), so she had to leave work in January 2010. Although she had symptoms from 2009, she was diagnosed as HIV positive in 2011.

Lynette

Lynette is a 24-year-old single Christian woman who has no children. She is only the second participant who completed high school; however, she has never been gainfully employed. She was just 18 years old when she was diagnosed with HIV in 2006. She was infected during her first sexual encounter with an older man. She said she became sick and ended up in hospital, and she was tested for HIV that turned out to be positive. She thought that the staff was joking with her, and she asked them to test her repeatedly and was refusing to accept the results.

Describing the Experience: Overview of the Findings

Those participants who met the criteria were contacted after the clinic visit to set up an appointment for the interview. All participants were met at the place and time that was mutually agreed upon. Prior to the commencement of the first interview, the researcher discussed the consent in detail, informed the participants of their rights, and allowed the participants to ask questions to ensure that they were knowledgeable about the interview process. Participants were allowed to select a pseudonym for the purpose of the study if they wanted to. The researcher remained watchful to all possibilities, thus maintaining engagement with the participants during the discovery process. The researcher collected data in a face-to-face interview conducted in a location and time that was mutually agreed upon. The interviews were recorded on audiotape and lasted approximately one hour. Time was allotted at the beginning of the interview to complete the consent, answer any questions the participant may have had regarding the study, and at the end of the study, to complete the demographic data. The interviews were audio-taped, and the participants were given the equivalent of a $10 gift card at the end of the first interview. The researcher spent the time after the interview writing her thoughts, observations, and anything specific about the preceding interview in her reflective notes.   These notes reflected the nonverbal, verbal, and the general affect of the participants.   The participants used their stories to describe their lives before and after they found out their HIV status. After the interviews were transcribed, the participants were contacted by telephone for a second interview at their convenience. Although some participants wanted to meet in person for the second interview, they all eventually decided on a telephonic interview because they "will not have to explain what they are doing with me." This interview was not taped but was important for the participants for transcript verification of the previous interview (member check), clarify statements, express additional thoughts, and verify the authentication of the participant's actual lived experience. Only one participant was unavailable for the second interview. vanManen (1997) described this follow-up as the phenomenological nod as "nods in agreement with the essence of the lived experience as described from within the lifeworld of others" (p. 36).

Saturation occurred after the fourth interview, but the researcher continued data collection for verification and confirmation with another six participants. Her notes on the non-verbal expressions, emotions, and facial expressions helped define the individual experience. The personal transcription of the interview by the researcher allowed her to gain the sense of the whole experience as she had to listen repeatedly to the audio interview. The narrations were the actual experience of these women with HIV/AIDS, they were intensely personal, and they allowed the researcher to fully comprehend the women's perspectives of their daily lives.   The interviews were compared mentally and visually on an Excel spreadsheet created by the researcher to find meaning in statements and similarities and differences. The spreadsheet allowed the researcher to view the individual responses and the meanings. This process was labor intensive and required the researcher to be focused and a good listener to the spoken word as well as the non-verbal cues. She read and reread the transcript, writing comments in the margins of the transcribed text that once again highlighted the individual experience. She continued reading to ensure the textural description of what the participant experienced was accurate before developing a list of phrases or sentences that appeared to describe the individual experience specifically. These sentences and phrases were color coded. Meaning units were established when the researcher grouped the color-coded phrases and sentences into groups and then clustered into themes. The researcher spent almost four months reflecting on the data collected, the numerous abstractions, the similarities, and differences before embarking on phenomenological writing. The related themes of struggling, isolating, supporting, and hoping emerged as a total representation of Indian women with HIV/AIDS living in South Africa. The researcher labeled these themes as an artistic interpretation ascribed by herself (see Figure 5). Artistic representation such as songs, movies, and poems were investigated by the researcher to exemplify the phenomenon.

Themes

Multiple readings of the narratives, listening to the participants' voices repeatedly, and remembering their moods, affect, and expressions resulted in the surfacing of thematic structures of this experience. Themes are the core or essence of an experience without which the experience would not be the experiences. Four major themes emerged from writing and re-writing: (a) Struggling, (b) Isolating, (c) Supporting, and (d) Hoping. The subthemes were (a) life after death, (b) social isolation and stigma, (c) support systems and spirituality, and (d) coping with the highs and lows. These themes highlight the lived experience of Indian women living with HIV/AIDS in South Africa. The themes also represent the women's existential life worlds of space, body, time, and human relation in addition to the totality of the experience of living with the "disease."

Figure 5.Subramoney's conceptual representation of the lived experience of Indian women with HIV/AIDS.

The lived experiences of Indian women with HIV/AIDS as described by the participants in this study are portrayed in the researcher's conceptual representation (see Figure 5). This phenomenological investigation revealed the themes of Struggling, Isolating, Supporting, and Hoping. These themes were not restricted to a specific participant because the experiences of a single participant could belong to more than one theme.

Struggling: Life after a Death Sentence

Struggling is a verb that is described as a great effort to deal with a challenge, problem, or difficulty. It is also defined as a strenuous or violent effort in the face of difficulties or opposition. Human beings require certain basic needs met to ensure health and well-being. The World Health Organization (2012a) defines health as a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. Basic needs are defined as the elements required for survival and health (food, water, shelter, sanitation, education, and medical care). When people cannot earn income to satisfy these needs, they are considered to be living below the poverty line. The participants' poverty-stricken status was exacerbated by pre-existing situations as evidenced by: Lack of education (only 2 of the 10 participants had completed high school, and only 1 participant had had a professional occupation), unemployment (9 of the participants were unemployed at the time of the interview, and none had the resources to care financially for themselves adequately), and 7 participants were unable to afford housing (lived with a family member). The theme of struggling emerged as the women provided rich descriptions of their lives with the disease. They usually had to depend on family for emotional and financial support or even assistance from governmental social services. Fe said this of her limited housing options: My son and I, we had a place quite near here in 501. We lived there for six months, but the landlady son and daughter gave us hell. Then, they just packed us up. I cannot afford a R1000 – R2000 ($150 – $200) per month rent. Therefore, I am living with my parents

Pamela echoed her housing struggles:

I live with my dad, and he gets abusive when he drinks. Also, my younger sister moved in with her husband. He is a forward man and is always asking me for sex. I told my sister, and we end up fighting because she blames me, and not her husband. I can't live like this, but I can't afford to go anywhere. I am worried about my daughter's safety also. The women were educated by the personnel at the ARV clinics about healthy diets and exercise, and they understood the importance of such, yet they did not have the income to meet those needs. "I cook what I can buy, and we eat it for several days," Pamela said. Sharon2 was gainfully employed yet she displayed financial hardships as well. After she paid her rent, she did not have adequate finances to cover the cost of milk and bread for the week. She said to the researcher of her limited income struggle:

God has used you to help me. I had just paid my rent, and I had no money for milk and bread this week. I prayed to God and left it in his hands. I came to the clinic, and I see you and you tell me about the research, and the gift card. God answers prayers! Sharon1 also admits financial hardship, and she says she cannot expect any help from her son as he is a drug addict and is dependent upon her: I am feeling it very hard. I am signing up for unemployment every month. I do not know for how many months more that I can. I am in arrears with the rent. I have to buy water separately. I have to buy power separately, and they all add up. The struggles with the HIV diagnosis can be physical, which affect the participants' ability to be gainfully employed or provide for their daily needs. Employment opportunities are scarce "due to the economy," said Lynette, and although most of the women indicated that they would work if given the opportunity, they were concerned with the barriers that prevented them from returning to the workforce. They were concerned about their capabilities to complete their work due to fatigue, increased requests for time off to go to appointments, and fear of the embarrassing side effects such as diarrhea. Dolly admits her complications left her physically drained: I was very sick after I was diagnosed with HIV. In the beginning, I had defaulted because I was vomiting so I did not take the ARV medication. I was spewing blood because the medications never agree with me. They had to give me drips to wash it out of my body. I was admitted several times for pneumonia, and even tuberculosis. You name it, and I had it. The doctors thought I will never walk and will need oxygen for the rest of my life. Most of the participants reported struggling with powerful emotions that started when they first heard about their diagnosis. Then, they experienced a vast range of emotions such as grief, guilt, fear, anger, depression, blame, and suicidal ideation. These emotions varied from person to person and were unique to each participant.HIV/AIDS-infected participants may not necessarily experience every emotion, and some may have catastrophic changes both physically and mentally. Fe said:

The pain is still there. I try my utmost best, but it won't go away. I want to lash out at someone, to let someone else feel the pain…my father made me an outcast; my family did not want me Some of the participants blamed themselves for getting infected. Sharon 2 stated: "I blame myself for being negligence. I should have used protection.You slip up, and then you realize that…too late." Lynette said: "I blame myself for being stupid. I blame myself for having sex at an early age. I blame myself for not listening and not obeying my parents." All the women were infected by their romantic partners. Their reaction to the emotional betrayal was shock, sadness, and anger. SN said, "I did not expect something like this at my age (57);" Dolly said, "how could he, how could he do this to me? I was inconsolable;" and Cheryl said: "I felt so embarrassed. I was in shock. I am not a fast girl. I never did anything wrong." In addition to being devastated, some of the participants blamed themselves for getting infected, while others struggled with powerful daily emotions. Lynette described her struggle "as a roller coaster. I don't know how I am going to feel the next moment."

All 10 participants had varying degrees of social and emotional difficulties and economic hardships. This diagnosis of HIV/AIDS altered these women's lives forever and had a profound impact on their physical, psychological, and psychosocial aspects of life. It is important to remember that even though HIV/AIDS has physiological effects, the impact psychologically (thoughts or emotions that affect the mental well-being of a person) on an individual are major, and therefore cannot be ignored. The diagnosis of HIV/AIDS has added yet another burden to the lives of women already struggling with poverty. These women struggled with socio-economic issues, powerful emotional responses, betrayal by romantic partners, physical changes, and severe side effects of medication. Their responses highlighted their daily struggle that this disease has inflicted upon them. The theme of struggle illuminated the vast range of emotions that causes chaos in the lives of women infected with HIV/AIDS.

Isolating: Social Isolation and Stigma

Another theme that emerged was isolation. The participants all stated that they had decided to isolate themselves from their friends and community to avoid having to explain what is wrong with them. Hill (2006) defined social isolation as the distancing either physically or psychologically from an individual's social network, thereby resulting in the loss of place within the network. Humans need the contact with fellow humans to ensure a richer life. Social isolation can occur in four layers: The outer layer is isolation from the community or the social structure; followed by the isolation from organizations such as schools or work; then, the social circle, which includes friends, family, and significant others; and finally self. Social isolation can be voluntary or imposed by others for a variety of reasons. The lack of social relationships is compounded by unemployment, drained relationships, and emotional and psychological stress. The participants stressed that they all withdrew from social contacts after they were diagnosed, and this self-imposed social isolation was seen as a coping mechanism. John Donne's "no man is an island" is a simple illustration that people need relationships. When an individual is ill and experiences a variety of disabilities, the person needs social support to help get back on his or her feet. Social isolation is not associated with location (hospitalized) or the number of people a person is surrounded with. The focus is on a reciprocal relationship between the isolated person and his or her social network that contributes to social support and emotional well-being. Boredom can occur in social isolation because of a lack of validation of a person's work; thus, daily routines become busy work. Dolly, Sharon1, and Candice all focused on busy work, such as cleaning the house, hand-washing the clothes, and conducting religious activities such as prayer, to avoid social interactions. Dolly said:

I don't go outside in a hurry. The only time I go outside is to put clothes on the line. Then, I come in; sometimes I go and check my garden in the backyard then come back in. I don't want to associate with people outside Candice said she spends her day "watching movies, praying, and reading the Bible," and these activities were common among all the women who described their day focused on busy work. Melissa described her social isolation: I just kept away from everybody. I don't go anywhere besides coming to the clinic. This is the only place I go to. I prefer to stay at home. In our Indian community, they shun you when they know. Indians can't make a difference between HIV positive and AIDS. As soon as you tell them you are HIV positive, they think you have AIDS. But it is not, it is two different things. Yet they fear contact like they are going to get it. It is fear.

Sharon2 described issues with disclosure:

This is why I chose not to tell anyone else, besides my children, nobody knows. You see, discussing any personal secrets things with people - you sometimes get people who cannot keep things to themselves; they will like to discuss. Now once you tell one person, it is going to go around, and that will really bring you down…everybody talking about you. Fe appeared to struggle with the social isolation: "I don't have friends, not because of my status, but because I choose not to and then she complained about her dad being too strict with her by refusing to allow her to socialize, which results in endless fights and dissatisfaction in her family. Sometimes the social isolation is unintentional as in the case of Cheryl whose physical health deteriorated rapidly to the point that she was dependent on her mom to care for her. The generational gap among the participants is clearly depicted by Lynette who said:
I don't have many friends. I prefer not to have a lot of friends. I do have Internet friends. I have a social network, 'Mix It'. So I have friends from there. They don't know my status. I don't go around telling them…I want them to know what kind of a person I am… I love being alone. I love the peace and quiet All participants clearly verbalized voluntary social isolation to reduce the chance of discovery. Isolation is clearly a problem for those with chronic illnesses because of the vast number of physical and psychological implications and the negative effects of loneliness on their lives. Social isolation can be seen as a protective mechanism to protect the women from the possibility of accidental discovery of their HIV status and the stigmatization that follows.

Goffman (1963) defines stigma as a powerful and discrediting social label that changes the way individuals view themselves and are viewed as persons. Stigma is also defined as a degrading attitude of society that discredits a person or a group because of an attribute (such as an illness, or deformity). Stigma can be divided into self-stigma, felt, and enacted. Self-stigma is anticipated, or internalized such as a personal feeling of shame that leads to unwillingness to seek help. The women infected with HIV believe that people will be quick to judge them, and they will more often be blamed for acquiring the disease regardless of the circumstances. Felt stigma is a constant battle that will remain with the women for the duration of their lives. Felt stigma can lead to poor self-esteem, and active social avoidance. Enacted stigma (external stigma) is discrimination, social rejection, and stereotyping.

Stigma can cause a delay in treatment, non-compliance, and hindrance to seeking health care even when the individual is willing. There has been a stigma attached to HIV/AIDS since it was first termed a gay man's disease in the formative stages, and 30 years later, stigmatization remains a persistent problem that has allowed HIV/AIDS dominate the lives of humans. Women currently outnumber men with HIV/AIDS infection and prevalence rates. Although most women are infected through heterosexual relations, they are often blamed as carriers of AIDS and participants in immoral behavior (drug use and prostitution). All participants in this study verbalized that they kept their diagnosis a secret from neighbors and friends to avoid HIV-related stigma. Participants were very secretive about their health, telling only told the closest family members whom they could trust, and they did this because they feared losing emotional support, friends, and jobs or having themselves, or their families forcibly isolated because of their disease. These women all struggled alone with feelings of shock, shame, and anger when first diagnosed. The one married participant did not condemn her husband.Sharon1 said: What I find is that a lot of people don't tell because not everyone understands. They think it is your fault you got the disease. They look down on you. I chose not to tell anyone because you cannot actually trust anybody today. This will remain between my children and me. As long as somebody important in my life knows what is going on, that is all that matters. Not even my brothers, sisters, or mom knows. In my family especially, they bring you right down. My children respect my decision. In the Indian community, they do not understand. The participants feared that disclosure would result in either their family or themselves losing friends, being avoided at social functions, or becoming socially isolated. In addition, the participants wanted to protect themselves, and their families from discrimination, and maintain their privacy. All participants eventually shared with either family members or friends. Pamela and SN (20%) both shared their diagnosis with their sisters (mom was deceased), Sharon1 (10%) shared with her niece (she had no other female support), Dolly, and Sharon2 (20%) disclosed to their adult daughters, and the other 50% all disclosed to the mothers as well as a male friend, father, and husband, respectively. Cheryl was the only one not concerned with stigmatization because she stated that she was an innocent victim.

In fact, it (HIV diagnosis) was brought to my mom's attention when I was in RK Khan Hospital. The doctors wanted to know from me if they must tell her. I said I can't bottle it up. And myself, I am getting sicker. It is good that they know about it. It wasn't something that I was sleeping around or something; it was given to me. This was given to me by my husband HIV/AIDS-related stigma builds upon the pre-existing forms of stigma of sexuality, gender, race, and poverty. Minority populations are very vulnerable to HIV infections, thus continuing the cycle of poverty and social inequalities in post-apartheid South Africa. The women's perceived stigma prevented them from reaching out to family and friends. Instead, they were embarrassed and ashamed, leading them to secrecy about their disease. All of the participants verbalized that they tend to avoid people so that they would not pry and expressed a profound sense of isolation. They did not leave their homes or socialize. Candice said: My mother and sister and basically a few people around here knows. I keep my distance from them. I speak to them like hello. I don't make conversation because they just want to dig and know

Cheryl said:

It is very depressing, and I feel so embarrassed among the Indian people. The way they carry on, the way they treat you, knowing you have this sickness. It is a very sad thing, it is not something good, and I don't like to face anybody because of my sickness All the participants acknowledged that they feared what people might say about them if they knew about their status. Melissa said that "I have friends, but I have to lie to them. I tell them I have cancer." Sharon1 also told everyone that she has cancer, so she is comfortable with neighbors asking about her health because they believe she has cancer instead of HIV/AIDS. Sharon1 believed by confiding in a neighbor, you run the risk of becoming the gossip topic: They told me at the clinic to keep it confidential. They said by telling everybody, people will talk behind your back, make us like a stupid. She told just keep it to yourself, not my family, not even my child knows…in the flats, when one person knows, then everyone knows. It is terrible. Everyone will be talking. These women feared that they would become outcasts in their community or that they would be excluded from social events. Some women were afraid of spreading the disease, as Melissa very painfully described that although she knows how HIV is spread, she feels unclean and feels like she can contaminate a person. She says when people know you have HIV/AIDS, they are afraid to touch you. When the researcher hugged her, she cried. Fe was most conflicted stating that she elected not to have friends, yet she craved social contact.

She stated she "hold her head up high" and "doesn't care" about her family's attitude, yet she appears to the researcher as a vulnerable person, yearning for acceptance, but obviously not achieving this goal. Lynette avoided close, personal, physical contact with people by opting for an online social network to mingle. This web-based network did not include any real-life friends so she did not have to fear rejection, and no one knew about her status. Cheryl lets everyone know that it was her husband who infected her and therefore does not accept any guilt feelings. Because of the fear of stigmatization if their diagnosis was discovered, the women verbalized a profound sense of isolation. They did not want to socialize, leave their homes, or try anything new. They just wanted to bealone to avoid being confronted with stigma. These women face a lifelong battle with anticipated stigma, and coping with stigma in real life is complicated.

Supporting: A Good SupportSystem and Spirituality

When highly active anti-retroviral therapy was introduced as a treatment choice for the management of HIV/AIDS, the face of HIV/AIDS changed from a death sentence to a chronic illness. People with chronic illness are affected differently, and treatment is aimed at the severity of the symptoms. Therefore, people with chronic illnesses often have to make mental, physical, or even social adjustments to cope. Chronic illness means that people are living longer with secondary symptoms and side effects of medication. Women infected with HIV/AIDS face unique challenges because of gender-related issues such as care giving roles and societal expectations. A chronic illness requires ongoing medical, psychological, and social support. Lynette described her fear at disclosure: It is quite difficult because I am actually quite young. When I first found out, I was 18 years old. I thought that maybe they were joking. I had to tell the nurse to do the tests a couple of times. You know, I did even know how to tell my parents. I did not know how they were going to react. How my family was going to treat me. It was…it was awful. But my mom has been very supportive. She has been my role model you can say, and she has always been there for me, and has helped me with whatever I was going through These women are vulnerable and are trying to adapt to the shock of being infected with this deadly disease. Given the overwhelming acknowledgement of stigmatization and that they all only confided in a few select people, all participants overwhelming stated that it is essential to have a good support system to survive. However, a lack of support increases stress in the lives of these women as evidenced by Fe's description of the lack of social support:

"My father does not care if I die. His exact words 'it is better if you were dead or not around because nobody needs you' …When you don't have anyone there for you …it can be very bad."

Pamela confided in her family, and while they pledged their support to her, she said:

But certain times, when we have a problem, they like pick it out. So like it worries you. You know you got a problem in your heart, and you'd like to talk to someone, and tell someone about it. If we fight, and they pick it out, I feel hurt, and upset. They throw it back in my face. Humans need a sense of belonging, which is fundamental to personality and social well-being. The other eight participants (80%) all had supportive family members who knew of their illness, allowed them to speak freely about their concerns, and supported them. This support group consisted primarily of female family members such as sisters, mothers, or nieces, but a few participants had also informed their fathers (not very supportive), husband, and significant other. Selective disclosures to female members of the family appeared to enable social support.

Lynette described her family support:

My families don't treat me any different…like most Indian people would treat you different if they touch or hug you. Indians feel you are contagious; they don't understand that it is a disease of the immune system. My family has been great, especially my aunt and mom who are there for me to talk to whenever I need somebody.

Her sentiments were echoed by Cheryl who said she was kicked out by her dad when her physical health deteriorated.

She said:

My mom gives me a bath, she makes my meals, she is there to sit and speak to me, and she cleans me up whenever, like when I wet the bed or something. She does everything for me. She even helps me with Joshua (her three-year-old son). This support made all the difference in the lives of the women inflicted by HIV/AIDS. The burden of keeping the disease a secret weighted heavily on the participants, but their HIV disclosure was often the first step in this coping process as it was crucial for social support and developing strategies for healthy living. The women (90%) overwhelmingly described the support from the staff at the ARV clinic as crucial to their care. One participant (10%) was dissatisfied with the time spent at the clinic and considered that as not being very helpful.

However, all of the participants verbalized than other than their confidants, the clinic was the only place that they could talk freely about the illness. They appreciated the non-judgmental attitude of the staff, the willingness to listen, provide advice, and encouragement. Sharon1 admitted she accepted her diagnosis because of the reassurances of the staff: I never felt anything (upon hearing her diagnosis). They (clinic staff) said that we must not worry. We are not the only ones with HIV. They showed us all the people at the clinic, some looked so nice and fresh, better than other sick people. They said you will be alright, you must not stress, and you must eat healthy.

Dolly described her experience with the staff:

They are very helpful. As for me, they really took care of me. Dr. Brij, do you know Dr. Brij? He is very good, and even all the nurses, especially the Indian nurses, they love me to bits. Support groups allow the women to connect by sharing their experiences of living with HIV/AIDS with each other. In addition to the support received from the medical staff, the women were passionate about the value of family as support systems in their lives. Initially, social isolation and secrecy prevented women from seeking the support they needed, yet when they disclosed their diagnosis strategically to certain trusted family members such as their mothers, this enabled social support, and increased participation in their care. Families can provide support and love, but they also come with power to manipulate. Therefore, it is crucial for the health care worker to assess the role of family in the lives of those infected with HIV/AIDS. Sharon described the difficulty of not sharing her diagnosis with anyone: The hardest part to deal with this diagnosis is to tell your children. It was hard, very hard. I did not know how to handle it. I was waiting for the right time. When no one was around, and I just came out of the blue and told her. I felt like a weight was lifted. With all the psychological and physical changes that occur after diagnosis, the fragility of life is a scary thought for most of these women. The threat of death can cause an emotional upheaval. Therefore, spirituality or a religious belief provides an important social connection, thus giving meaning to their lives. These women believe in a need for a higher power to help them. The participants in this group were 80% Christian and 20% Muslim. All participants stated that they became more spiritual or religious after they were diagnosed. Lynette stated that: HIV has brought me closer to God than before. If I didn't push and push Jesus away, maybe I should not be where I am. I do not blame him, and I know that he is always there for me Although she blames herself for premarital sex that was against her Christian values, Dolly is emphatic stating that only God could have saved her as she describes the major complications she endured when she was first diagnosed. She also strongly believes that God has helped her overcome physical limitations that the medical personnel had told her she would have to endure for the duration of her life.

It was hard accepting HIV, and I was thinking…plus my family was preparing for my death. I was critically ill, I was very sick, and they (doctors) lost all hope on me. But by the grace of God, I am OK now. I know that I got favor from God. God's grace fell on me. Spirituality can be a religious concept, or for the non-religious, a search for a meaning or purpose of their existence. The religious definition of spirituality is a journey or connection to God, or higher power through prayer, church attendance (spiritual expression) resulting in spiritual support such as peace, and purpose to the individual despite his physical ailments (Dalmida, Holstad, Dilorio, & Laderman, 2012). Religious groups are beneficial in providing social support for an individual, thus providing an opportunity for human connectedness. Spirituality provides an active coping mechanism for people who are ill, so that they can find meaning or purpose of their lives. The WHO realizes that spirituality is an important dimension of quality of life (WHO, 2012b). People seek spiritual support in many ways such as prayer, spiritual reading, meditations, or membership in religious organizations. The religious organizations can be a source of social support through regular scheduled activities and promote prayer for spiritual support. Prayer is a personal connection to a higher power. Sharon2 stated: I told God when you created me, you created me without sickness. I am not dying with this sickness. I am telling myself that I am going to get healed. I also pray to God that scientists will come up with a medication that will cure it Spirituality is also expressed in spiritual reading, as Candice described: "I spend my time reading my Bible. I re-committed to God, and asked him to take away the bad thoughts. I also stopped smoking." Melissa described her prayer and routine: "I am Muslim. We pray five times a day. I also read the Koran." Some people use meditation, as Sharon1 said: "I always have my beads. I read. My prayers have been answered; I have no side effects to the medication."Overall, all the women described a relationship with a higher power to help them re-focus and cope with their illness. Addressing spiritual needs are equally important as the physical, emotional, and social well-being of people with chronic illnesses.

Hoping: Coping with the Highs and Lows

Hope is an adjective, a noun, and a verb. It involves trust, is related to goal attainment, and provides meaning and direction, especially when hopelessness can lead to death. Hockley defined hope as an active process that is more than just expectation (Hockley, 1993).The women's experiences with HIV/AIDS all resonated a renewed purpose for living. They were able to find meaning in their lives and have grown personally to readjust their thinking to optimism for their future. They have realized that they don't have to die, as Melissa stated: They say when you find out it is like a death sentence. It is up to you. It depends on you. I am just living. Cancer will kill you. This won't—if you take the medicines accordingly, you can live for the next 50 years. The aim in HIV management is for those who are infected to come to terms by normalizing the diagnosis and being informed by accessing information and care. Several factors facilitated the adaptive coping and hope for the future such as being healthy, having responsibility for children, and joining support groups. Sharon2 said on being healthy: I treat my life as if nothing is wrong with me. I don't ever look at myself and say I am sick. I always have a positive outlook on life. I feel like I have a new life to deal with now. I feel like the old self is out. I am back to how I used to feel. In fact, I feel even younger than what I used to be. Children and maternal roles increased the determination of the women to be active participants in their care as they valued their role as mothers. Cheryl said: When I first came to know (about my diagnosis), I was giving up, and then I overcame it. So because of my son, I am being strong. I want to be there for Joshua…I am trying to be there, to take life as normal Struggling with the highs and lows of the disease is shared by all the participants. They say they cannot explain it— they appear to do well and suddenly for no reason feel depressed or sad. Candice described her struggles is follows:

Actually, I try not to worry about my illness. However, sometimes when you alone, it just gets to you! Not all the time, certain times. When I feel it is getting to me, I quickly try to read the Bible, sing a song, and just try to get it off my mind. You know when you have an illness; you feel…there is nothing you can do about it. I have to accept what I have in me. I am fine with it. Dolly said, "I carry on as normal. Nothing bothers me about HIV now. I just have to take my medicine and not default." Sharon1 said, "I am not negative about this sickness, so I am positive. I feel normal." SN stated that her fear is that "I have HIV, and I won't get better." Fe described her future as "you can't cry over spilt milk. It's just like I want to run away, but I don't know where to run to." These women were all dealt a heavy hand, yet despite the adversities, have found hope and meaning. HIV was supposed to destroy them, yet despite the struggles, they persevere.

Lynette believed that:

It all depends on you. I believe I will get better. My family has been so inspiring to me. I hope to find someone that will accept my status, and I hope to get a job These women appeared to have come to terms with their infection, and the majority appears to be coping adequately, the stress, and psychological effects can affect coping and the outlook on life. In this study, all the women contracted HIV through heterosexual intercourse and all were infected by husbands or long-term romantic partners. They were clear about the effects of HIV on their health and appreciated the support from the health care providers and their selected confidantes. Chronic diseases have psychological effects on those infected as well as those in the immediate family and caregivers. Creating a positive mindset is vital so that people can lead productive lives. While living with HIV/AIDS maybe a constant challenge for those infected, rising above the highs and lows and achieving a balance is paramount to positive living with the disease. The themes that emerged from the participants' narration in this study describe the experience of finding meaning and purpose in life despite the circumstances. Patricia Stark (1985) developed the theory of meaning based on the work of Victor E. Frankl (1969). There are three concepts in the theory of meaning life purpose, freedom to choose, and human suffering that will be discussed in the next chapter.

Summary

The narrative stories in this study were an evocation of an emotionally laden, complex, and multidimensional life phenomenon experienced by Indian women living with HIV/AIDS. Through phenomenological descriptions, the researcher attempted to elucidate the meaning ascribed by these women to their everyday lives. Guided by Max van Manen's (1990) phenomenological method of inquiry and analysis, this investigation provided the researcher with rich and thoughtful descriptions and increased understanding of what it is like for Indian women to live with HIV/AIDS. The descriptions were developed from the women's experiences and provided a clear and vivid view into these women's lives. A deeper understanding of this was obtained. Chapter Five explains the meaning of the study.

Chapter Five

Discussion and Conclusion of the Inquiry

The purpose of this study was to explore the lived experience of Indian women living in KZN with HIV/AIDS, and in this chapter, a discussion of the findings of the phenomenological inquiry is presented. The significance and the meaning of this study was explored to reflect the multiple truths and realities for each participant. The characteristic of phenomenology is that despite the words chosen by the researcher to describe and explain the participants' life experiences; their words are open to different interpretations (Sandelowski & Barrosa, 2007). An interpretative analysis of the themes that emerged from the study will be presented and correlated with published literature and film. A discussion of the relationship between the findings of the study and the theory of meaning will be analyzed. The implications to nursing education, practice, research, and public policy and the limitations of this study will also be discussed.

Exploration of the Meaning of the Study

"What is the lived experience of Indian women with HIV/AIDS in South Africa?" was the overarching question that guided this phenomenological research. This qualitative, phenomenological study began with a personal interest and a need to uncover something specific about this particular population's experiences with this phenomenon. The rationale for this study was supported in the nursing literature by the limited data regarding the lived experience of Indian women with HIV/AIDS in South Africa. The researcher was able to discern meaning and the essence of this phenomenon by listening to the voices of the women as they told their stories of life with HIV/AIDS. These narratives provided a clearer understanding of life with this life-changing disease. The researcher engaged in various activities that involved journaling and discovering expressions of meaning through music, literature, and film, while sifting through the implications of words in conversations, searching for the essence of this phenomenon. This research mainly exposed the challenges confronting Indian women with HIV/AIDS and the difficulties that they had to endure. A surprising dimension of the experience of living with HIV/AIDS among the women in this study was the search for meaning or hope, which compelled them to move forward in their lives. The effort to find hope for the future posed a substantial paradox to all participants. Many spoke of hope specifically in the context of life's purpose, and the necessity to find meaning in order to reframe the future of their life. The researcher was able to re-live each interview through her notes, transcription, and listening to the interview, thus ensuring that she had described the participant's story accurately. When the ideas and language became recurring and repetitive during data collection, the researcher realized she had reached saturation.

The soundness of qualitative research is judged by credibility, authenticity, transferability, dependability, and conformability (Lincoln & Guba, 2000). Credibility is ensuring that the results are credible or believable and that the interpretations are true. This was achieved by prolonged engagement, which is the time the qualitative researchers spent in the field collecting data, observing, and interviewing to gain in-depth knowledge. In addition, credibility was also ensured by the continuously peer review of the data, analysis, interpretations by members of the dissertation committee who are experts in this field (Creswell, 2007). To ensure authenticity, the researcher included all data upon which conclusions were made, always sought professional feedback, and used semi-structured interviews with open-ended questions. Transferability is the degree to which the discoveries of this inquiry can transfer beyond the research project. The researcher ensured transferability by providing a detailed description of the study from purposive sampling to data analysis to provide a "paper trail," thereby providing opportunities for replication or to determine transferability of results. The researcher provided a detailed, descriptive data in the research report so that others can evaluate the contents, to either make a transfer or form a conclusion (Gay, 2009). Dependability is described as auditability or reliability of the study or is simply the assessment of the data collection and data analysis process. This was achieved by describing in detail the sampling procedure and data collection procedures so that others can read them and evaluate the method. Conformability is a measure of how well the study's discoveries are supported by the data collected and will be established by a paper trail and by linking the words of the participants and with the discoveries (Lincoln & Guba, 1985). Qualitative researchers are the instruments and can be easily biased; therefore, to maintain the integrity of qualitative studies, the studies have to be trustworthy. Trustworthiness can be achieved when the findings reflect the meanings as described by the participants as closely as possible.

The aim of trustworthiness in a qualitative inquiry is to support the argument that the inquiry's findings are "worth paying attention to" (Lincoln & Guba, 1985, p. 290).Bracketing allows the researcher to analyze data without confirming her presuppositions and thus enter into the world of the participant. The audio-taped interview was transcribed verbatim by the researcher. Listening, reading, and re-reading together with the reflective notes helped the researcher to understand the essence for each participant.

Interpretative Analysis of the Findings

Struggling: Life after Death

The overall impact of HIV/AIDS infection on individuals differs greatly and is influenced by structural violence. Structural violence refers to problems such as gender inequalities, poverty, and social status (Copeland, 2011). The participants all struggled with meeting their daily needs financially because they had limited or no income, limited education, and inadequate housing and were given the devastating diagnosis of being HIV/AIDS positive. These women's sentiments echoed their struggle in life that was compounded by the HIV/AIDS infection. They were in a state of constant turmoil, trying to absorb the fact they were infected, fearing death, shame, disclosure, and concern for their families (Medley, Kennedy, Lunyolo, & Sweat, 2009; Krishnan et al., 2008). The study conducted by Barrosoet al. (2010)highlighted the physical challenges of an HIV infection such as fatigue, chronic gastro-intestinal issues, peripheral neuropathy, cognitive impairment, and general complaints (malaise, joint pain, sleep disturbances, and night sweats) in addition to side effects of the drugs, co-morbidities, and premature aging. Upon receiving the positive HIV diagnosis, an emotional crisis was evoked in these Indian women as they battled shock, hurt, shame, and betrayal from a romantic partner. Sharon1 realized that stress adds to the detriment of the being HIV/AIDS positive. "The doctors say to be positive; they will help me. I cannot do anything else." The theme of struggle emerged as the participants described their experiences with structural violence, in addition to the devastating diagnosis of HIV positive. The research participants reported feelings of helplessness, of life being destroyed, of life becoming meaningless, of having no hope or purpose - just because they were diagnosed with HIV/AIDS. The feelings of being insignificant, diseased, defective, and amounting to no good were similar to those experiences of a crisis in a family. HIV/AIDS affect people in every part of the world. It is an illness that affects not only the individual but also the family and the community (Bor, Miller, & Goldman, 1993).Although these women are struggling, they are persevering, and their perseverance has been captured as an artistic representation in the lyrics of *Life Ain'tAlways Beautiful* by Gary Allan.

> *Life Ain'tAlways Beautiful*
> Life ain't always beautiful
> Sometimes it's just plain hard
> Life can knock you down, it can break your heart
> Life ain't always beautiful
> You think you're on your way
> And it's just a dead end road at the end of the day
> But the struggles make you stronger
> And the changes make you wise
> And happiness has its own way of takin' its sweet time (Allan, 2009)

The treatment of HIV/AIDS has two faces: The developed countries have the treatment and resources, thus reducing the disease status of their citizens to a chronic condition rather than a death sentence. In the developing countries, HIV/AIDS is an acute illness, and sometimes a death sentence because of the lack of resources. Unfortunately, the proportion of women living with HIV/AIDS throughout the world has increased; however, Sub-Saharan Africa is the only area where more women than men are infected with the virus. The increased prevalence among women has been attributed to the biological reasons, such as a larger mucous surface resulting in exposure to the virus for a longer period; a plethora of social issues has contributed to a vicious cycle of poverty; and gender inequities such as insufficient income, limited access to education and jobs, and little autonomy for decision-making are fueled by gender-based norms and values that reinforce women's lower social and economic status. The heterosexual spread of HIV makes the cycle worse as increased poverty increases the women's vulnerability to HIV (Loewenson, 2007). Women's dependence upon their male partners, economic resources, and education make them extremely vulnerable to HIV infection, further emphasizing that the social environment of poverty and gender inequalities pose the most risk for women (Demi, Bakeman, Moneyham, Sowell, & Seal, 1997).

Amuyunzu-Nyamongo, Okengo, Wagura, and Mwenzwa(2007) explored the challenges women living with HIV/AIDS faced. They found that poverty and poor living conditions increased the risk for HIVand opportunistic infection. They discovered that coping strategies were focused on survival evidencing the theme of struggle. This study was conducted in five informal settlements in Nairobi, Kenya consisting of 390 women living with HIV/AIDS and 20 informant interviews through an interview-based questionnaire. Copeland (2011) also explored a shared cultural model of HIV/AIDS management among the poor Kenyan women to understand how these women managed HIV/AIDS in extreme marginal conditions. Interviews were conducted on 177 women, and the findings were that although the women knew that meeting basic needs (diet, caring for children, paying rent, and accessing medical care) were important to stay healthy and manage HIV/AIDS, they simply did not have the means to meet the needs. A literature review by Nyindo (2005) also supported the theme of struggle when a review was conducted to establish factors that contributed to the high prevalence of HIV-1 in Sub-Saharan Africa. The researcher reviewed published data from 1981 to September 2004 to determine cause and possible measures to combat the spread of HIV/AIDS in this region. The main risk factors were poverty, famine, low status of women in society, corruption, and naïve risk-taking measures. The conclusion was that care should be aimed at the cultural and ethnic beliefs of the population as well as reducing women's vulnerability by empowerment. A retrospective study conducted at an HIV/AIDS center in South India on 134 HIV-infected females to characterize socio-demographics, risk factors, and clinical presentation is similar to the demographics of this study's participants. All the participants were currently or previously married, reported a monogamous relationship, and reported heterosexual sex as their only risk factor. The majority of these participants (80%) were of a reproductive age creating a potential for vertical transmission. Similarly, the risk factors for both these participants were single partner heterosexual sex with their husbands or significant other. Therefore, education, and intervention need to be focused on monogamous Indian women whose risk factors are linked to behaviors of their husbands or partners (Newmann et al., 2000).

A study conducted on 10 pregnant Thai women about their lived experience after their diagnosis of HIV/AIDS mirrors the experience of the participants in this study. The researchers used a phenomenological approach and discovered four themes, namely, struggling alone, sharing one's struggle, struggling for the baby, and struggling through ups and downs, which provide crucial information to health care workers on the provision of a holistic approach (Ross, Sawatphanit, Draucker,& Suwansujarid, 2007).

In many developing countries, human capital is largely undermined as HIV/AIDS affects the adult populations in their most productive years, reducing incentives to save and invest. This epidemic of HIV/AIDS destroys whole communities and undermines the government's ability to provide basic social services, thus curtailing the potential for sustained economic development and social transformation. This was evidenced in this study that the participants were not able to meet the basic needs of housing (all participants lived with a family member). Sharon1 said, "I used to work, but not since I got sick. I have to look for a job again." Fe admitted that she was unable to afford living alone, and therefore she was forced to live with her parents. Because of the stigma, struggles, and discrimination. The theme of struggle in the lives of Indian women with HIV/AIDS runs parallel with a similar experience captured in a novel *The Help* by Kathryn Scott (2009). In 2011, the book was adapted for a motion picture with the same title. The film, set in the civil rights era, is about a young White woman Eugenia "Skeeter" Phelan who wanted to tell the lived experience of the maids who spent all their lives working in White homes while struggling with their own structural violence and discrimination. The maids are fearful because no one has ever asked them about their opinion before and are nervous to talk. However, further acts of discrimination persuade them to tell their stories because they realize it is the only chance to let their voices be heard. Once they start, it is like a dam had burst. They express relief at being able to share their stories. This is what Viola Davis' character Aibileen Clark said after she was able to tell her story:

God says we need to love our enemies. It is hard to do. But it can start by telling the truth. No one had ever asked me what it feels like to be me. Once I told the truth about that, I felt free. The literature review has provided consistent findings of a woman's struggle following a HIV/AIDS diagnosis (du Plessis, 2011; Kagee, 2010; Bogart et al., 2000; Hackl, 1997). However, the consistencies of these researchers clearly highlight that education and free medication is insufficient when poverty, gender inequalities, and stigma affect women's access to basic needs, medical care, and psychological care (Copeland, 2011). No social, racial, or income group is immune from HIV, yet there is sufficient data that HIV severely impacts communities of color and poverty.

The following verse written by Joyce Alcantara is a reflection of the sentiments shared by these research participants:

"You Will Never See Fall"
You may see me struggle
 you won't see me fall.
Regardless if I'm weak or not I'm going to stand tall.
Everyone says life is easy
but truly living it is not.
times get hard,
people struggle
and constantly get put on the spot.
I'm going to wear the biggest smile
even though I want to cry.
I'm going to fight to live
even though I'm destined to die.
and even though it's hard and I may struggle through it all.
you see me struggle...you will NEVER see me fall.(Alcantara, n.d.)

Isolating: Social Isolation and Stigma

Another theme that emerged as the Indian women described their lives with HIV/AIDS is the theme of isolating with the subthemes of social isolation and stigma. Social isolation is defined as a person with few to no meaning relationships. Regardless of whether social isolation is voluntary, or imposed by others, the basic human need of intimacy is unmet. Social isolation has long been associated with health risks such as smoking, obesity, loneliness, increased mortality and morbidity across all ages (Cornwell& Waite, 2009). The literature review has suggested that social isolation is becoming norm among the chronically ill and especially the elderly, resulting in several psychological changes such as depression, anger, and despair (Greaves & Farbus, 2006). Hawkley, Masi, Berry, and Cacioppo (2006) conducted a study on 299 adults and found that loneliness increases blood pressure and pyschosocial issues in vulnerable population. Their risk for cardiovascular problems increased as a result of the loneliness, thus increasing the mortality and morbidity among the elderly. However, in HIV/AIDS, social isolation occurs as an effect of stigma and is used as a defense mechanism or a coping strategy. This is because people with HIV/AIDS are aware of the stigma associated with the disease, and they want to protect themselves and their families from stigmatization (Lekganyane& du Plessis, 2011). Melissa stated that when she found out: I just stayed at home. I did not want to go anywhere. I only told my mom…you have to have a lot of support. You have to have the people closest to you, support you. You need to tell your family; they need to know. You need that support system.

Bravo, Edwards, Rollnick, and Elwyn (2010) conducted a literature review on the challenges people with HIV/AIDS that involved psychological and emotional issues. They found that people with HIV/AIDS faced three key decisions about disclosure, adherence to treatment, sexual activity, and parenthood that often resulted in isolation, depression, anxiety, lack of access to social support, and refusal to seek treatment in these patients. Similarly, in this study, all the participated verbalized that they had selected disclosure, and they avoided contact with their neighbors and extended families to prevent them from prying or accidentally discovering their status. However, Corbin and Strauss (1987) clearly stated that people with chronic illnesses struggled to understand their body failure and the effects on their daily lives. Thus, they struggled to overcome psychological and social obstacles, resulting in a loss of hope, thereby isolating themselves from people important to them. The ARV clinic does refer the patients to counselors and support groups, helps to rebuild the family network by incorporating the family members in the plan of care, and encourages the patient's spirituality. However, social isolation is clearly a problem for those with chronic illnesses because of the vast number of physical and psychological implications and the negative effects of loneliness (Dingfelder, 2006). Galvan, Davis, Banks, and Bing (2008) conducted a quantitative research study to examine the relationship between perceived social support and perceived HIV stigma among 283 HIV-positive African Americans. They discovered that high perceived social support from friends was associated with less perceived HIV stigma. Thus, the beneficial effects of perceived social support from friends can help to provide guidance to those working to decrease the negative impact of HIV stigma among HIV-positive African Americans.

Stigma is the single major factor that hinders prevention and care of people infected with HIV/AIDS. People are afraid, so they delay getting tested, accessing health care, and withholding status from family members. In addition, social isolation can affect their lives negatively (Health Resource Service [HRSA], 2009).

An ethnographic study conducted by Duffy (2005) in rural Zimbabwe, where one-third of adults are infected, revealed how the mutually supporting concepts of stigma, suffering, shame, and silence are challenging health promotion efforts, thus increasing HIV/AIDS morbidity and mortality rates. In the current research study, Lynette said: "I am more enlightened now because in the past we never knew about this disease. They just tell you to have safe sex, just one advertisement on TV, but that wasn't much." Sowell and Phillips (2010) acknowledged that stigma and discrimination are a worldwide challenge in the care and treatment of persons with HIV/AIDS. They found that fear of negative social consequences causes persons with HIV/AIDS to keep their infection secret, resulting in negative psychological and physical outcomes and continued spread of the disease. This is consistent with what Melissa said: "I am sorry, but I have to lie. I have to say I have cancer or something of that sort. In our Indian community, they shun you." Zukoski and Thorburn (2009) conducted a study that examined the experiences of 16 individuals with HIV who lived in rural area with low HIV prevalence. They found that the individuals described feeling socially rejected and being treated differently. They also experienced stigma and acts of discrimination in different settings like physician offices and from different health providers such physicians and nurses. In this study, the participants' responses to perceived acts of stigma and discrimination included anger, shame, and social isolation, as evidenced by Cheryl when she said, "It is very depressing, and I feel so embarrassed among the Indian people. It is very sad, it is not something good, and I don't like to face anybody because of my sickness." HIV/AIDS has been attacking the human race for over 30 years, yet the disease has not been successfully contained. The single biggest contributor to the prevalence of HIV/AIDS is still stigma. The powerful effect of stigma is captured in the poem "The Stigma."
"The Stigma"

> …Caught up in the claws of the most fearsome
> calamity ever to befall humanity
> Trapped in the unforgiving tentacles of HIV the terminator
> He wept not for the syndrome yet to follow
> For it was yet to follow
> He wept more for the stigma of the present
> The rejection
> The scorn
> The hatred … (Martha's Corner, 2009)

Gilbert and Walker (2010) conducted a study on how patients perceived and experienced stigma and how it shaped their behavior and understanding of the epidemic. They found that the level of felt and anticipated stigma was intense and affected all dimensions of living with HIV/AIDS, especially disclosure, and treatment. Sharon2 epitomized these findings: I was diagnosed in 2005, but I refused to acknowledge it. The counselor stayed on me for about a year, talking to me, encouraging me. I finally decided to give it a chance. I said if it helps, it helps, if not. Now, I am so thankful she never gave up on me. She saved my life. Social isolation and stigma can hamper the fight against HIV/AIDS. However, laws or policies are insufficient to combat HIV/AIDS related discrimination. Stigma and discrimination will continue to exist so long as societies have a poor understanding of HIV. HIV/AIDS-related discrimination needs to be tackled at the community and national levels, together with HIV/AIDS education. The task is to change the biased social attitudes in order to reduce the discrimination and stigma of people living with HIV and AIDS. We can fight stigma. Enlightened laws and policies are key. But it begins with openness, the courage to speak out. Schools should teach respect and understanding. Religious leaders should preach tolerance. The media should condemn prejudice and use its influence to advance social change, from securing legal protections to ensuring access to health care. (Ki-moon, B., Secretary-General of the United Nations, 2008) The theme of isolating is so cold and lonely. The human race thrives on love, empathy, acceptance, and support. The bonds of close, supportive relationships can never be undermined. The concept of human suffering is analogous to the isolating theme experienced by the participants in this current research as expressed during the narrative interviews.

6 reflects the interconnectedness of the concept of human suffering and isolation as captured by LaNette Buras in her first-place submission of the *2011 Fight HIV Your Way Contest.*

Figure 6: Buras, L. (2011). 1st place winner to the 2011 Fight HIV Your Way Contest

Supporting: Social Support and Spirituality

Social support is crucial to people with chronic illness. This support system can be made up of friends, family, and health care personnel who allow the individual to express his or her fear and concerns, thereby receiving support from people who accepts them as they are. When a person does not have a support system, he or she tends to be very guarded, which can lead to increased stress because he or she has no outlet to vent. Social support allows the individual to feel that he or she matters to the people who are important to him or her. These social networks can help a person during times of stress; they provide unconditional support and encourage adherence to medical regimens and seeking health services. Gallant(2003) conducted a literature review to examine the relationship between social support and chronic illness self-management. Gallant found a positive relationship between social support and chronic illness self-management. Sharon2 said: You cannot do this alone. You need your family. You need support. They can help you keep your appointment; they encourage you to take your medication. A study conducted by Arora, Finny-Rutton, Gustafson, Moser, and Hawkins (2007) evaluated the helpfulness of support from family, friends, and health care providers to newly diagnosed breast cancer women. The researchers discovered that the participants received more support when they were newly diagnosed, and support significantly decreased within the first year of diagnosis. HIV/AIDS patients need consistent support, and health care personnel can be one avenue of support, especially in this study where the women were afraid to discuss their status freely except at the clinic.Health carepersonnel can be the constant source of support at the ARV clinics. Melissa described this relationship: "The staff are very good. They are non-judgmental. They listen to you, and they give you advice."

Russell and Seeley (2010) conducted a two-phase qualitative research study on 70 participants in rural Uganda using the grounded theory approach. The purpose was to analyze the productive activities of people living with HIV following their uptake of antiretroviral therapy (ART).   Their thematic analysis was on how the participant "transitioned" to living with HIV as a chronic condition. Transition is referred to as a person incorporating a long-term illness, treatment regimen, and its effects into his or her life. The themes from the first study were *loss and disruption (unexplained illness and death of a child or partner), a growing fear of HIV,* and *anxiety about the future.* Themes of adjustment struggles included: *Loss of meaning to life: giving up hope; disruption and disorder: impoverishment; loss of control over decisions: increasing dependence on others for food and care; prejudice: labeled "already dead;" and the break-down of relationships, isolation, or "social death."*However, a new chance of life on ART motivated a transformation in the purpose and activities of some participants that were evidenced by their "quests" to regain control, create order, and feel "normal" again. Poverty and vulnerability hindered the transition process. The researchers postulated that meaningful economic and social lives are essential if people incorporate HIV as a long-term chronic condition and adhere to treatment. Support is needed for these participants to adjust to their HIV status and to ensure the success of antiretroviral therapy.

Spirituality

When a person receives a diagnosis of HIV/AIDS, it can be very devastating for him or her, and for some, the emotional aspects of HIV/AIDS are as difficult as the physical aspects. HIV/AIDS affects the physical, emotional, and spiritual aspects of a person.After diagnosis, some people turn to family and others to health care providers, but the majority get their support from spirituality or religion.

Therefore, the role of religion and spirituality play an important part in the emotional well-being of a HIV/AIDS-infected person. People with HIV/AIDS seek a belief in a higher power, and religious beliefs shape individuals' outlooks on living. Religious beliefs and practices are attributed with providing a sense of peace, hope, and even help people to prepare for and accept death (Kaldjian, Jekel, & Friedland,1988; Baldacchino & Draper, 2001). People come to terms with being HIV-infected by turning to religion to make sense of their infection. Individuals living with HIV/AIDS often use prayer, meditation, faith in God, or some forms of religious participation to cope (Zou et al., 2009; Litwinczuk, 2007). Dolly was certain that she would not have survived had it not been for God. She stated: "God has shown me his favour...I never miss a church service." Cotton et al. (2006) conducted a study in the United States on 450 participantsto characterize spirituality/religion in a large and diverse sample of patients. They found that people living with HIV/AIDS coped with their illness through religion, people's faiths were strengthened after being diagnosed with HIV, that slower disease progression is correlated with an increase in spirituality religiousness, and that spiritual beliefs about HIV influence end-of-life decisions. Sharon2 stated: "my religion plays an important role in my life. Our faith helps. God works through the physicians." The health patterns of people with HIV/AIDS differ among countries based on the economy and health policies. There is also a difference in the severity of the symptoms ranging from mild to severe or life threatening. Being chronically ill can lead to dwindling support from family and friends. People look for spiritual support. Ironson, Stuetzle, and Fletcher (2006) conducted a study to determine the extent to which spirituality or religiousness changes after HIV diagnosis and if changes predict disease progression. They found that there was a substantial increase in spirituality after diagnosis and that there was a slower disease progression. Melissa and Sharon1, both of the Muslim faith, claimed that they maintain their custom. Melissa said that she "prays fives a day, reads the Koran, and meditates on the beads." Sharon1 believed that her prayers are answered: "My prayer works. I don't have any of the side effects of the medication. The doctor said I am lucky. My prayers are helping me a lot."

Genrich and Braithwaite (2005) conducted research in Trinidad to explore how the experiences of people living with HIV/AIDS impacted healing and coping with HIV/AIDS. They found that while they were some stigmatization during religious gatherings, the HIV/AIDS infected people expressed that faith and religion were important to them to cope. This study confirmed the role that leaders in the church play and are crucial in the fight against HIV/AIDS and stigma. Positive attitude from the leaders result in more acceptance by the congregation. The positive aspect was evidenced by Lynette who said after her diagnosis: "I am always busy at the church. My pastor and his family know about it. They have been great to me as well. They have helped a lot, you know."Tuck, McCain, and Elswick (2008) conducted a quantitative study to examine the role of spirituality and psychosocial factors in people living with HIV/AIDS. The purpose of this descriptive, correlational study was to determine whether spirituality would be positively related to quality of life and social support or inversely related to illness and stress. They discovered social support was positively related to effective coping strategies, and spirituality plays an important role in the complete well-being of patients inflicted with HIV/AIDS. People also have to deal with consistent clinic appointments, side effects of medications, exacerbations of the disease that can cause changes in lifestyles, activities, and relationships. Some changes are minor yet some are substantial resulting in losses related to physical appearance, abilities, and friendships, which can lead to devaluation. A belief in a higher power has proved to have positive effects on the psyche of individuals with HIV/AIDS and should be encouraged by the health care professional. The human bond (social support) coupled with a belief in a higher power (religion and spirituality) are powerful coping mechanisms in the adjustment with HIV/AIDS and were reiterated by the participants of this study through their narrative descriptions. Artistic expression of this spirituality was captured by Heather Flood in her poem, "God's Flight."

"God's Flight"
On the ground sits a bird
that's too afraid to fly.
Beautiful wings could make it soar,
but the pain of past failure is its lonesome cry.
God has said unto this bird,
"Trust and have faith in me,
for I will carry you in your flight.
The miracle of life is waiting for you to see."
The bird said to God, "But I can't fly.
I am weak. I will fall and feel pain
it's happened before when I tried to fly.
I'm afraid of being hurt again."…
So, stand up, bird, and spread your wings.
The wings I lovingly created to let you fly.
If you fall I'll pick you up,
and lift you back into the sky."…
The little bird, once so scared,
learned to soar to new heights.
The occasional fall no longer scared the bird,
choosing to have faith in Gods flight (Flood,n.d.)

Hoping: Coping with the Highs and Lows

The final theme that emerged was that of hope. Hope is based on how well the individual copes with the disease. When a person receives a life-threatening diagnosis such as HIV/AIDS, it can be devastating, causing emotional, social, and physical challenges. These women experience increased distress and loss of hope because of the challenges they faced (Hockley, 1993). The hardest thing for those infected with HIV/AIDS is coming to terms with the illness. Some people use faith and others counseling, and some make a conscious decision to experience their lives as fully as they can. The women in this study were already struggling, when they were dealt the heavy blow of being HIV/AIDS positive. Yet despite the odds against them, they appeared to have taken the "hand life has dealt them" and were focusing on the future. There was an element of hope in their voices. People who have hope are determined, ready to face the odds no matter what, and they have an optimistic view about the future. Humans need hope. They cannot live without it. Hope provides humans the coping skills to pull themselves out of the pit of despair, pain, and hurt (Groft & Robinson, 2007). Some people with HIV/AIDS use coping by seeing themselves as okay. This strategy reflects a strong will to survive in the face of illness. This is manifested through being socially active and participating in social activities. This was evidenced by Sharon2:

No, you see what happens. In my case, even if I feel sick, I will not put on a sick face. I will get up, and be up and about. You see once it is in your mind, it is set in your mind. If you feel sick, you will look sick, and you will always be like that. I just get up, get dressed, and go out even if I don't want to do anything…I treat my life as if nothing is wrong with me. I don't ever look at myself and say I am sick. Even if anybody tells me you look sick today…I say no, nothing is wrong with me. I always have a positive outlook Kylma, Vehvilainene-Julkunen, and Lahdevirta (2000) conducted a grounded theory study on 10 women to describe the dynamics of living with HIV/AIDS.They found the core category in the dynamic of living with HIV/AIDS was the alternating balance between hope, hopelessness, and despair.These new definitions could be used in the clinical setting to determine the phenomena in individuals with HIV/AIDS. The factors contributing to these concepts could be used to help the individuals in everyday life while dealing with the changes of self and life with HIV/AIDS. Hinton and Earnest(2002) conducted an interpretive, ethnographic research on women in Papua New Guinea to determine their perception of health and the ways these were linked to coping with challenges. They discovered that women were socially and culturally vulnerable to the social strain thataffected their emotional health. The women used avoidance strategies that reduced their quality of life and increased their anxiety levels. The study revealed that these women need to be taught coping strategies that are resilient when addressing life issue. Lynette described her coping as Some of the people have been coming to the clinic 20 to 30 years, and they look good. They have been inspiring to me. I am managing it (HIV). The most important thing they say is not to stress as HIV feed of it.

I am fine Cutcliffe (2006) examined how nurses inspired and instilled hope in terminally ill HIV patients. The researcher used a grounded theory approach and focused on the interventions, attitudes, principles, and process used by nurses working in the care of terminally ill HIV patients.   The data analysis produced a theory of hope and inspiration that exists in terminally ill HIV patients when they are nursed holistically. The researcher suggests that hope is linked to effective nursing practice and intertwined with the concepts of caring and helping (Cutcliffe, 2006).

The participants of this study were happy with the quality of care at the ARV clinic. Pamela said:

I am happy going to the clinic there. The doctors and nurses are very good. If I have any problems, I speak to them. They are very helpful to me. They understand the situation that I am going through Mayers, Naples, and Nilsen (2005) conducted a qualitative study on nine mothers with HIV to understand how they coped with the uncertainties of HIV and the psychological adaptations of low-income mothers. They discovered that the mothers suffered from a myriad of issues such as guilt, anxiety, death, loneliness, isolation, and hopelessness. They found that despite their poverty and stigmatization, these women turned their health crisis into a meaning-giving experience. Their children were the meaning-giving experience that encouraged them to face whatever challenge lay ahead. This study emphasized that as long as the women had meaning, they had hope. This was clearly noted in this study as Cheryl stated: "I have one (son), and I love him so much. I always pray that God would keep me to see him grow, to go to school. He is such a bundle of joy." Anderson et al. (2009) conducted a qualitative study on 25 Caribbean people living in South London to determine how they were coping with HIV/AIDS. They found that the coping strategies used were restrictive disclosure, faith, and positive appraisal. The researchers advocate recognition of reluctance to disclose, severe initial reaction, and external stressors among the Caribbean people. Using faith and selective disclosure was common among the participants in this study as well, such as Dolly who limited her disclosure to her daughter, niece, and nephew.

A diagnosis of HIV/AIDS is a traumatic experience that can have life-altering effects on an individual. Therefore, it is vital for an individual to come to terms with the illness for physical and mental well-being. Adequate coping strategies are essential to provide "normalcy," thus creating some control in the management of this illness. Effective coping also results in hope for the future and the strength to face the challenges that comes with living with HIV/AIDS. The findings of this current research study have led the researcher to a connection between Starck's theory of meaning and the lived experience of Indian women with HIV/AIDS. The associated themes of struggling, isolating, supporting, and hoping connect with the major concepts of this theory.   These women could not help but ask why as they faced with this life-threatening disease that devastated their lives. Despite this devastation, they were able to construct meaning by finding life after death and coping with the ups and downs in order to confront their diagnoses positively. They began to adopt a positive attitude and took an active role in their health care. Their experience of hope in the face of death, ups, and downs are captured in this poem, "Hope Is Always There" by Joanna.

> "Hope Is Always There"
> In a sea of darkness
> Searching for the light
> But those who you once loved
> Have left you to deal; alone
> Ask for help, no one will come
> But most of all, don't you lost hope
> Hope is always there …
> You need something to hold onto …
> The demon inside you, grows stronger every day
> We all have our demons …
> Everybody hopes
> Everybody cries
> Don't you cry

      There's always hope
      "I need help"…
      I will not be silenced
      because hope's always there
      Even in the darkest times
      I fall into your sunlight (Joanna, n.d.)

Theory of Meaning

Every individual has a desire to find some sense, meaning, or purpose in life that becomes more earnest after a life-altering event like a HIV/AIDS diagnosis. The people try to comprehend "why me?" and "where do I go from here?" Victor E. Frankl (1961) postulated that humans can find meaning regardless of the circumstance they are in. This meaning is unique, specific, and must be achieved by the individuals themselves. Patricia Starck (1985) developed the theory of meaning to support individuals, groups, or communities to handle stressful, traumatic, life-changing events psychologically. The underpinnings of this theory were based on the work of Victor E. Frankl (1984). The assumptions of the theory of meaning are as follows: According to Fabry (1991), a person may discover meaning in life, even when challenged by a hopeless situation, the effects of trauma, or when coping with a fate that cannot be changed. First, the search of meaning is the primary motivation of life (Frankl, 1984). This means that every individual in the world regardless of the circumstance he or she is in can find meaning. Every circumstance hides meaning that can only be unlocked by the individual experiencing it. Second, people have the freedom to choose their responses to their environment (Frankl, 1984). This means that every individual has a duty to themselves to find meaning in whatever they do, they experience, or when faced with challenging situations laced with unavoidable suffering. Third, when a person finds meaning in life, they can confront any situation regardless of how hopeless the situation is. When people find meaning, they have purpose in life that can lead to satisfaction (Frankl, 1984).

Concepts of the Theory of Meaning

The three concepts of Starck's theory of meaning (1985) are life purpose, freedom to choose, and human suffering. This theory was developed to help people experiencing unimaginable suffering and show them that they could still discover meaning in their lives. Finding meaning allows the people to look deeper into their circumstances, even though it may mean unspeakable suffering, and take the journey in the direction of achieving life's purpose. The person is free to choose a position despite his or her suffering. Meaning cannot be bought, given, or invented, and is present in every life experience waiting to be found (Frankl, 1984).

Life Purpose

Life purpose is the central concept for the theory of meaning. According to Starck (1985), life purpose summarizes the reasons for an individual's existence such as "who am I, why am I here? It is via life purpose that the individual finds satisfaction with his place in life. Frankl stated that every person is "indispensable and irreplaceable (Frankl, 1973).The theme in life purpose is making a contribution or leaving the world a better place. Frankl (1984) specified three ways to find meaning on the path to uncovering life purpose: (1) creating a work or deed that moves beyond self (2) experiencing or encountering someone, (3) choosing an attitude to your fate (Starck, 2008). This concept is related to the theme of hoping. Experiencing an unalterable event such a positive HIV/AIDS diagnosis remained a challenging endeavor in accomplishing their individual life purpose. However, these women accepted life's challenges and were finding ways of living beyond this devastating diagnosis. Essentially, they were able to regain some sense of purpose to continue with their respective lives, thus choosing an attitude to their fate. All of the women used religion as a coping mechanism to deal with this diagnosis. Some of the women engaged in personal hobbies like gardening (Dolly). Melissa said: "I am just living," refusing to allow HIV/AIDS to dictate her life. She was determined to make the best of her life. Similar emotions were mirrored by other participants, and Fe emphatically stated "it is no use crying over spilt milk."These women appeared to have accepted their diagnosis and were looking for ways to carry on living life to bring back some resemblance of their purpose in life. All of the women overwhelmingly stated that they would encourage other newly diagnosed women who were fearful about their future. Candice said she would tell the women: "I will encourage them to be on the medication. Try to be healthy, focus on the good and not on the sickness. Try not to do anything stupid like kill themselves or overdose themselves." The attitudes of these women bring to mind the song "I Will Survive" by Gloria Gaynor that reflects the indomitable spirit of these women.

… Did you think I'd crumble
did you think I'd lay down and die
Oh no, not I
I will survive
Oh, as long as I know how to love
I know I'll stay alive
I've got all my life to live
I've got all my love to give
And I'll survive
 I will survive, hey hey… (Gaynor, 1979)

Freedom to Choose

Freedom to choose is the second concept of the theory of meaning. Starck (2008) described this approach as selecting options over which one has control (p.91). Lukas (1986) expanded the understanding of freedom to choose by classifying life events into fate or freedom. The situation cannot be changed in fate, but freedom allows person to choose what attitude to adopt or how to answer "What can I do?" Frankl (1984) stated that people have the freedom to rise above their circumstances by choosing what attitude to adopt even in unalterable situations. Lynette described her thoughts on living with HIV/AIDS: Some of the women having been coming for treatment for the past 20 years, and they look good. That has been inspiring to me because I know I can live a long healthy life. It all depends on you and your body. The concept of freedom to choose supports the theme of supporting that emerged in the study. The women had an unalterable situation of being diagnosed positive with HIV/AIDS. They had to find ways and means of adapting and moving forward despite their diagnosis. Candice described her adaptation: "It made me realize that family is important, and it made me realize that I need to hold onto God. That is something this sickness has made me really think of."

These women are resilient; they have already struggled with life, were devastated by their diagnosis, but they wanted to regain a sense of control over their lives because "life goes on. "The participants had the right to choose their attitude and coping mechanisms in order for their lives to go on regardless of how the world will judge them. All of the participants demonstrated some type of behavior to find protective mechanisms to shield themselves from the consequences of being infected with HIV/AIDS. These behaviors included self-inflicted social isolation and selective disclosure, and all agreed that it was important to take the medication as prescribed to combat the deadly effects of HIV/AIDS. Mahatma Gandhi described the importance of mental well-being in the following poem:

Keep your thoughts positive
Because your thoughts become your words.
Keep your words positive
Because your words become your behavior.
Keep your behavior positive
Because your behavior becomes your habits.
Keep your habits positive
Because your habit becomes your values.
Keep your values positive
because your values become your destiny (Gandhi, n. d.)

Human Suffering

Human suffering is the third concept of the theory of meaning. Suffering is an unavoidable part of the human experience that is all-consuming and subjective (Frankl, 1984). Stark and McGovern defined suffering as "unique to an individual and varies from simple transitory discomfort to extreme anguish and despair (Stark & McGovern, 1992). Frankl stated that there is no meaning in actual suffering because sometimes the suffering is unexplainable or undeserved. Put simply, bad things (suffering) can happen to anybody. Meaning is derived from the individual response to the suffering, and Frankl(1975) was emphatic that when you are suffering and have no meaning, that is the state of total despair (p. 137). The concept of human suffering supports the theme of struggle and isolation for these Indian women because their world wascrushed when they were diagnosed as HIV positive.

Fe described her reaction when she was diagnosed: "It was very hard. I tried to commit suicide. My family made me an outcast, and they did not want me." These women were already struggling to meet basic needs when they were dealt an additional blow of being infected with HIV. The participants were trusting of their monogamous partners; they did not exhibit any high-risk behaviors for an HIV infection, yet they were betrayed by their most intimate partners through heterosexual sex and thus unfairly ended up with and HIV/AIDS infection. This was narrated best by Cheryl who said: "I did not ask for this. It was given to me by my husband. I was shocked. I am not a fast girl. I never did anything wrong."

Unfortunately for Cheryl, she was the only participant at the time of the interview that appeared unhealthy and was really struggling to regain physical health. Dolly said she just cried inconsolably, "how could he do this to me?" All participants felt the aspect of human suffering in one form or the other. MayaAngelou described the struggles that a disenfranchised person endures in her poem "Still I Rise."

> You may shoot me with your words
> You may cut me with your eyes
> You may kill me with your hatefulness
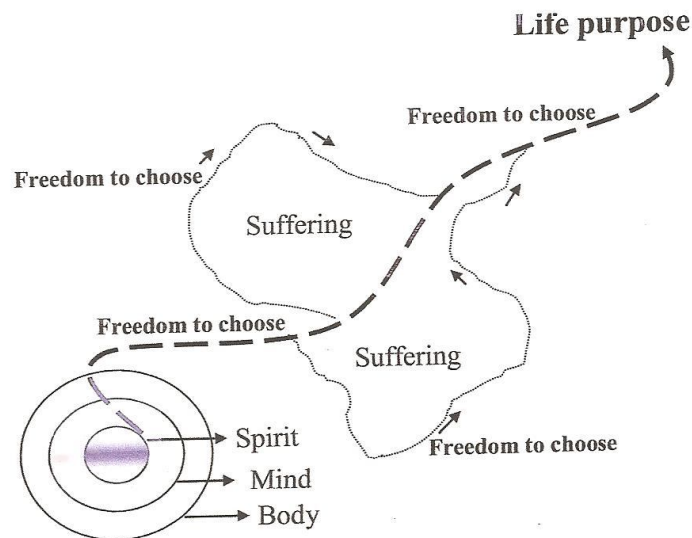> But still, like air, I rise (Angelou, 2003)

Figure 7: Theory of Meaning (Starck, 1985).

The scope of the theory of meaning provided a framework to generate a deeper and more authentic understanding of the lived experience of Indian women with HIV/AIDS in South Africa. Underpinning this phenomenon are the themes of struggling, isolating, supporting, and hoping. The women were devastated when they received the diagnosis of HIV, fearing stigmatization, concern for their young children as well as their mortality. A positive HIV/AIDS diagnosis provided a route for the participants to explore different ways to ascribe and make sense of their lives by finding meaning in their individual lives while dealing with HIV/AIDS.

Implications of the Study for Nursing Education

This study explored the lived experience of Indian women with HIV/AIDS in South Africa and gained an understanding of the meaning of this lived experience. Implications of this study for nursing education are significant for quite a number of reasons. South Africa is the country with the highest rate of HIV infection in the world. The findings of this study clearly illustrated a fundamental need for healthcare professionals to become more aware and knowledgeable about the challenges these women face when they are diagnosed with HIV/AIDS to reduce the prevalence of HIV in this country. The approach from the health care workers needs to be empathetic to ensure compliance with antiretroviral therapy and health outcomes for the HIV/AIDS patients (Beach, Keruly, & Moore, 2006). This is essential if South Africa will win the battle against losing many of its citizens in their prime economic years. Cultural awareness was raised in this study about these women's personal struggles and emotional turmoil. The acknowledgement of these women's experiences by the nursing profession is vital to a successful treatment regime.

Thus, a cultural competence awareness course as well as an introductory knowledge of meaning construction in the basic education of the nurses will provide the nurses with the skills to assist their patients to make sense of their health and how to move forward. Meaning occurs when the healthcare professional and patient engage one another to create understanding and coherence in which possible meanings or choices emerge to serve as a catalyst for healing (Beach et al., 2006). Nursing education must be reflective of health-promoting and health-sustaining behaviors, especially in marginalized population and have a global perspective. Thus, the nursing profession needs to evolve to meet the changing demographic needs of the societies in which they serve. These findings will add to the body of nursing knowledge and help to develop educational programs geared toward culturally appropriate care.

Implications of the Study for Nursing Practice

This study highlighted the crucial importance of continual mental health assessments during clinic visits. The women diagnosed with HIV/AID Sexperienced structural violence (gender inequalities, poverty, and social status) as discovered by Copeland (2011), in addition to extensive psychological issues. While the concern for immediate medical treatment is crucial to their well-being, acknowledgment of the psychological, physical, and psychosocial aspects needs to be incorporated in the care. The need for a comprehensive assessment of the woman's overall well-being and mental health status is essential because of emotional and psychosocial challenges these women experienced. Health care personnel need to assess the support systems of the individuals and incorporate them in the care to ensure greater adherence and reduce social isolation. The need for aggressive mental health care must not be undermined. A structured program that prescribes a strong focus of care about mental health for the first year of diagnosis maybe advocated, helping the individuals adjust to his or her status. Thus, the individuals can receive more counseling sessions and support group meetings to prepare them to deal with this disease effectively. The counseling strategies need to be culturally appropriate and be gender sensitive. The clinics can also use their clients to encourage and support each other to help overcome the negative aspects of this disease by discussing their fears and concerns.

All women in this study reported that the religion and spirituality played a crucial role in their lives as they readjusted to find meaning and purpose. Therefore, in nursing practice, acknowledging, supporting, and encouraging religious activities should be incorporated in the care of these women as this is viewed as a source of support. In addition, the assessment of the presence of a support group is necessary. The family and friends who make up the support system need to be educated on the physical changes, the side effects of medications, and the emotional upheaval the individual may undergo, and the importance of unconditional support. Pamela narrated this best when she said, "I have asked the social worker to come home, and talk to my family, and tell them to not pick on my HIV status when we fight. They need to know it is not OK." It is essential to include the assessment for risk of domestic violence in routine HIV/AIDS testing and counseling in nursing practice. However, this policy adoption would require the nursing staff to be trained in skills on how to ask about violence and how to refer the women for additional services. It is essential because women with HIV/AIDS do face a higher risk of violence. The nursing profession must be sensitive when rendering care to those afflicted with HIV/AIDS to continue to educate them about diet, medication adherence as well as emotional well-being and domestic violence.

Implications for Nursing Research

The findings from this research study contributed to the existing gap of nursing knowledge regarding the phenomenon of Indian women with HIV/AIDS in South Africa. There are very minimal studies conducted on this population in the nursing literature regarding this phenomenon. However, more in-depth investigations using the positivist and post-positivist approach should be conducted that focus on meaningful insights into the health-related beliefs and dilemmas faced by this population to HIV/AIDS. The analysis of empirical and experiential data is needed to build a strong foundation for designing relevant and meaningful interventions to improve treatment outcomes for this underrepresented population and therefore warrants that this phenomenon is looked at with different lenses.

Implications of the Study for Health/Public Policy

South Africa has been touched by the vengeance of AIDS in many ways (Crewe, 2000)for several reasons: Failure of the government to intervene appropriately and effectively created a society thatat the beginning of the epidemic was ignorant. The government launched a delayed educational campaignthat was racist (depicted only White and Black) and judgmental, resulting in a prejudiced society, and failedto address the social factors that enabled the rapid growth of this epidemic.

The prerequisites for a healthy society are access to the basic necessities of life (adequate food, clothing, sanitation, housing, and healthcare). The government has a responsibility to ensure universal access to quality healthcare and social services according to the people's needs. Health is clearly a reflection of a society's commitment to equity and justice. The failure of the South African government to address the threat HIV/AIDS adequately was blamed on the apartheid-era politics resulting in gross social inequalities. The government has since had no choice but to adopt an aggressive approachto the epidemic. TheSouth Africancitizens are vulnerable because of class, race, and gender, and if the epidemic is not curtailed, South Africa stands to lose it most economically productive citizens in their prime age, thus affecting the economy, population structure, and society.

The South African government has no choice but to be aggressive in their approach to this epidemic. HIV/AIDS prevention and control depends on the success of strategies to prevent new infections and treat individuals currently infected. Social support through support groups and counseling can help women overcome barriers.Thus,public policy should recognize the importance of HIV testing as well the need for counseling, and stigma reduction because addressing the emotional, social, and practical sequela of theirpositve status may make women more willing to adopt and maintain healthy behaviors. Although adopting a public health policy that addresses violence as a threat to women with HIV/AIDS is essential to protect the women's safety, appropriate support, and protection of these women are important. This phenomenological investigation provided meaningful insight into the cultural experiences of Indian women with HIV/AIDS. This insight is important because HIV/AIDS is clearly no longer a White or Black disease. All race groups are vulnerable. Therefore, advocating health care that is culturally appropriate is essential to deal effectively with this epidemicby developing initiatives to decrease the impact on this disenfranchised population. Government policy should include widespread advertising that aims to reduce the stigmaand create an increased awareness. HIV is not merely a medical problem but a social one as well because clearly, medication has not been able to curb the problem. Therefore, South Africa needs a multi-sectorial approachthat requires commitment and a strong political will.

Strengths/Limitations of the Study

This study embraced its strengths and concurrently the limitations. The purpose of this study was to explore the lived experiences of Indian women with HIV/AIDS in South Africa. This study provided insight into the participants' lived experiences with HIV/AIDS and expanded the understanding of living with HIV/AIDS as a minority population. The findings of this research study are limited by the homogenous demographic characteristics of the research participants such as the same economic background. The researcher had to wonder if the gift card was the driving force behind the participants' willingness to talk (although they volunteered to share their story), and only those with economic issues volunteered to talk. The researcher acknowledges that the descriptions of the women's experiences were based on the researcher's perception and that another researcher may obtain a different outcome. Therefore, it is difficult to generalize the findings of a qualitative study, but qualitative studies are not intended to be generalized. The destination of the research and the time allocated to conduct research could be described as a limitation. The researcher encountered great difficulty and resistance in the recruitment of potential research participants due to the sensitive nature of this topic despite having approval to access the population. Several of the potential research participants decided not to participate in the study because of fear of being seen with the researcher and having to explain the reason for the visit. Limiting the study to Indian females alone was a limitation because of this conservative culture that made achieving the sample size difficult.

Recommendations for Future Research

Concept development is an integral component in validating a profession's current body of knowledge; therefore, further development of the concepts meaning construction is vital. Research studies conducted on this sample is very limited, thus providing ample opportunities for further studies on this population on a variety of topics. Further inquiry of this nature is warranted on different economic backgrounds as well as different geographical locations. Future research on the lived experiences of South African women with HIV/AIDS regardless of race or location is encouraged to validate or provide a comparative study is encouraged. Research studies focused on a structured mental health program in addition to the medical regime to foster therapeutic environments that encourage the discovery of meaning should also be investigated.

Summary and Conclusion

Chapter Five discussed the findings of the phenomenological inquiry into the lived experience of Indian women with HIV/AIDS in South Africa. This study sought to explore the lived experience of Indian women with HIV/AIDS in South Africa to gain an understanding of the essence of the lived experience. Thus, a phenomenon of interest was explored, and a gap in the body of knowledge for nursing research was filled. Ten willing participants shared their stories, allowing the researcher to understand their experiences, thereby accomplishing the goals of the study. The principles of phenomenology were applied, and four themes became evident while the researcher immersed herself in participants' narratives (spoken words). Underpinning this phenomenon were the themes of struggling, isolating, supporting, and hoping. These four themes are a powerful expression of human experiences from the perspectives of the Indian women from South Africa infected with HIV/AIDS.

These themes explicated from these participant's narratives are commensurable with the central concept of the theory of meaning by Frankl (1984), which essentially focuses on human beings primary motivation that is to find meaning and purpose in life. Frankl specified three ways to find meaning on the path to uncovering life purpose, one of which is choosing an attitude to your circumstance and the drive toward your fate (Starck, 2008). The Indian women with HIV/AIDS adopted an attitude of hope, and they decided to fight this disease. Thus, the concept of life purpose supports the theme of hoping. The concept of freedom to choose supports the theme of supporting. The women have an unalterable situation of being diagnosed positive with HIV/AIDS. They had to find ways and means of adapting, such as family support and spirituality to help them adjust and move forward despite their diagnosis. The third concept of human suffering supports the theme of struggle and isolation for these Indian women because their world was crushed when they were diagnosed as HIV positive. They self-isolated as a protective mechanism resulting in lonely lives. However, according to Frankl (1984) meaning is not derived from the suffering but from the response to the suffering (Stark, 2008). Although HIV/AIDS does not discriminate against race, social standings, and age, minority populations are the hardest hit and most vulnerable as evidenced in this study. The researcher is indebted to the participants because they openly conveyed their experiences, although recollection of the day of diagnosis brought an onslaught of emotions, reducing every participant to tears. The scope of the theory of meaning provided a framework to generate a deeper and more authentic understanding of the lived experience of Indian women with HIV/AIDS in South Africa. This study offered meaning, illuminated the participant's rich narrative stories, and exposed the depth of the challenges confronting the Indian women with HIV/AIDS. A significant dimension of this experience of living with HIV/AIDS was the search for meaning, which the women were compelled to address in order to move forward in their respective lives. The Indian women's ability to construct meaning despite the odds against them provided great insight and understanding of this phenomenon.

References

Alcantara, J. (n.d.). You will never see me fall. Retrieved from http://www.familyfriendpoems.com/poem/you-will-never-see-me-fall

Allan, G. (2009). Life ain't always beautiful. Retrieved from http://www.elyrics.net/read/g/gary-allan-lyrics/life-ain_t-always-beautiful-lyrics.html

Amuyunzu-Nyamongo, M., Okengo, L., Wagura, A., &Mwenzwa, E. (2005).Putting on a brave face: The experiences of women living with HIV and AIDS in informal settlements of Nairobi, Kenya. AIDS Care, 19(Suppl 1), 25-34. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/17364385

Anderson, M., Elam, G., Solarin, I., Gerver, S., Fenton, K., & Easterbrook, P. (2009).Coping with HIV: Caribbean people in the United Kingdom. Qualitative Health Research, 19(8), 1060-1075. doi: 10.1177/1049732309341191

Angelou, M. (2003). Still I rise. Retrieved from http://www.poemhunter.com/poem/still-i-rise/

Arora, N. K., Finney-Rutton, L. J., Gustafson, D. H., Moser, R., &Hawkins, R. P. (2007). Perceived helpfulness and impact of social support provided by family, friends, and health care providers to women newly diagnosed with breast cancer. Psycho-oncology, 16(5), 474-486. doi:10.1002/pon.1084

Avert. (2011). History of HIV and AIDS. Retrieved from www.avert.org/hiv-aids-history.htm

Badenhorst, G., van Staden, A., & Coetsee, E. (2008). HIV/AIDS risk factors among residence students at the University of the Free State. Curationis, 31(3), 27-35. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/19177968

Baldacchino, D., & Draper, P. (2001). Spiritual coping strategies: A review of nursing literature. Journal of Advanced Nursing, 34(6), 833-841. doi:10.1046/j.1365-2648.2001.010814.x

Barroso, J., Hammill, B. G., Leserman, J., Salahuddin, N., Harmon, J. L., & Pence, B. W. (2010). Physiological and psychological factors that predict HIV-related fatigue. AIDS and Behavior14(6), 1415-1427. doi: 10.1007/s10461-010-9691-2

Beach, M. C., Keruly, J., &Moore, R. D.(2006). Is the Quality of the Patient-Provider Relationship Associated with Better Adherence and Health Outcomes for Patients with HIV? Journal of General Internal Medicine, 21(6), 661-665. doi: 10.1111/j.1525-1497.2006.00399.x

Beaudin, C. L., & Chambre, S. M. (1996). HIV/AIDS as a chronic disease. Emergence from the Plague Model. American Behavioral Scientist, 39(6), 684-706. doi:10.1177/0002764296039006006

Bing Images. (2012). Apartheid images. Retrieved from www.bingimages.com.

Bogart, L.M., Catz, S. L., Kelly, J. A., Gray-Bernhardt, M. L., Hartmann, B. R., Otto-Salaj, L.L., … & Bloom, F.R. (2000, July). Psychosocial issues in the era of new AIDS treatment from the perspective of the persons living with HIV. Journal of Health Psychology, 5(4), 500-516. doi:10.1177/135910530000500408

Bor, R., Miller, R., & Goldman, E. (1993). HIV/AIDS and the family: A review of research in the first decade. Journal of Family Therapy, 15, 187-204. doi/10.1111/j.1467-6427.1993.00753.x/pdf

Bravo, P., Edwards, A., Rollnick, S., &Elwyn, G. (2010, Apr-Jun). Tough decisions faced by people living with HIV: A literature review of psychosocial problems. AIDS Review, 12(2), 76-88. Retrieved fromhttp://www.ncbi.nlm.nih.gov/pubmed/20571602

Brincks, A. M., Feaster, D. J., & Mitrani, V. B. (2010). A multilevel mediation model of stress and coping for women with HIV and their families.Family Process, 49(4), 517-529. doi: 10.1111/j.1545-5300.2010.01337.x

Bunting, S. (1996). Sources of stigma associated with women of HIV. Advances in Nursing Science, 19(2), 64-73 . Retrieved from apollolibrary.com

Buras, L. (2011). Fight HIV your way winners. Retrieved from http://www.fighthivyourway.com/winners.aspx

Centers for Disease Control and Prevention. (2011). National Center for Health Statistics. Retrieved from http://www.cdc.gov/nchs

Cohen, L., Manion. L., & Morrison, K. (2000). Research methods in education (5th ed.).New York, NY: RoutledgeFalmer.

Colvin, C. J., & Robins, S. (2009). HIV/AIDS in South Africa 25 years on: Psychological perspective (155 - 164). In L. S. P. Rohleder (Ed.), Social movements and HIV/AIDS in South Africa. New York, NY: Springer.

Coovadia, H. M., & Hadingham, J. (2005). HIV/AIDS: Global trends, global funds, and delivery bottlenecks. Global Health, 1(13). doi:10.1186/1744-8603-1-13

Copeland, T. J. (2011). Poverty, nutrition, and a cultural model of managing HIV/AIDS among women in Nairobi, Kenya. Annals of Anthropological Practice, 35(1), 81-97. doi:10.111/j.2153-9588.2011.01068.x

Corbin, J.,&. Strauss, A. L. (1987). Accompaniments of chronic illness: Changes in body, self, biography, and biographical time. Sociology of Health Care,6, 249-281

Cornwell, E.Y., &Waite, L. J. (2009). Social disconnectedness, perceived isolation, and health among older adults. Journal Health Social Behavior, 50(1), 31-48. Retrieved from http://search.proquest.com.ezproxy.apollolibrary.com/docview/201665408

Costello, J. (2012, February). Women and HIV: 30 years on. HIV Australia, 9(4). Retrieved from http://www.afao.org.au/library/hiv-australia/volume-9/number-4

Cotton, S., Puchalski, C. M., Sherman, S.N., Mrus, J. M., Peterman, A.H., Feinberg. J., … Tsevat J. (2006). Spirituality and religion in HIV patients. Journal of General Internal Medicine, 21(S5), S5-S13. doi:10.1111/j.1525-1497.2006.00642.x

Crew, M. (2000). South Africa: Touched by the vengeance of AIDS - Responses to the South African epidemic. South African Journal of International Affairs, 7, 23 - 37.Retrieved from http://www.ebscohost.com

Creswell, J. W. (1998). Qualitative inquiry & research design: Choosing among five approaches. Thousand OaksSage.

Creswell, J. W. (2007). Qualitative inquiry & research design: Choosing among five approaches (2nd ed.). Thousand Oaks, CA: Sage.

Crotty, M. (1998). The foundations of social research. Thousand Oaks, CA: Sage.

Cutcliffe, J. R. (2006). The principles and processes of inspiring hope in bereavement counseling: A modified grounded theory study - Part one. Journal of Psychiatric and Mental Health Nursing, 13(5), 598-603. doi: 10.1111/j.1365-2850.2006.01019.x

Dageid, W. D., & Ducker, F. (2008, February). Balancing between normality and social death: Black, rural, South African women coping with HIV/AIDS. Qualitative Health Research, 18(2), 182-195. doi:10.1177/1049732307312070

Dalmida, S G, Holstad, M. M., Dilorio, C., Laderman, G. (2012). The Meaning and Use of Spirituality Among African American Women Living With HIV/AIDS. Western Journal of Nursing Research, 34(6), 736-765. doi: 10.1177/0193945912443740

Department of Health: Republic of South Africa. (1995). Zuma's response to Sarafina II. (1995). Retrieved fromhttp://www.doh.gov.za/show.php?id=14

Demi, A., Bakeman, R., Moneyham, L., Sowell, R., & Seal, B. (1997). Effect of resources and stressors on burden and depression of family members who provide care to HIV-infected women. Journal of Family Psychology, 11(1), 35-48. doi:10.1037/0893-3200.11.1.35

Dingfelder, S. F. (2006). Socially isolated and sick. Monitor Staff, 37(10), 18. Retrieved from http://www.apa.org/monitor.nov6/isolated.aspx

Downing, D. (2004). Apartheid in South Africa. Chicago, IL: Reed Elsevier.

Duffy, L. (2005). Suffering, shame, and silence: The stigma of HIV. Journal of Association of Nurses in AIDS Care,16(1), 13-20. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/15903274

Dunkle, K. L., Jewkes, R. K., Brown, H. C., Gray, G. E., McIntrye, J. A., & Harlow, S. D. (2004). Gender-based violence, relationship power, and risk of HIV infection in women attending antenatal clinics in South Africa. Lance, 363(9419), 1415-1421. doi: 10.1016/S0140-6736(04)16098-4

du Plessis, G. (2011). Individual responsibility for health and HIV infection: A critical investigation of the lived experience of HIV-positive women. South Africa Journal of Psychology, 41(4), 465-476. Retrieved from http://www.apollolibrary.com

Fabry, J. B. (1991). Guideposts to meaning: Discovering what really matters.   Oakland, CA: New Harbinger.

Fauci, A. S. (2008). 25 years of HIV. Nature, 453, 289-290. doi:10.1038/453289a

Flick, U. (2009). An introduction to qualitative research (4th ed.). Thousand Oaks, CA: Sage.

Fawzi M. C. S., Lambert, W., Boehm, F., Finkelstein, J. L., Singler, J. M., Leandre, F. …& Mukherjee, J. S. (2010). Economic risk factors for HIV infection among women in rural Haiti: Implications forHIV in poor settings. Journal of Women's Health, 19(5), 885-892. doi: 10.1089/jwh.2008.1334

Flood, H. (n.d.). God's Flight. Retrieved from http://www.familyfriendpoems.com/poem/gods-flight

Flowers, P., Davis, M., Hart, G., Rosengarten, M., Frankis, J., & Imrie, J. (2006). Diagnosis and stigma and identity among HIV positive Black Africans living in the UK. Psychology and Health, 21(1), 109-122. doi:10.1080/14768320500286286

Frankl, V. E. (1961). Dynamics, existence, and values. Journal of Existential Psychiatry, 11(5), 5-16. Retrieved from http://www.ebscohost.com

Frankl, V. E. (1969). The will to meaning. New York: New American Library.

Frankl, V. E. (1973). The doctor and the soul. New York: Vintage.

Frankl, V. E. (1975). The unconscious God. New York: Simon & Schuster.

Frankel, V.E. (1984). Man's Search for Meaning: An Introduction to Logotherapy. Boston, MA: Beacon Press.

Gallant, M. P. (2003). The influence of social support on chronic illness self-management: A review and directions for research. Health Education and Behavior, 30(2), 170-195. doi: 10.1177/1090198102251030

Gallo, R. C. (2006). A reflection on HIV/AIDS research after 25 years. Retrovirology. 3, 72. doi:10.1186/1742-4690-3-72

Gandhi, M. M. (n.d.). Mahatma Gandhi quotes. Retrieved from http://www.notable-quotes.com/g/gandhi_mahatma.html

Galvan, F. H., Davis, E. M., Banks, D., & Bing, E. G. (2008, May). HIV stigma and social support among African Americans. AIDS Patient Care and STDs, 22(5), 423-436. doi: 10.1089/apc.2007.0169

Gay, L. R. (2009). Educational research. competencies for analysis and application (9th ed.). Upper Saddle River, NJ: Pearson.

Gaynor, G. (1978). I will survive. Retrieved from http://www.metrolyrics.com/i-will-survive-lyrics-gloria-gaynor.html

Genrich, G. L., & Brathwaite, B. A. (2005). Response of religious groups to HIV/AIDS as a sexually transmitted infection in Trinidad. BMC Public Health, 16(5). Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/16288659

Gilbert, L.,&. Walker, L. (2010). My biggest fear was that people would reject me once they knew my status...': Stigma experienced by patients in an HIVAIDS clinic in Johannesburg, South Africa. Health and Social Care in the Community, 18(2), 139-146. doi:10.1111/j.1365-2524.2009.00881.x

Goffman, E. (1963). Stigma: Notes on the Management of Spoiled Identity. New York, NY: Simon & Schuster.

Gow, J. A. (2009). The adequacy of policy responses to the treatment needs of South Africans living with HIV (1998-2008): A case study. Journal of International AIDS Society, 12(37). doi:10.1186/1758-2652-12-37

Greaves, C. J., & Farbus, L. (2006). Effects of creative and social activity on the health and well-being of socially isolated older people: Outcomes from a multi-method observatonal study. Perspectives in Public Health, 126(3), 134-142. doi: 10.1177/1466424006064303

Groft, J. N., &Robinson V. A. (2007). Seeking serenity: Living with HIV/AIDS in rural Western Canada. Rural and Remote Health, 7(2), 677. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/17516839

Hackl, K. L., Somlai, A. M., Kelly,J. A., & Kalichman., S.C. (1997). Women living with HIV/AIDS: The dual challenge of being a patient and caregiver." Health and SocialWork,22, 53-62. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/9021418

Hawkley, L. C., Masi, C. M., Berry, J. D., &Cacioppo, J. T. (2006). Loneliness is a unique predictor of age-related differences in systolic blood pressure. Psychology and Aging, 21(1), 152-164. doi:10.1037/0882-7974.21.1.152

Health Resources and Services Administration [HRSA]. 2009. HRSA CAREAction. The Graying of HIV. Retrieved from http://hab.hrsa.gov/newspublications/careactionnewsletter/february2009.pdf

Heidegger, M. (1962). Being and time (J. Macquarrie & E. Robinson, Trans.). New York, NY: Harper and Row. (Original work published 1927)

Hill, D. L. (2006). Sence of belonging as connectedness, American Indian worldview, and mental health. Archives of Psychiatric Nursing, 20(5), 210-216. Retrieved from http://dx.doi.org.ezproxy.apollolibrary.com/10.1016/j.apnu.2006.04.003

Hinton, R.,& Earnest, J. (2010, February). Stressors, coping, and social support among women in Papua New Guinea. Quality Health Research, 20(2), 224-238. doi:10.1177/1049732309357572

Hockley, J. (1993). The concept of hope and the will to live. Palliative Medicine, 7(3), 181-186. doi:10.1177/026921639300700303

Husserl, E. (1931). Ideas: General introduction to pure phenomenology. London: George Allen & Unwn.

Ironson, G., Stuetzle, R., & Fletcher, M. A. (2006). An increase in religiousness/spirituality occurs after HIV diagnosis and predicts slower HIV. Journal of General Internal Medicine, 21(S5), 62-68. doi: 10.1111/j.1525-1497.2006.00648.x

Jewkes, R. K., Dunkle, K., Nduna, M., & Shai , N. (2010). Intimate partner violence, relationship power inequity, and incidence of HIV infection in young women in south Africa: A cohort study. Lancet, 376(9734), 41-48. Retrieved from http://www.ebscohost.com

Joanna. (n.d.). Hope is always there. Retrieved from http://www.familyfriendpoems.com/poem/hope-is-always-there

Kagee, A. (2010, December). Psychological distress among persons living with HIV, hypertension, and diabetes. AIDS Care, 22(12), 1517-1521. doi:10.1080/09540121.2010.484458

Kaida, A., Laher, F., Strathdee, S. A., Janssen, P. A., Money, P., Hoggs, R. S., … & Gray, G. (2011). Childbearing intentions of HIV-positive women of reproductive age in Soweto, South Africa: The influence of expanding access to HAART in an HIV hyperendemic setting. American Journal of Public Health, 101(2), 350-358. doi: 10.2105/AJPH.2009.177469

Kaldjian, L. C., Jekel, J. F., &Friedland, G. (1988, Jan). End-of-life decisions in HIV-positive patients:The role of spiritual beliefs. AIDS, 12(1), 103-107. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/9456260

Kaiser Family Foundation. (2011). Fact sheet: The global HIV/AIDS epidemic. Retrieved from http://www.kff.org/hivaids/upload/3030-17.pdf

Kaiser Family Foundation. (2012a). Fact sheet. The HIV/AIDS epidemic in the United States. Retrieved from http://www.kff.org/hivaids/upload/3029-13.pdf

Kaiser Family Foundation. (2012b). Fact sheet: Black Americans and HIV/AIDS. Retrieved from http://www.kff.org/hivaids/upload/6089-10.pdf

Kaiser Family Foundation. (2012c). Fact sheet. The HIV/AIDS epidemic in sub-Saharan Africa. Retrieved from
        http://www.kff.org/hivaids/upload/7391-08.pdf

Ki-Moon, B. (2008, 6 August). The stigma factor. The Washing Times. Retrieved from
        www.washingtontimes.com/news/2008/aug/06/the-stigma-factor/

Knoedel, J., Zimmer, Z., Kim, K. S., & Puch, S. (2007). The effects on elderly parents in Cambodia of losing an adult
        child to AIDS. Population and Development Review, 33(3), 479-500. doi: 10.1111/j.1728-4457.2007.00181.x

Koch, T. (1995). Interpretive approaches in nursing research: The influences of Husserl and Heidegger. Journal of
        Advanced Nursing, 21, 827-836. doi: 10.1046/j.1365-2648.1995.21050827.x

Kon, Z. R., & Lackan, N. (2008). Ethnic disparities in acess to care in post-apartheid South Africa. American Journal
        of Public Health, 98(12), 2272-2277.doi: 10.2105/AJPH.2007.127829

Krishnan, S., Dunbar, M., Minnis, A., Gerdts, C., Medlin, C., & Padian, N. (2008). Poverty, gender inequities and
        women's risk of HIV/AIDS. In S. G. Kaler & O. M. Rennert (Eds.), Reducing the impact of poverty on
        health and human development: Scientific approaches. Special issue of the Annals of the New York Academy
        of Sciences, 1136.

Kylmä, J. J., Vehviläinen-Julkunen, K. K., &Lähdevirta, J. J. (2001). Hope, despair and hopelessness in living with
        HIV/AIDS: A grounded theory study. Journal of Advance Nursing,33(6), 764-75. doi: 10.1046/j.1365-
        2648.2001.01712.x

Leininger, M. M. (1978). Transcultural Nursing: Concepts, Theories, and Practices. Toronto, Canada: John Wiley &
        Sons.

Lekganyane, R.,& du Plessis, G. (2011). Dealing with HIV-related stigma: A qualitative study of women outpatients
        from the Chris Hani Baragwanath Hospital. Journal of the Association of Nurses in AIDS Care, 23(2), 155-
        162. doi:10.1016/j.jana.2011.05.003

Lincoln, Y. S., & Guba, E. A. (1985). Naturalistic inquiry. Beverly Hill, CA: Sage.

Lincoln, Y. S., & Guba, E. A. (Eds). (2000). Handbook of qualitative research. Thousand Oaks, CA: Sage.

Litwinczuk, K. M. (2007). The relationship between spirituality, purpose in life, and well-being in HIV-positive
        persons. Journal of the Association of Nurses in AIDS Care, 18(3), 13-22. doi:10.1016/j.jana.2007.03.004

Loewenson, R. (2007). Exploring equity and inclusion in the reponse to AIDS. AIDS Care, 19(Suppl 1), 2-11.
        doi:10.1080/09540120601114790

Lukas, E. (1986). Meaning in suffering: Comfort in crisis through logotherapy. Berkeley, CA: Institute of Logotherapy
        Press.

Mamaila, K.,&Brand, R. (2000, Sept 14). HIV might very well cause AIDS-Mbeki. The Star, p. 1. Retrieved from
        http://www.virusmyth.com/aids/news/starmbeki.htm

Makoae, L. N., Greef, M., Phetlhu, R. D., Uys, L. R., Naidoo, J. R., Kohi, T. W., ... Holzemer, W. L. (2008). Coping
        with HIV/AIDS stigma in five African Countries. AIDS Care, 19(2), 137-146. doi:
        10.1016/j.jana.2007.11.004

Martha's Corner. (2009). The Stigma. Retrieved from
        http://www.inprofiledaily.com/index.php?option=com_content&task=view&id=601&Itemid=73

Mayers, A. M., Naples, N. A., &Nilsen, R. D. (2005). Existential issues and coping: A qualitative study of low-income
        women with HIV. Psychology and Health,20(1), 93-113. doi: 10.1080/08870440410001722949

McIntosh, R.C., &Rosselli, M. (2012). Stress and coping in women living with HIV: A meta-analytic review. AIDS and
        Behavior, 16(8), 2144-2159. doi:10.1007/s10461-012-0166-5

Medley, A. M., Kennedy C. E., Lunyolo, S., &Sweat, M. D. (2009). Disclosure outcomes, coping strategies, and life
        changes among women living with HIV in Uganda. Qualitative Health Research, 19(12), 1744-1754.
        doi:10.1177/1049732309353417

Merleau-Ponty, M. (1962/2008). Phenomenology of perception. (C. Smith, Trans).New York, NY: Routledge Classics.
        (Original work published in 1945)

Moustakas, C. (1994). Phenomenological research methods. Thousand Oaks, CA: Sage.

Mugambi, J. (2006). The impact of HIV/AIDS on Kenyan rural women and the role of counseling. International
        Social Work,49(1), 87-95. doi:10.1177/0020872806057084

Munhall, P. L. (2010). Nursing research: A qualitative perspective (5th ed.). Sudbury, MA: Jones & Bartlett Learning.

National Institute of Allergy and Infectious Diseases (NIAID). (2010a). How HIV causes AIDS. Retrieved from
        http://www.niaid.nih.gov/topics/hivaids/understanding/howhivcausesaids/Pages/cause.aspx
National Institute of Allergy and Infectious Diseases (NIAID). (2010b). HIV infection in women. Retrieved from
        http://www.niaid.nih.gov/topics/hivaids/understanding/population%20specific%20information/pages/wo
        menhiv.aspx
National Institute of Health. (2011). The 30th anniversary of the first reported cases of AIDS. Retrieved from
        http://www.ncbi. nlm.nih.gov
Newmann, S.,Sarin, P., Kumarasamy, N., Amalraj, E., Rogers, M., Madhivanan, P., … &Solomon, S. (2000).
        Marriage, monogamy, and HIV: A profile of HIV-infected women in South India. International Journal of
        STD and AIDS, 11(4), 250-253. doi:10.1258/0956462001915796
Nyindo, M. (2005). Complementary factors contributing to the rapid spread of HIV-1 in sub-Saharan Africa: Areview.
        East African Medical Journal, 82(1), 40-46. Retrieved from
        http://www.ncbi. nlm.nih.gov/pubmed/16122111
Palattiyil, G., & Chakrabarti, M. (2008). Coping strategies of families in HIV/AIDS care: Some exploratory data from
        two developmental contexts. AIDS Care, 20(7), 881-885. doi: 10.1080/09540120701767166
Patton, Q.M. (2002). Qualitative research and evaluation methods (3rd ed.). Thousand Oaks, CA: Sage.
Parker, R. (2002). The global HIV/AIDS pandemic: Structural inequalities, and the politics of international health.
        American Journal of Public Health, 92, 343-347. doi:10.2105/AJPH.92.3.343
Phila Legislative Update. (1996). The Sarafina II controversy. Retrieved from
        http://www.healthlink.org.za/pphc/Phila/sarafina.htm
Rahangdale, L., Banandur P., Sreenivas A., Turan J. M., Washington R., &Cohen C. R.
         (2010). Stigma as experienced by women accessing prevention of parent-to-child transmission of HIV
        services in Karnataka, India. AIDS Care, 22(7), 836-842.doi: 10.1080/09540120903499212
Rhatigan, J. C. (1996). Rereading in public health. In M. C. P. Farmers (Ed.), Women,poverty, and AIDS: Sex, drugs,
        and structural violence(pp.207-243). Monroe, ME: Common Courage Press.
Rose, R. C., House, A. S., &Stepleman, L. M. (2010). Intimate partner violence and its effect on the health of African
        American HIV-positive women. Psychological trauma: Theory, research, practice, and policy,2(4), 311-317.
        doi: 10.1037/a0018977
Ross, R., Sawatphanit, W., Draucker, C. B., & Suwansujarid, T. (2007). The lived experience of HIV-positive,
        pregnant women in Thailand. Health Care for Women International, 28(8), 731-744.
        doi:10.1080/07399330701465218
Russell. S., &. Seeley, J. (2010). The transition to living with HIV as a chronic condition in rural Uganda: Working to
        create order and control when on antiretoviral therapy. Social Science and Medicine, 70(3), 375-382.
        doi:10.1016/j.socscimed.2009.10.039
Sandelowski, M., & Barrosa, J. (2003). Writing the proposal for a qualitative research methodology project. Qualitative
        Health Research, 13(6), 781-820. doi: 10.1177/1049732303013006003
Sarkar K., Bal, B., Mukherjee R., Chakraborty S., Saha S., Ghosh A., … Parsons S.
        (2008). Sex-trafficking, violence,negotiating skill, and HIV infection in brothel-based sex workers of Eastern
        India, adjoining Nepal, Bhutan, and Bangladesh. Journal of Health, Population, and Nutrition, 26(2), 223-231.
        Retrieved from http://www.ncbi.nln.nih.gov/pmc/articles/PMC2740670/
Sartre, J. P. (1956). Being and nothingness. (H. E. Barnes, Trans). New York, NY: Washington Square Press. (Original
        work published in 1943)
Scandlyn, J. (2000, February). When AIDS became a chronic disease. Western Journal of Medicine, 172(2), 130-133.
        Retrieved from http://www.ncbi.nln.nih.gov/pmc/articles/PMC107
Schwartlander, B. G. (2006). The 10-year struggle to provide anti-retroviral treatment to people with HIV in the
        developing world. Lancet,368(9534), 541-546. doi:10.1016/S0140-6736(06)69164-2
Sowell, R. L., & Phillips, K. D. (2010). Understanding and responding to HIV/AIDS stigma and disclosure: An
        international challenge for mental health nurses. Issues in Mental Health Nursing, 31(6), 394-402. doi:
        10.3109/01612840903497602
Starck, P. L. (1985). Logotherapy comes of age: Birth of a theory. The International Forum of Logothearpy: Journal
        of Search for Meaning, 8(2), 71-75.
Starck, P. L. (2008). The theory of meaning. In M. J. Smith, & P. R. Leihr, (Eds), Middle Range Theory for Nursing
        (pp.85-103). New York, NY: Springer.

Stark, P. L., & McGovern, J. P. (1992). The meaning in suffering. In P. L. Stark & J. P. McGovern (Eds.), The hidden dimensions of illness: Human suffering (pp. 25-42). New York, NY: National League for Nursing Press.

Statistics South Africa. (2010). Mid year populations estimates 2010. Retrieved from http://www.statssa.gov.za

Swendenman, D., Ingram, B. L., & Rotheran-Borus, M. J. (2009, October). Common elements in self-management of HIV and other chronic illnesses: An intergrative framework. AIDS Care, 21(10), 1321-1334. doi:10.1080/09540120902803158

Tiamson, M. L. A.(2002). Challenges in the management of the HIV patient in the third decade of AIDS. Psychiatric Quarterly, 73, 51 - 58. Retrieved from http://www.apollolibrary.com

Trevino, K. M., Pargament, K. I., Cotton, S., Leonard, A. C., Hahn, J., Caprini-Faigin, C. A.,…Tsevat, J. (2007, December). Religious coping and physiological, psychological, social, and spiritual outcomes in patients with HIV/AIDS: Cross-sectional and longitudinal findings. AIDS Behavior, 14, 379-389. doi: 10.1007/s10461-007-9332-6

Tuck, I., McCain, N. L., & Elswick, R. K. (2008). Spirituality and psychosocial factors in persons living with HIV. Journal of Advance Nursing, 33(6), 776-783. doi: 10.1046/j1365-2648.2001.01711.x

UNAIDS. (2009). HIV transmission in intimate partner relationships in Asia.Retrieved from http://www.unaids.org

UNAIDS. (2010). UNAIDS 2010 Global Report. Retrieved from http://www.unaids.globalreport.com

United Nations News Service. (2010, June). Noting progress to date: Ban urges greater efforts against HIV/AIDS. Retrieved from http://www.un.org/apps/news/story.asp?NewsID=34977&Cr=aids&Cr1

van Manen, M. (1990). Researching lived experience: Human science for an action sensitive pedagogy. New York: State University of New York Press.

van Manen, M. (1989). Researching lived experience: Human science for an action sensitive pedagogy: London: Ontario: Althouse Press, University of Western Ontario

van Manen, M. (1997). Researching lived experience: Human science for an action sensitive pedagogy (2nd ed.). Ontario, Canada: The Althouse Press.

van Staden, A., & Badenhorst, G. (2009). Reviewing gender and cultural factors associated with HIV/AIDS among university students in the South African context. Curationis, 32(4), 19-28. Retrieved from http://www.curationis.org

Varni, S. E., Miller, C. T., McCuin, T., & Solomon, S. (2012). Disengagement and engagement coping with HIV/AIDS stigma and psychological well-being of people with HIV/AIDS. Journal of Social and Clinical Psychology, 31(2), 123-150. doi:10.1521/jscp.2012.31.2.123

Vatanoglu, E. E., & Ataman, A. D. (2011). A sexually transmitted disease: History of AIDS through philately. Journal of the Turkish-German Gynecological Association, 12(3), 192-196. doi:10.515-/jtgga.2011.45

Weiss, R. A. (2008). Special anniversary review: Twenty-five years of human mmunodeficiency virus research: Successes and challenges. Clinical and Experimental Immunology, 152(2), 201-210. doi: 10.1111/j1365-2249.2008.03645.x

Wood, M. J., & Ross-Kerr, J. C. (2011). Basic steps in planning nursing research (7th ed.). Sudbury, MA: Jones & Bartlett Publishers.

World Health Organisation (WHO). (2012a). Gender inequalities and HIV. Retrieved from http://www.who.int/gender/hiv_aids/en/

World Health Organisation [WHO]. (2012b). Definition of health. Retrieved from http://who.int/about/definition/en/print.html

World Health Organisation [WHO]. (2012c). Quality of life and spirituality.Retrieved from http://www.who.int/mental_health/media/en/622.pdf

Zou, J., Yamanaka, Y., John, M., Watt, M., Ostermann, J., & Thielman, N. (2009). Religion and HIV in Tanzania: Influence of religious beliefs on HIV stigma, disclosure, and treatment attitudes. BMC Public Health, 9. doi:10.1186/1471-2458-9-75

Zukoski, A. P., &Thorburn, S.(2009). Experience of stigma and discrimination among adults living with HIV in a low prevalence context: A qualitative analysis. AIDS Patient Care and STDs, 23(4), 267-276. doi: 1089/apc.2008-0168