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# The University of Southern Mississippi

#### MAXIMIZING DOCTOR-PATIENT COMMUNICATION

#### OF A POSITIVE HIV/AIDS TEST RESULT:

#### A BEST PRACTICES APPROACH

by

Vikki Yashandra Spann

Abstract of a Dissertation Submitted to the Graduate School of The University of Southern Mississippi in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy



#### ABSTRACT

#### MAXIMIZING DOCTOR-PATIENT COMMUNICATION

#### OF A POSITIVE HIV/AIDS TEST RESULT:

#### A BEST PRACTICES APPROACH

by Vikki Yashandra Spann

#### May 2014

The purpose of this study was to examine healthcare practitioner (HCP) communication of a positive human immodeficiency syndrome/acquired immunodeficiency syndrome (HIV/AIDS) test result in an effort to find best practices. The population of this study included healthcare practitioners who had to disclose a positive HIV/AIDS status to a patient. Data from specific accounts recalled by the healthcare practitioners were analyzed using grounded theory approach. The first research question was concerned with the strategies used by healthcare practitioners. The results indicated that there are two primary strategies used in HIV/AIDS disclosure: strategic interactive facilitation and strategic interactive force. The second and third research questions focused on contextual factors and intervening conditions of the interaction, respectively. Contextual factors included a range of feelings experienced by the HCPs such as shock, nervousness, hope, and reluctance. Intervening conditions often included patient identity crisis, sexual orientation, marital status, and culture. These issues of identity are integral to moving individuals forward and to hindering them from making reasonable decisions that impact their own health as well as others. Results of this study also suggest that stigma awareness is both a contextual factor and



an intervening condition. The fourth research question considered the consequences of the healthcare practitioner and patient interaction regarding the HIV/AIDS status.

Consequences of the healthcare practitioner communication of a positive HIV/AIDS test result included patient follow-up rates, HCP experience, and lack of a protocol. The results heightened the importance of exploring the initial communication of a positive HIV/AIDS test result. Further, they lend credence to the need for a protocol and a best practices communication tool for delivering a positive HIV/AIDS status to patients. A protocol would lessen inconsistencies among provider disclosure. Therefore, a protocol for a disclosure of a positive HIV/AIDS test result was introduced.



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by

Vikki Yashandra Spann

A Dissertation Submitted to the Graduate School of The University of Southern Mississippi in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy

Approved:

Steven Venette
Director
W. 14 P. 1
Keith Erickson
Erua Jung
Wendy Atkins-Sayre
John Meyer
Maureen A. Ryan
Dean of the Graduate School



May 2014

#### **DEDICATION**

I would like to dedicate my dissertation to my son, Ryan, and my mother,

Neuaviska. Ryan has been patiently by my side every step of the way. My mom inspired

me to conduct this research because of her relentless dedication to the healthcare

profession. Both of you have motivated and encouraged me throughout my life,

reminding me that all things are possible through Christ Jesus.



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Because no one does it alone . . . I am thankful for my family whose shoulders I have stood on as I embarked and completed this journey. I am forever indebted to my son, Ryan, for his energy and patience with Mommy; my mother, Neuaviska, for her constant support, wisdom, love, and motivation; my sisters, Taime, Karyn, Tiffany, Vatecia, and Kimberly Spann, for their prayer, friendship and understanding; and my other sister, Arlanda Mays, for her support and encouragement. You are truly a gift from God.

Last, but not least, I must thank my prayer partner, Gabrielle Bradshaw, and my prayer warrior, Ruthie Hooper, for constantly reminding me that the battle is not mine.

You are my angels on earth. I am a victor only through (The Father, The Holy Spirit)

Christ Jesus. Thank you.



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#### CHAPTER I

#### INTRODUCTION

Christine Maggiore's path to dissidence began in 1992 when she was diagnosed with human immunodeficiency virus (HIV) during a routine medical examination. This news came 2 years after the end of a long-term relationship with her ex-boyfriend whom she later found out had tested HIV positive (ABC News, 2001). She was frightened and confused because life as she "lived, planned and hoped came to a grinding halt" ("Message From The Author," Maggiore, 2000, para. 5). Initially, she became withdrawn from friends and family, dropped out of college, and lost interest in routine activities in order to keep her "tragedy a secret" ("Message From The Author," Maggiore, 2000, para. 5). Maggiore was the "person that HIV should have never happened to. . . . The embodiment of the slogan that everyone is at risk for AIDS" ("Message From The Author," Maggiore, 2000, para. 7).

Soon, Maggiore became angry, frustrated, desperate, and skeptical of HIV tests after inconsistent testing results and unanswered questions from doctors. She began to question the linkage between HIV and AIDS. After reading research and reports from Dr. Peter Duesberg, a contentious virologist at the University of California, Berkeley, Maggiore was convinced that HIV was not the cause of AIDS, a theory Duesberg has held for years (ABC News, 2001).

Maggiore's book, What If Everything You Thought You Knew About AIDS Was Wrong?, refuted the theory that HIV leads to AIDS and made choices that the established medical community would strongly discourage. She had sex without protection with her husband who is also a filmmaker, Robin Scovill, even though research indicated that one



of the primary ways to prevent HIV transmission is by using latex condoms (Centers for Disease Control and Prevention [CDC], 2010). Maggiore refused to take antiretroviral HIV medications although a combination of antiretroviral therapy (ART) medications could reduce the replication of HIV virus in the bloodstream to undetectable levels. Additionally, observational studies with heterosexual populations suggest that the use of ART can significantly decrease the chances of sexual transmission to sexual partners (Castilla et al., 2005; Quinn, Wawer, & Sewnkanbo, 2000; Reynolds et al., 2009; Sullivan et al., 2009).

Maggiore gave birth to two children without taking HIV medicine. Experts say that taking antiretroviral medication helps prevent HIV transmission to children if mothers take the medication before and during birth. If the baby is given antiretroviral medication after birth, HIV transmission is reduced (CDC, 2007). Meanwhile, Maggiore breastfed her son, Charlie. Mother-to-child is the most common way to transmit HIV to children as mothers can infect their babies during pregnancy and delivery or through breastfeeding (CDC, 2007). Still, Maggiore refused to test her children for fear of them being subjected to the stigma of HIV (ABC News, 2001). The CDC (2007) has reported that one in four mothers will transmit HIV/AIDS to their children. Also, it reports that children born with HIV benefit from early diagnosis and treatment. As a consequence, many children are living longer and healthier lives due to lifesaving drugs, new treatments, and other preventive measures.

AIDS physicians, researchers, experts, and activists have dismissed Maggiore's views and as they were troubled by her growing influence (ABC News, 2001) at the time.

Dr. Mathilde Krim, co-founder of the American Foundation for AIDS Research (amfAR),



feared that Maggiore was doing immeasurable harm in the "fight against AIDS" (amfAR, 2001, "HIV Causes Aids," para. 1) and amfAR (2001) published a petition against denialists that was signed by "5,000 physicians and scientists around the world known as the Durban Declaration," which restated mainstream stance on HIV/AIDS and pronounced "to argue otherwise costs lives" (amfAR, 2001, "Treatment of HIV Infection," para. 3).

A close reading of this true account reveals that the beginning of this tragedy could have possibly been avoided through doctor-patient communication when disclosing Maggiore's HIV-positive results at the initial and later visits. Researchers have studied doctor-patient communication including strategies and message reaction because "health communication is the singularly most important tool health professionals have to provide health care to clients" (Kreps & Thornton, 1992, p. 2). Yet, research has not enlightened investigators on how doctors and other medical practitioners actually communicate HIV/AIDS positive results to patients.

Presently, no commonly agreed-upon protocol or best practices-based communication tool exists to aid doctors in disclosing a positive HIV/AIDS status to patients. Moreover, research has not explored how doctors communicate positive HIV/AIDS results to patients. A protocol is a written plan specifying the procedures to be followed in a particular situation/medical examination; whereas, best practices are generally referred to as empirically confirmed actions that can be applied to specific circumstances. The absence of a protocol and best practices for disclosing a positive HIV/AIDS test result signifies an absence in the available working knowledge of communication tools and techniques when disclosing positive HIV/AIDS test results.



In general, doctors and administrators have recognized the need for proper training in effective communication skills for physicians when disclosing bad news. This stance is echoed in medical literature emphasizing that medical education hardly offers formal preparation for this task (Hebert, Butera, Castillo, & Mega, 2009; Orgel et al., 2010; Ptacek, Ptacek, & Ellison, 2001; Von Gunten, 2009). The general task of disclosing bad news has been associated with several barriers (Dosanjh, Barnes, & Bhandari, 2001): lack of confidence (Orgel et al., 2010), cultural barriers (Constantini et al., 2009), and stress/anxiety and fear (Ptacek & McIntosh, 2009), to name a few.

At the point of initial communication of a positive HIV/AIDS status, patients face the problem of viewing themselves differently (as one who is now the permanent carrier of an incurable communicable infection). In other words, an immediate shock occurs to an individual's identity. A need exists to understand how patients communicate the beginning of their identity crisis and how doctors should best support their patients.

Current information trends (for example, health topics common in books, on television, news programs, advertisements, and computer databases) have helped to improve patient empowerment. Empowered patients increasingly want information and options for making their own decisions. As a result, their changing expectations necessitate "new communication skills and different styles of interaction on the part of patients and caregivers" (du Pré, 2005, p. 77).

The purpose of this study was to address this gap in the literature by revealing communication best practices as well as by creating a context-specific protocol for communicating HIV/AIDS positive test results. To this end, the first and overarching

research question is presented: How do healthcare practitioners communicate a positive HIV/AIDS test result to patients?

Relationships between the healthcare provider (doctor, nurse practitioner, midwife, etc.) and patients are critically important. Due to HIV/AIDS's infectious, life-threatening, socially stigmatized, and psychologically damaging nature, healthcare providers must become more knowledgeable of doctor-patient relationships and communication. The heart of a patient's understanding of any and all health-related issues begins with communication.

Because millions of people are living with HIV in the United States (CDC, 2008), the opportunity to become well-informed about doctor-patient relationships in this context persists. HIV/AIDS is considered an epidemic due to its widespread incidence rate throughout the world (Singhal & Rogers, 2003). Globally, 33.4 million people are living with HIV/AIDS and in the U.S., every 9.5 minutes someone is infected with HIV (U. S. Department of Health and Human Services, 2012). These numbers reflect the crucial need to learn more about this context.

An understanding of how medical practitioners communicate a positive HIV/AIDS test result to patients and how the patients respond could reveal emerging issues as well as contribute to the body of literature surrounding HIV/AIDS prevention, intervention, and treatment. Concomitantly, a review of HIV/AIDS' communicative origins and its dynamics (both static and non-static) are important to recognize. Specifically, HIV-related stigma and identity are documented in the following literature review. Additionally, a general overview of communication identity theory, doctorpatient communication, communication strategies and message reaction will be included.



#### History

The history and urgency of HIV/AIDS have been marked by various identification elements. These elements include being a "gay man's disease" (Shilts, 1987), impacting hemophiliac children, and becoming potentially everyone's disease (Fisher, 1992). Past descriptions and formerly existing attitudes, beliefs, and behaviors demonstrate the evolution or gradual change of the phenomena. Still, the aforementioned supports some attitudes, beliefs, and behaviors that remains static today.

The 1970s and 1980s marked dramatic historical events for gay men. Gay men in San Francisco, California, made strides towards visibility, social change, and political victories. The Gay Freedom Day Parade, the White Night Riot, and the rejection of the Briggs Initiative (banning gays from teaching in public schools) were all notable accomplishments of the gay movement (Shilts, 1987). This movement was also marked by a fight against venereal diseases such as syphilis, gonorrhea, hepatitis B, and gay bowel syndrome (gastrointestinal parasites due to anal intercourse). Bathhouse businesses spawned commercialism of gay sex and were a place where various sexually-transmitted diseases were spread.

This period marked a significant turning point for the homosexual community. Shilts (1987) recalls, "Before would encompass thousands of memories laden with nuance and nostalgia. Before meant innocence and excess, idealism and hubris. More than anything this was the time before death" (p. 12). During the early 1980s, reports surfaced in San Francisco and New York City of a rare form of cancer affecting young gay men. This "gay cancer," also referred to as gay-related immune deficiency (GRID), later became known as AIDS (a disease acquired through the immune system by way of



contact with blood or mucus membranes). This acronym set the stage for (a) HIV/AIDS-related stigma of the disease, (b) the acceptance of gay men as sole carriers, (c) false beliefs about contagion, and (d) fear of the unknown.

Shilts (1987) provides one of the most comprehensive detailed accounts on the AIDS epidemic, the CDC reported 1,279 cases of AIDS and 485 died from the disease as of March 31, 1983. By 1985, the word *AIDS* was familiar in the United States. Gay men in San Francisco gave from 5% to 7% of donated blood. Children were being infected through blood transfusions.

By 1992, HIV/AIDS was recognized as having the potential of becoming everyone's disease. Consider Mary Fisher's 1992 Republican National Convention Address entitled *A Whisper of Aids*. Fisher warned,

Unlike other diseases, this one travels. Adolescents don't give each other cancer or heart disease because they are in love . . . HIV is different. . . . We have helped it along. We have killed each other with our ignorance, our prejudice, and our silence. It does not care whether you are Democrat or Republican; it does not ask whether you are black or white, male or female, gay or straight, young or old. This is not a distant threat. It is a present danger. We may take refuge in our stereotypes but we cannot hide there long, because HIV asks only one thing of those it attacks. Are you human? (Fisher, 1992, para.4)

Fisher goes on to say that no one is deserving of cruelty, meanness, and isolation (1992).

Many strides have been made to prevent the spread of HIV/AIDS and prolong the life of those infected. The use of antiretroviral medication has proven helpful; however, no cure has been found. HIV/AIDS has spread across the world and is now considered a



pandemic due to its global spread (Singhal & Rogers, 2003). An estimated 944,306 people were diagnosed with AIDS as of December 2004. The death rate of those diagnosed was 529,113 (Singhal & Rogers, 2003).

In 2006, an estimated 1.1 million adults and adolescents were living with HIV in the United States. According to the CDC (2009), many new infections were caused by people who are unaware of their status. By the end of 2006, an estimated 232,700 people were living with HIV and did not know their status (CDC, 2008). In the United States, the most recent statistics show about 50,000 newly diagnosed people each year in 2008, 2009, 2010, and 2011 (CDC, 2013). Although more than 619,000 people have died since the beginning of the epidemic, more than one million people are still currently living with HIV in the United States. One in five living with HIV is unaware of his or her infection and some individuals fear stigma more than knowing their HIV/AIDS status and may continue to be at-risk and infect others (CDC, 2009).

#### CHAPTER II

#### LITERATURE REVIEW

This chapter presents HIV-related stigma followed by the identity concerns of individuals impacted by HIV/AIDS. This information is followed by a theoretical orientation of the Communication Identity Theory as a frame of reference to view relationship factors regarding HIV/AIDS disclosure. Next, the significance of doctor-patient communication, communication strategies, and message reaction are all identified from the available literature.

#### HIV-related Stigma

HIV-related stigma refers to all negative perceptions (beliefs, attitudes, and understandings) toward people who have or are perceived to have HIV. A HIV-related stigma is also directed toward family members, friends, associates, communities, and other groups that are affiliated with people who have or are thought to have HIV/AIDS. Persons who are infected by HIV/AIDS experience patterns of prejudice. These patterns include being devalued and discriminated against which reinforces present social inequalities of sexuality, race, and gender (Brimlow, Cook, & Seaton, 2003).

Goffman (1963) conceptualized *stigma* as "an attribute that is deeply discrediting within a particular social interaction" (p. 3). Within this framework of stigma, Goffman focused on the public's attitude toward a person who has an attribute that is unfavorable according to societal expectations. Because of this attribute, the *person* is "reduced in our minds from a whole and usual person to a tainted, discounted one" (p. 3).

The categories of stigma outlined by Goffman (1963) were abominations of the body, blemishes of individual character, and tribal stigma of race, nation, and religion.



Abominations of the body from HIV/AIDS may include sores, skin blemishes, weight loss, patches on the tongue, shortness of breath, or other physical deformities (National Institutes of Health, 2013). A blemish of individual character is having "weak will, domineering or unnatural passions, treacherous and rigid beliefs, or dishonesty.

Blemishes of character are inferred from, for example, mental disorders, imprisonment, addictions, alcoholism, homosexuality, unemployment, suicidal attempts, or radical political behavior" (Goffman, 1963, p. 3). Blemishes of a person's character living with HIV/AIDS can consist of psychosis, depression, substance abuse, mood disorders, and sexual dysfunction (Fernandez & Ruiz, 2006). Goffman (1963) defines tribal stigma of race, nation, and religion as "beliefs that are transmitted through lineages and equally contaminate all members of a family" (p. 3). Zilber (2006) indirectly addressed the tribal stigma as follows:

HIV infection is often associated with gay men and intravenous drug users, groups that are often judged negatively and rejected by others. Patients are frequently afraid or ashamed to disclose their serostatus, and when they do reach out they are vulnerable to discrimination and rejection, as well as others' irrational fears of infection. (p. 357)

According to Goffman (1963) and other researchers (e.g., Herek, 1999; Jones et al., 1988), the degree of stigma is contingent upon the disease. Further, these diseases are thought to have the highest level of stigma and share general characteristics: The responsibility of having the disease is attributed to the person who is diagnosed with the illness, the disease itself has no cure and is progressive, the public does not totally understand the disease, and concealment of the disease's symptoms is unlikely.



HIV infection is a condition with a high degree of stigma because it shares the above word mentioned common attributes (Goffman, 1963; Herek, 1999; Jones et al., 1988). First, many people believe that HIV/AIDS is an avoidable disease by way of safe sex and moral behavior; thus, they blame the individual for their condition. However, individuals who acquire the disease through no fault of their own such as hemophiliacs or babies are not evaluated negatively. Instead, they are viewed as innocent (Herek, 1999). Second, HIV is an incurable, progressive disease. Yet, symptoms of HIV are treatable (Herek, 1999; Stoddard, 1994). Nevertheless, while its symptoms are treatable, the stigma of HIV/AIDS contributes to distress, shame, and silence of the adults infected (Duffy, 2005). Third, the communicable state of HIV is not always understood by people within the general population. Misunderstandings lead to feelings of threat of the disease. As a final point, the symptoms of HIV infection cannot be concealed beyond an asymptomatic state and may be seen as a very unpleasant, unattractive interruption to social interaction (Herek, 1999).

In addition to sharing the common characteristics of the highest level of stigma, previous studies show that people living with HIV/AIDS are viewed more negatively than people who have other incurable diseases. Healthcare workers share this negative view and often avoid contact with people who have AIDS (Gerbert et al., 1991; Nyblade, Stang, Weiss, & Ashburn, 2009; Weinberger, Conover, Samsa, & Greenberg, 1992). Because the first research question concerns how doctors communicate a positive HIV/AIDS test result, the second research question asks the following: What contextual factors are associated with the delivery of a positive HIV/AIDS test result?



Research has found that on an individual level, a HIV-related stigma has negative effects on mental and physical health, including, but not limited to, low self-esteem (Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001), feelings of worthlessness and high self-blame (Kang, Rapkin, Remien, Mellins, & Oh, 2005), extreme levels of depression and anxiety among HIV-positive women (Goggin et al., 2001), and increased depression among adults 50 years old and older (Goggin et al., 2001; Heckman et al., 2002). The extension of HIV/AIDS-related stigma stretches beyond individuals living with HIV/AIDS to other individuals in their lives. Families, volunteers, colleagues, caregivers, and professionals who offer services to people with HIV/AIDS are also affected by this stigma (Bond, Valente, & Kendall, 1999; Brown, Macintyre, & Trujillo, 2003; Cameron, 1993; Greene, Frey, & Derlega, 2002; Herek, 1999). The pervasiveness of stigma, particularly related to HIV in its capacity to ruin lives (Lange, 2003), interpersonal relationships (Kang et al., 2005), prevention and intervention efforts (Chesney & Smith, 1999), and other public health initiatives establishes its significance in health communication, practice, and research.

Velimirovic (1987) contends that "AIDS is an infectious but also a social disease" (p. 541). AIDS is a social disease that highlights important implications of HIV-related stigma on an individual level as well as to society (Kang et al., 2005). Brimlow et al. (2003) contend:

The discrimination and devaluation of identity associated with HIV-related stigma do not occur naturally. Rather, they are created by individuals and communities who, for the most part, generate the stigma as a response to their own fears. HIV-



related stigma manifests itself in various ways. For these reasons, HIV-related stigma must be recognized and addressed as a life-altering phenomenon. (p. 36)

In other words, the phenomenon of HIV- related stigma forces individuals to view their lives differently. Unfortunately, because of stigma, this new view will have negative associations for many people. Additionally, the lack of a cure leads to an ongoing identity concern (i.e., stigmatization) for the rest of an infected individuals' life.

### Identity

Green and Sobo (2000) contend that the social burden of HIV-related stigma overshadows the burden of disease progression and the decline in physical health. A general prerequisite for taking on the identity of HIV is receiving the news of a positive HIV test result (Green & Sobo, 2000). Receiving this news has shown to have a major impact upon individuals, especially initially. In the period following diagnosis, individuals felt "out of control and hopeless" (Green & Sobo, 2000, p. 68). Green and Sobo (2000) have conducted multiple studies and have found that individuals have reacted by bingeing on alcohol, using drugs, showing little to no interest in appearance, withdrawing socially, and attempting suicide. Additionally, the offer of treatment to manage HIV causes psychological distress among individuals. Further, individuals interpreted this offer as a sign of disease progression. Green and Sobo also suggest that these data imply that the strain of being HIV-positive is episodic. Thus, the first episode likely occurs when receiving a positive test result. The word *HIV/AIDS* is terrifying to most people and; individuals who receive the diagnosis have to confront the stigma associated with their illness.



Freimuth, Linnan, and Potter (2000) assert that the key to dealing with AIDS-related issues in absence of a cure lies in the application of communication theory and techniques. Applying communication theory and techniques should help in understanding, explaining, and improving HIV/AIDS related concerns. An application of Hecht, Warren, Jung, and Krieger's (2005) Communication Identity Theory (CIT) points out an interpenetrated process that plays a part in how individuals deal with HIV/AIDS.

### **Communication Identity Theory**

There are two groups: (a) those without HIV/AIDS (in-group) and (b) those infected with HIV/AIDS (out-group). Labels of in-group and out-group relate to the general population but can be reversed depending on the majority and minority of the present group. For example, if the group consists of majority of individuals with HIV/AIDS, then those individuals without HIV/AIDS become the out-group. Considering at-risk individuals' decision to not get tested is a revelation of avoiding an identity crisis. If individuals choose to test for HIV/AIDS and the results are positive, they immediately become a member of the out-group and are forced to consider negative stereotypes as the minority. Thus, the situation becomes prominently salient to the individual. The individual cannot avoid the significant discovery of status because choices have to be made. How an individual chooses to enact or not to enact this part of their identity is communicative.

Communication Identity Theory (CIT) examines four identity layers: personal, enacted, relational, and communal (Hecht et al., 2005). A personal layer is a map of how individuals generally define themselves. "Self-concept, self-image, self-cognitions, feelings about self and/or spiritual sense of self-being" make up the personal layer (Hecht



et al., 2005, p. 140). Some at-risk individuals fear stigma more than knowing their HIV/AIDS status and may continue to be at-risk and to infect others (CDC, 2009). The concept of identity is prevalent. Individuals affected and infected by HIV/AIDS will reevaluate their self-concept, image, cognitions, and feelings in light of a positive HIV/AIDS test. This reevaluation forces individuals to consider stereotypes and other public perceptions about those infected by HIV/AIDS in order to make decisions concerning how to interact with others. The enactment layer refers to the expressed self or how someone communicatively acts out of the self (Hecht et al., 2005). A person with HIV/AIDS may choose to disclose or not to disclose his or her status to others because of the fear of how he or she would be perceived. Either way the disclosure or lack thereof contributes to the relational level. In the relational level, identity is mutually created in relationships with others on three levels.

First, other people's views (categories and attributions) portrayed through interaction influences formulation and modification of the identity of the individual diagnosed as HIV-positive. Relationships with others or social roles is the second way individuals identify themselves. In other words, being a mother, father, friend, or coworker has an impact on communication and relational identity. Third, the relationship itself serves as an identity marker for the relationships that individuals have (Hecht et al., 2005). If a person discloses his/her HIV positive status to friends, relatives, and/or acquaintances, their relationship would go through a process primarily involving how other people feel about HIV/AIDS. They would also be forced to consider how interaction would change or stay the same. Taking all levels into consideration, the relationship will likely change to some extent after diagnosis. The communal layer refers

to group membership of common characteristics and history (Hecht et al.). Once an individual is diagnosed, he/she shares a common characteristic--being infected by HIV/AIDS. This status also represents the in-group/out-group relations. In other words, communal identity will now include the individual as a member of the HIV/AIDS community while maintaining ties with the previous community. Personal, enacted, relational, and communal layers are an interpenetrated process that plays a part in how individuals deal with HIV/AIDS. Understanding this process is also indicative of how HIV/AIDS presents a threat to the stability of previous relationships. Ultimately, HIV/AIDS threatens the health of those who are infected.

#### **Doctor-Patient Communication**

Hippocrates promoted the idea of health as a harmonious balance between many factors including diet, contact with nature, relationships, and physical strength (DuPre', 2005). The World Health Organization (1948) defined *health* as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (p. 1). This meaning has been unchanged for more than 60 years. Both explanations remind us that health is more than not being sick. It is the state of conformity and balance between many aspects of life (du Pré, 2005).

Someone has to deliver information that threatens health, specifically a positive HIV/AIDS test result. Hippocrates contends that the physician should be accountable for delivering bad news to patients (Gillotti & Applegate, 1999; Maynard, 1996). Bad news is "any news that drastically and negatively alters the patient's view of her or his future" (Buckman, 1992, p. 15). The physician should consider the amount of information patients receive about their diagnosis because the report has the potential to cause a



patient's condition to worsen (Mueller, 2002). Because physicians are at the focal point of delivery, the third research question asks the following: What intervening conditions exist concurrent to healthcare practitioner delivery of a positive HIV/AIDS test result? VandeKieft (2001) noted the American Medical Association's first code of medical ethics in 1847 stated that:

The life of a sick person can be shortened not only by the acts, but also by the words or the manner of a physician. It is, therefore, a sacred duty to guard himself [sic] carefully in this respect, and to avoid all things which have a tendency to discourage the patient and to depress his [sic] spirits. (p. 235)

The ethical consideration of this code is threefold. Hippocrates' notion of being apprehensive about conveying bad news to patients because of the possible effects disclosure could have on the patient is reinforced. The vitality of effective and ineffective communication in medical settings is also emphasized. Finally, the code alludes to the doctor-patient relationship.

Disclosure often involves relational concerns. Duggan (2006) considered advances in the last decade and challenges for the next by reviewing health-related articles in the last decade to understand the interpersonal communication process. The reviewed articles echoed a relationship-centered perspective on doctor-patient communication. Current research indicates a shift from the traditional approach of doctor- patient relationships from the doctor as dictator-like to the doctor emphasizing patient autonomy and empowerment. The concept of relational communication helps explain this transformation of power from the physician to one of negotiation and shared power between the physician and patient. Patients increasingly want to know as much



about their diagnosis as possible, which further emphasizes the necessity of physicians to be able to communicate effectively (Gillotti & Applegate, 1999). Specifically in the context of HIV/AIDS, the infectious risk associated with contracting the disease allows no justification for withholding an individual's status. Thus, the task of disclosing the bad news of positive HIV/AIDS status to patients is unavoidable. Buckman (1992) asserts, "Unfortunately, there can be no anesthetic that removes the pain of hearing bad news" (p. 18). Effective communication at this point can reduce suffering and save lives.

The value of a cogent, usable protocol cannot be overstated. The approach by which bad news is communicated to patients has implications for doctor-patient interaction and is directly correlated with communication variables, patient satisfaction, and compliance (Thompson, 1994). Other research indicates that giving terrible reports necessitates communicative tactics unlike other kinds of health interaction (Gillotti, Thompson, & McNeilis, 2002).

#### Communication Strategies

Sparks, Villagran, Parker-Raley, and Cunningham (2007) identified five communication strategies: indirect, direct, comforting, and empowerment with patient satisfaction, and empowerment with patient dissatisfaction. Indirect communication has minimal to no disclosure and includes avoidance in verbal communication and nonverbal distancing (Miller, 1994). Indirect strategies are often used to help doctors maintain an emotional detachment from the patient (Sheldon, 2004). An indirect strategy must not be applied when communicating bad news because this news threatens the life of the patient (Miller, 1994). Direct communication, a straightforward approach (Smith, Nicol, Devereux, & Cornbleet, 1999), is used to increase a patient's autonomy, thus decision-



making (Pellegrino, 1992). Patients appreciate direct strategies and view them as educational. However, some patients may view directness as ineffective, unemotional, and unprofessional and may be discouraged by this style of communication (Sparks et al., 2007).

Comforting, such as touching (Buis, de Boo, & Hull, 1991) and holding hands (Buckman, 1992), attempts to convey verbal and nonverbal messages that will help alleviate distress (Rosch, 2000). Patients perceive that doctors are compassionate and feel comforted during face-to-face interactions after comforting strategies are used (Sparks et al., 2007). Empowerment acknowledges the power of the individual as a patient by providing the patient with choices (Ross, Doan, & Church, 1991). Patient satisfaction is enhanced when the empowerment strategy is used in discussing options after the bad news has been disclosed (Sparks et al., 2007). Additionally, empowerment respects the autonomy of individuals and tends to increase coping skills (Tengland, 2012).

VandeKieft (2001) posits the ABCDE Mnemonic for Breaking Bad News. In short, the letter *A* represents advance preparation of self while allowing and arranging for adequate time for disclosure; *B* represents building a therapeutic environment/relationship, that may include other family members; *C* represents communicating well by familiarizing self with what the patient or family already knows, allowing silence, compassion, and concluding with follow-up plans; *D* represents dealing with patient and family reaction by assessing and responding to the patient and family, displaying empathy, and avoiding criticizing; and *E* represents encouraging and



validating emotions by exploring how the patient defines the news and offering hope in accordance with a patient's goals.

VandeKieft (2001) contends that professional groups have published guidelines about how to communicate bad news. However, of those that have been published, few are evidence-based; less than 25% are based on original data with flawed methodologies, and most lack clinical efficacy. Although articles encourage best practices for breaking bad news, the concept itself has received little research attention with modest empirically tested recommendations about how to improve communication. The degree to which certain medical behaviors are accepted lie within a diverse influential variables that are often incomplete. Thus, adapting a single strategy for conveying bad news to a patient is unlikely (Campbell & Sanson-Fisher, 1998; Ptacek & McIntosh, 2009).

Baile et al. (2000) describe a six-step protocol for communicating bad news to patients about their cancer diagnosis. SPIKES is the acronym he uses to help physicians obtain information from the patient, provide medical information and support to the patient, and encourage patient participation in future treatment and options. In short, *S* stands for setting up the interview. *P* and *I* include open-ended questions to address, and *P* assesses perceptions of the patient including the likelihood of denial before disclosing medical findings, while obtaining the patient's invitation (*I*). Patient's invitation represents whether or not the patient would like certain medical information indirectly communicated or not communicated at all. *K* represents sharing knowledge and information with the patient about the medical condition. *E* represents identifying, observing, and addressing patients' emotions empathetically. The final *S* represents both strategy and summary. Strategy is a plan for the future such as treatment. The summary



provided by the physician is intended to create a sense of shared responsibility with the patient for the strategy.

During this process a patient's readiness for discussions about treatment is discussed. Physicians often experience massive discomfort when prognosis and treatment are unfavorable. Physicians are unsure of the patient's expectations and fear destroying hope for the patient. Physicians also fear their own failures related to an incurable disease and the humiliation of offering too much optimism. Ninety-nine percent of oncologists who have assessed SPIKES report it as being useful and understandable. However, 52% say responding to a patient's emotion presents the greatest challenge, specifically, the use of statements that helps understanding the patient's feelings and establish their soundness of the medical condition (Baile et al., 2000).

Conversely, communication strategies needed to disclose the health threat of an HIV diagnosis would likely need to incorporate elements of education, prevention, intervention, and treatment. The first research question asks the following: How do healthcare practitioners communicate a positive HIV/AIDS test result to patients? This research question will reveal communicative strategies used by healthcare practitioners to disclose a positive HIV/AIDS status to patients.

Scholars have documented the importance of assessing the ways the patient understands and engages in the relationship as well as the ways physicians engage and validate patient participation. Yet, research is necessary to fully understand these communication processes and the link between interpersonal communication and health-related outcomes (Duggan, 2006).



#### Message Reaction

When information or diagnosis that a person's health is threatened is presented, Witte (1992, 1994) asserts that individuals either attend to the health threat or to their fear, whichever is most salient for the individual at that time. Fear appeals have been studied and found to be effective persuasive messages in certain contexts. Because practitioners felt differently about fear appeals, Witte, Meyer, and Martell (2001) considered all perspectives and provided an explanation for effective and ineffective health risk messages with the development of the Extended Parallel Process Model (EPPM). EPPM is an integration of several fear appeal and behavior change theories.

EPPM predicts individuals' perceptions of threat and efficacy. Heightened perceptions of threat and efficacy motivate individuals to control the danger. A danger control response means that individuals are primarily concerned about the health threat. Whereas, individuals with low perceived efficacy may be uncertain about performing precautionary recommendations but rather tend to focus instead on controlling fear. The attempt to control the fear of the health threat is manifested psychologically through defensive avoidance (blocking thoughts/feelings, denial), disavowing or refusing to acknowledge, or reactance (belief that the message or source of message wishes to manipulate them/resulting in resistance to or rejection of the message) (Witte et al., 2001). Research Question 4 asked the following question: What are the consequences of the healthcare practitioner and patient interaction of a positive HIV/AIDS test result? In other words, outcome indications of how the patient received and reacted to the interaction of communicating the news should be present.

As mentioned in this chapter, HIV/AIDS' incurable state has had many social issues that have impeded progress. Complications have been noted beginning with early historical contexts of misunderstandings of HIV/AIDS. Adding fear to misunderstanding helped create a lasting stigma. HIV-stigma leads to identity crisis which adds an additional burden to the decline of health and often overshadows the burden of disease progression. Although social complications are intense, social advantages abound as noted in other areas of health within doctor-patient interactions, communication strategies, and message reactions. Because research has not addressed messages/strategies used by doctors and other medical practitioners to communicate a positive HIV/AIDS status to patients, the following methodology sought to do so.



#### CHAPTER III

#### **METHODOLOGY**

President Barack Obama reinvigorated a national dialogue about HIV/AIDS in July 2010 by releasing a National HIV/AIDS Strategy (NHAS). The primary goals for NHAS include reducing HIV incidence, increasing access to care, optimizing health outcomes, and reducing HIV-related health disparities (Office of National AIDS Policy [ONAP], 2010). Although NHAS seeks to implement tactics to combat incidence rates, increase access to care, optimize health outcomes, and reduce disparities, the strategies themselves are either incomplete or nonexistent. In tackling these issues, researchers are charged with evaluating what has been done and what is being done presently, while identifying novel approaches that will strengthen the response to HIV/AIDS. To this end, the ultimate goal is to build theory. Strauss and Corbin (1990) assert that:

Building theory, by its very nature, implies interpreting data, for the data must be conceptualized and the concepts related to form a theoretical rendition of reality (a reality that cannot actually be known, but is interpreted). The theoretical formulation that results not only can be used to explain reality but provides a framework for action. (p. 82)

Exploring how doctors communicate a positive HIV/AIDS status to patients is a step toward reaching the goals of the NHAS as well as the completion and creation of strategies within. In other words, NHAS identifies priorities presented as a roadmap, but it is not "a comprehensive list of all activities needed to address HIV/AIDS in the United States" (ONAP, 2010, p. 3). An exploration will reveal doctors and/or medical



practitioners' strategies used in the past and present and lend credence to the conception of a protocol and best practices for disclosing positive HIV/AIDS test results to patients.

A gap in the literature exists regarding how doctors and other medical practitioners communicate a positive HIV/AIDS status to patients. To address this gap, this research project sought to explore healthcare professionals' experiences of disclosing a positive test to a patient. To promote depth of understanding, the present study employed qualitative research methods. A qualitative approach provides the best means of collecting and interpreting "intricate details of a phenomena that are difficult to convey with quantitative methods" (Strauss & Corbin, 1990, p. 19). Creswell (2007) suggests that a qualitative research method is best suited for a study that seeks a complex level of detail and an understanding of a phenomenon that can only be established by interviewing or observing individuals in their natural environments.

This project integrated a phenomenological lens because the information was sought from lived experiences of physicians and/or medical practitioners of the phenomenon (disclosing positive HIV/AIDS status) in order to explore the individuals' descriptions of their experiences. The application of phenomenology is concerned with lived experiences of people who are or were involved with a particular issue worthy of research (Welman & Kruger, 1999). The issue or phenomenon worthy of study is disclosing a positive HIV/AIDS test result. Thus, medical practitioners are the primary subjects of this study because they are the bearers of this news. The researcher was not present when the doctors or medical practitioners disclosed the positive HIV/AIDS status to patients. Rather, the researcher conducted in-depth interviews with medical practitioners about communicating a positive test result.



Qualitative research seeks rich, descriptive data from a fresh perspective to obtain a deeper understanding of experiences of several individuals to grasp a more universal essence of a phenomenon (Creswell, 2007). From this perspective, the task of a researcher is to elicit participant reflection of past experiences. An examination of the participant's lived experiences allows the investigator to relate "the particular to the universal, the part to whole, and the episode to totality" (Van Manen, 1990, p. 36).

Therefore, the purpose of this qualitative study was to examine the experiences of medical practitioners' disclosure of a positive HIV/AIDS test result. Face-to-face preinterviews were initiated to determine if a potential participant had delivered a positive test result to a patient. If the medical practitioner met this criterion of communicating a positive HIV/AIDS result, he or she was asked to participate in the study. An interview was scheduled for a later time. Face-to-face in-depth interviews with doctors and medical practitioners were conducted and audiotaped (with permission) by the researcher after the oral presentation (see Appendix A). Generally, interviews lasted approximately an hour with the exception of two interviews; one lasted about 12 minutes and the other lasted over an hour and a half. Interviews allowed a more detailed account of recalled descriptions of disclosing a HIV/AIDS status. Analyzing and interpreting interview data from the medical practitioners' perspective helped to identify: (a) those aspects of the experiences which are similar and dissimilar, (b) the priorities and influences which affect those experiences, and (c) the most critical issues that provide an in-depth understanding of the experiences and help define the essence of the phenomenon. The semi-structured interview process elicited verbal accounts of the medical practitioners' firsthand experiences in order to create an authentic picture of the lives of the participants



and the meaning of the essence of the experience as suggested by Creswell (2007), Moustakas (1994), and Van Manen (1990).

The interview questions included direct open-ended questions designed to answer the overarching research question. Grounded theory research questions allow for indepth exploration, flexibility, and freedom to help identify or understand poorly developed or undeveloped concepts (Strauss & Corbin, 1990). The central question that guided this study is as follows: How do doctors and/or medical practitioners communicate a positive HIV/AIDS result to patients? This primary research question within grounded theory research would be an interactional question because the primary focus of the interviews and analysis is interaction (Strauss & Corbin, 1990). Through individual interviews, the participants' attitudes, emotions, thought processes, understanding of patient knowledge and compliance, and reflections on their own disclosure effectiveness were revealed. Individuals construct meaning from prior experiences. These experiences influence not only how individuals analyze, interpret, and apply the information in future experiences, but also shape their attitudes and perceptions (Von Glasersfeld, 1995). Structured and semi-structured interviews are projected to make known participant attributes such as emotions, reflections, and judgments (Moustakas, 1994). Through interviewing, the researcher assisted the medical practitioners in reconstructing their experiences of disclosing a positive HIV/AIDS test result, which allowed the researcher to build upon and explore the participants' responses by helping to (a) situate the experience into context, (b) reconstruct specific details of the experience, and (c) reflect on the experience and their observed actions as recommended by Seidman (2006).



# Participant Recruitment, Selection, and Participation

Purposive sampling was used to identify participants for this study. According to Welman and Kruger (1999), purposive sampling is the most important type of nonprobability sampling to identify key participants. Hycner (1999) asserts that "the phenomenon dictates the method (not vice-versa) including even the type of participants" (p. 156). Participants were recruited based on the purpose of the research (Babbie, 1995; Greig & Taylor, 1999; Schwandt, 1997), seeking individuals with experience related to the phenomenon of communicating a positive HIV/AIDS status to patients. Interviews were arranged with doctors and other medical practitioners. Requests to participate were conducted face-to-face. Additionally, snowball sampling was used to expand the sample size by asking participants to recommend other potential participants (Babbie, 1995; Crabtree & Miller, 1992).

Seidman (2006) recognized sufficiency and saturation as the two criteria for deciding the number of participants. *Sufficiency* refers to the amount and range of participants needed to reflect the population, while *saturation* of information refers to the point where the data collection no longer reveals new information. Boyd (2001) recommended from 2 to 10 participants as usually sufficient to attain saturation. Guest, Bunce, and Johnson (2006) noted that the idea of saturation is most useful after it has been operationalized. Guest et al. found that the "basic elements for metathemes were present as early as six interviews" (Guest et al., 2006, p. 59). Ritchie, Lewis, and Elam (2003) summarized seven characteristics that may shape the potential sample size:

There are a number of issues that need to be taken into account in determining sample size: the heterogeneity of the population; the number of selection criteria;



the extent to which 'nesting' of criteria is needed; groups of special interest that require intensive study; multiple samples within one study; types of data collection methods use; and the budget and resources available. (p. 84)

This study considered seven characteristics that may impact sample size. If diversity is high in nature, an increase in sample size is required. Conversely, if the population is generally homogenous, then the sample size could be smaller because it will take into account all the inner diversity necessary (Ritchie et al., 2003). The population of this study was relatively homogenous. All participants were healthcare practitioners who had delivered a positive HIV/AIDS test result to a patent. The results were generally the same. Medical school did not prepare the healthcare practitioners for disclosure of a positive HIV/AIDS status to patients. Second, the fewer criteria used in designing the study, the smaller the sample size should be. The defining criteria for designing this study were healthcare practitioner and disclosure of a positive HIV/AIDS status to a patient. Third, the extent to which nesting of criteria is needed is concerned with interdependent criteria. If one criterion is linked to another to control another criterion, they may require nesting or controlling for diversity. Nesting increases sample size because it seeks to control for one or more variables within another (Ritchie et al., 2003).

A method was not used to reduce the effects of variables within this study. Although multiple research questions were posited, they required exploration for diversity. Fourth, groups of special interest that require intensive study increases sample size. The more special interest groups that exist within a study requires an increase of the sample size to include sufficient representation and diversity of the groups (Ritchie et al., 2003). This study created a special interest group of its own, HIV/AIDS disclosing



healthcare practitioners. Fifth, multiple samples such as several paired interviews and focus groups within one study will require comparison and control of variables and an increase in sample size (Ritchie et al., 2003). Again, multiple interest groups did not exist within this study; therefore, no comparisons were made. Sixth, type of data collection methods includes single interviews or group discussions (small or large, or paired interviews). Overall sample size will increase depending on the types used (Ritchie et al., 2003). The data collection process of this study was in-depth individual interviews. Seventh, the budget and resources available place limits on sample size. Intensive resources are required for collecting and analyzing data. Budget or funding will directly impact the number of participants or sample size. Significant attention was devoted to the role of the doctor or medical practitioner within the initial interaction of positive HIV/AIDS test result disclosure.

Participation in this study was voluntary. The University of Southern

Mississippi's Human Subjects Protection Review Committee reviewed and approved this

project to ensure compliance with all applicable regulations (see Appendix B).

Institutional Review Board (IRB) protocol was followed for the protection of human subjects.

## **Analysis**

According to Moustakas (1994), "An empirical phenomenological approach is the process of returning to the experience in order to obtain comprehensive descriptions that provide the basis for a reflective structural analysis that provides the essence of the experience" (p. 13). The researcher highlighted and examined commonalities and differences that existed among the medical practitioners, including diverse occurrences of



the phenomenon. Strauss and Corbin (1990) noted "the discovery and specification of differences among and within categories, as well as similarities, is crucially important and at the heart of grounded theory" (p. 111). Further, the audio-recorded interviews were listened to several times. Repeated keywords and phrases were documented. Relevant quotations were transcribed. Notes were made to gain an understanding of the sensitive phenomena of disclosing a positive HIV/AIDS test result.

The aim of this data analysis in its most direct form involved preparing and organizing the data and reducing the data into categories or themes in order to identify the essence of the phenomenon (Creswell, 2007; Moustakas, 1994; Seidman, 2006; Yin, 2003). In other words, the unrestricted processes of open, axial, and selective coding were employed. Categories were identified, conceptualized, and labeled according to property of HIV/AIDS disclosure during open coding. In axial coding, connections between categories were made. Grounded theory seeks a theoretical interpretation grounded in empirical reality as reflected by the data.

Building theory through qualitative research allows for a greater understanding of the unknown and "for developing action strategies that will allow for some measure of control over it" (Strauss & Corbin, 1990, p. 9). A simplified version of the paradigm model which delineates the systematic process of coding in grounded theory is specified by Strauss and Corbin (1990):

(A)CAUSAL CONDITIONS  $\rightarrow$  (B) PHENOMENON  $\rightarrow$  (C) CONTEXT $\rightarrow$  (D) INTERVENING CONDITIONS  $\rightarrow$  (E) ACTION/INTERACTION STRATEGIES  $\rightarrow$  (F) CONSEQUENCES. (p. 99)

Causal conditions refer to the incidents that lead to the phenomenon's occurrence (Strauss & Corbin, 1990). The causal condition that led to the occurrence of this phenomenon was a patient testing positive for HIV/AIDS. The current research phenomenon was healthcare practitioner (HCP) disclosure of positive HIV/AIDS status to a patient. The second research question is concerned with the contextual factors associated with the delivery of a positive HIV/AIDS test result. Strauss and Corbin (1990) asserted that context "represents the specific set of properties that pertain to a phenomenon . . . is also the particular set of conditions within which the action/interaction strategies are taken to manage, handle, carry out, and respond to a specific phenomenon" (p. 101). In other words, context represents location along with distinctive components that are necessary to describe phases within the phenomenon.

Next are intervening conditions. Research question three asked, what intervening conditions exist concurrent to a healthcare practitioner's delivery of a positive HIV/AIDS test result? Intervening conditions may facilitate or constrain action or interaction because they include bearings on time, culture, economic status, history, and career, to name a few (Strauss & Corbin, 1990).

Additionally, interaction strategies are processual and purposeful, goal-oriented and reflexive. In other words, strategies and tactics are used to manage or respond to a phenomenon (Strauss & Corbin, 1990). The first and overarching research question (How do healthcare practitioners communicate a positive HIV/AIDS status to patients?) aimed to unveil and explore these strategies. Revealing healthcare practitioners' purposeful, goal-oriented tactics and how they have or can manage the variables of causal



conditions, phenomenon, context, and intervening conditions answered the first research question.

The final element mentioned by Strauss and Corbin (1990) within this paradigm model is consequences. The fourth research question posed the following: What were the healthcare practitioners' perceptions of the consequences of delivery of a positive HIV/AIDS test result? Consequences are the outcomes of the action or interaction which could be perceived as positive or negative and may not always be anticipated (Strauss & Corbin 1990).

The researcher anticipated that the data gathered and analyzed through open, axial, and selective coding would lend to the credence to the generated theory. At this juncture, the researcher anticipated discovering best practices for disclosing a positive HIV/AIDS status. The results and conclusion elaborate on these findings.

#### CHAPTER IV

## **RESULTS**

This study examined healthcare providers' reports of delivering a positive HIV/AIDS test result to patients. Seven health care providers (three doctors, three family nurse practitioners (FNP), and one mid-wife) participated in this study. The specific accounts of the healthcare practitioners will be noted by HCP followed by a number (HCP1, HCP2, HCP3, HCP4, HCP5, HCP6, and HCP7). Following the primary data analysis coding process for grounded theory, data within this study indicated that the primary phenomenon is interaction management within the disclosure of a positive HIV/AIDS test result. The first research question asked the following: How do healthcare practitioners communicate a positive HIV/AIDS test result to patients? Simply stated, healthcare practitioners try to manage the interaction strategically. The interaction is in a constant flux and is primarily facilitated by the healthcare practitioner. However, patients are not completely passive recipients of the bad news. They too provide guidance in managing the disclosure interaction.

Patients actively make immediate and permanent decisions about the future disclosure of their status to their families, friends, and communities. Patients consider the harm status disclosure will do to their outward identities by weighing the risks and making judgments to protect their identities rather than to protect the health of those with whom they are or have been sexually involved. Although healthcare practitioners use strategies to manage the interaction, it is important to understand that contextual factors within and outside the immediate healthcare practitioner and patient interaction exist. Further, intervening conditions, which will be explained later, impede the interaction and



often determine the outcomes and strategy that will be used due to their competing interests.

# Strategies

Because patients are making important decisions during the initial interaction of communicating a positive HIV/AIDS test result, successful management of the interaction is extremely important. An extensive interaction is needed to maximize the successful interactive effects or consequences. The emergent themes for strategies presented within this study are strategic interactive facilitation and strategic interactive force. An interactive force and interactive facilitation are ever present, and both change the dynamics of overall disclosure effectiveness.

Interactive Force: Open the Bag of Worms

Interactive force actively seeks information that will enable interactive facilitation yet leads to information giving. Healthcare practitioners insist on responses from patients when asking questions. Thus, the main property of interactive force is information-seeking. Information-seeking is a strategy used by the healthcare practitioner and a counter strategy used by the patient to cope with the news. Healthcare practitioners primarily use information-seeking in order to make informed choices to provide the best care for their patients. Healthcare practitioners seek personal information about the patient. HCP2 recalled an extraordinary review system:

Now we are getting real personal, we are getting very personal with people, that, we've never done before. Nobody has ever come to you and talked to you about their sexual preference, nobody has ever talked to you about if you liked men or women. Do you do it this way, or that way, or what hole do you prefer? . . . So, it



takes you a minute to learn, to look a person in the eye and say okay. You ask them straight up. Are you having multiple sex partners? Same sex partners? That's gonna open up a whole new bag of worms. You have to be point blank.

It's going to be important that I know that so that I can do the things I need to do.

This system allowed for candid conversations and the building of trusting relationships with patients.

No other healthcare practitioner that participated in this study mentioned this review system for asking the patient about his or her sexual history and orientation, especially in such detail. In fact, HCP3 and HCP4 confessed to being extremely uncomfortable with questions pertaining to sex and did not ask their patients about their sexual history or any other sex-related question. Although most HCPs interviewed were primary care providers, HCP2 recognized the significance of asking such candid questions to better care for and treat the patient. In male-to-male sexual contact, HCP2 expounded on the importance of knowing if the person was the "receiver" because the receiver is more prone to contracting other diseases or infections. Additionally, HCP5 did ask "homosexual" patients about their sexual history because "homosexuals are more susceptible to anal and rectal cancer." HCP2 said:

You learn over the years, as you mature. . . . If I don't open the bag of worms for you, the bag of worms will not be opened. Cause people will dance around it until they've put their foot in the grave almost and then come running for help.

Physical space is also used as a co-strategy within information-seeking. For example, HCP7 purposely delivered the news in her office where there was a couch for seating. In general, the news is delivered in the examination room. The change of the



physical space was done to help patients become more comfortable with sharing and receiving information.

On the other hand, patients seek information too. Patients want to know if the healthcare practitioners can help them pinpoint their exposure to HIV/AIDS. Also, patients want to have an idea of the trajectory of their lives after diagnosis. HCP6 said:

Some ask if they are going to die. When they are going to die? Where did it come from? Who gave it to them? How long have they had it? Many of those questions, I can't answer. . . . I can't tell them how long they have had it, who they got it from.

HCP5 talked about inquiries from patients after hearing the news, "People always want to know if they are able to have children. . . . They always want to know. It's like the first thing that a woman asks, can I have children, you know. The answer to that is yes."

Interactive force is only a fraction of the phenomenon of how healthcare practitioners communicate a positive HIV/AIDS test result to patients. Additionally, healthcare practitioners seek to increase efforts with facilitation. Because of the intricate dynamics needed to handle this phenomenon, both strategic interactive force and strategic interactive facilitation are necessary. Both occur unevenly depending on the patient's individual needs and on the patient's disclosure. Yet, only, interactive facilitation serves as a strategy to care for the patient and to relieve the healthcare practitioner's uneasiness. *Interactive Facilitation: Survival* 

Interactive facilitation guides the communication. Interactive facilitation also helps healthcare practitioners cope with and survive this interface as they attempt to help patients do the same. Within the theme, strategic interactive facilitation, several



categories emerged: information giving, conferring with the patient, monitoring patient reaction and response, and relationship development and sustenance.

Information-giving. Information-giving includes educational aspects of the infection and disease and treatment. Patients were educated about different medical terminology. Concern for educating patients about the epidemiology of HIV/AIDS was high for the HCPs interviewed. HCP1 explained, "What I like to do, if the test is positive, is give them information about epidemiology, what is likely going to happen." HCP2 said, "It strips the defense mechanism of the body off, and so you're susceptible to getting those diseases that were rare diseases." HCP4 also thinks educating the patient is very important. Yet, HCP4 did not provide education to her patient because the patient said he was familiar with HIV/AIDS since a family member was positive as well. However, because the patient was interested in becoming educated about qualifying for Medicaid and Medicare, HCP4 referred the patient to the clinic's social worker for help. HCP5 tells patients about the facts, specifically about T cell counts dropping within the range of 200-250. HCP6 explained, "The disclosure of a positive HIV/AIDS result should be used as a teaching moment."

Additionally, HCP2 warned patients of the likelihood of contracting HIV/AIDS especially if a patient was treated for other sexually transmitted diseases or infections:

Now let me go over this again with you. Gonorrhea and syphilis, they ride together, they ride together. But guess who is also riding with 'em? Chlamydia and HIV. They're all riding together, so if you make yourself susceptible to getting gonorrhea every six months you are putting yourself at risk of getting HIV also.



In other words, a patient who contracts one sexually-transmitted disease (STD) is at risk of contracting other STDs as well.

All healthcare practitioners expressed hope to patients primarily by letting them know that treatment for HIV/AIDS is available. Healthcare practitioners communicated that HIV/AIDS is now viewed as a chronic disease due to its treatable, yet currently, incurable status and insisted on keeping the hope alive. HCP6 said:

If treated, we now consider AIDS a chronic disease like tuberculosis, diabetics, or rheumatoid arthritis or high blood pressure. If the individual chooses to take their medication and use good health practice then they can live or expect to live a basically normal life and a normal life span.

## HCP1 added:

Then it was a death sentence but because of 20 years of research, people with HIV are living 25 years if they take care of themselves . . . if you are treated.

## HCP7 recalled an interaction:

So, now look at me look at my life. What am I going to do? . . . I let them know that they are not in a death sentence at this time. That there is medicine available for them to help the mom and baby.

# HCP5 recalled telling patients the following:

Treatment options are available . . . triple therapy once a day, one pill or single pill of two medications.

Healthcare practitioners provide patients with relevant information about HIV/AIDS. In providing this relevant information, healthcare practitioners present hope and intervention as solutions to the current state of HIV/AIDS because there is no cure.



After receiving this information, patients can make informed decisions concerning treatment. Patients can also make decisions to protect themselves and prevent their partner(s) from contracting HIV/AIDS.

Monitoring patient reaction and response. Patients are given an opportunity to respond to the diagnosis. Listening to patient responses and gauging understanding from their responses allow the healthcare practitioner to reiterate certain attempts, if and when needed. All seven healthcare providers recognized a combination of drastic changes in their patients' communication during the interaction of delivering this news. Patients experienced shock and exhibited fainting and turning colors. Patients also displayed grief and stress by showing symptoms of anxiety, worrying, and franticness. For example, HCP3 recalled "sweat popping off his face. He got up and ran to the sink and started splashing water on his face."

Another provider (HCP7) stated that the patient did not know her partner had HIV and recalls the patient saying, "If I had known, I never would've slept with him." Other patient reactions included crying, denial, angry feelings towards partner, frustration, and blaming. Three providers (HCP2, HCP5, and HCP6) recalled patients saying, "You don't know what you are talking about." Healthcare providers also recalled occasional reactions of resolve, reconciliation, suspense, and eagerness by patients who were aware of the likelihood of a positive HIV status as a result of the individual's high-risk exposure. When monitoring patient response, HCP4 said her patient made the interaction more comfortable for her because "it seemed as if he kind of knew." Also, the recorded notes documented from previous visits indicated that the patient had received a false negative result before, which indicates that the patient likely anticipated the result due to



possible risky behavior and HIV/AIDS exposure. After hearing the news of the positive status, the patient did not express immediate signs of depression. Yet, there was an air of sadness, but acceptance of the news, according to HCP4.

In addition to education, treatment, prevention, and intervention efforts of the infection and disease itself, HCP7 quizzes patients to make sure they have understood the attempts. HCP7 reiterated:

You question them . . . to reassure that they understand what has been said, you ask them, do you know what HIV is? Do you know what AIDS is? And you make sure that they understand by going over the test results again.

All of the healthcare practitioners await patient responses on some level. HCP7 reads her patients nonverbal communication such as the eyes and body language to gauge acceptance of the test result. These patients likely sought treatment and wanted to know their options. For example, HCP4 recalled one patient wanted to know if he qualified for Medicaid, Medicare, and disability.

By monitoring patient reaction and response, healthcare practitioners can have an idea of how well the patient understands the diagnosis and the likelihood of the patient following up. Moreover, healthcare practitioners can route patients to other resourceful avenues such as counseling and financial assistance. What patients say verbally and nonverbally within the interaction is of utmost importance for providing care to the patient in this interaction and afterwards. The interaction of communicating a positive HIV/AIDS test result can lead to relationship development and sustenance.

Relationship development and relationship sustenance. HCP2 recognized nonverbal communication and relational dimensions such as patience, confidentiality,



trust, and comforting as key elements for patient care and the best outcome for patient compliance. HCP2 is a male medical doctor specializing in primary care with over 39 years of experience. He disclosed a positive HIV/AIDS test result to over 25 patients. He does not wear the traditional white coat anymore. He sits closer to patients when interacting and adjusts seating position lower than that of the patient. All of these factors contribute to the development of trust and the establishment of credibility for HCP2.

Additionally, HCP2 provides scenarios and examples for understanding. Unlike any other HCP interviewed, he used fear appeals and humor as strategies or tactics to get his patients to comply. HCP2 used the following examples from interactions with his patients. In his first example, he said:

You know there are some people everybody knows what they are doing, right? And you can always say, you know Joe Blow? You see what happened to Joe Blow don't you? You can be just like this."

The second example he said,

I got a friend in town who will take care of you . . . He's an undertaker.

The use of fear appeals and humor are mostly used with patients that HCP2 felt a relationship existed. According to HCP2, one patient responded:

Awe man, you sure are cold blooded. I say naw, you're the one that's cold blooded. Look at your behavior. I say look at your behavior. Why do you keep going back to this same situation?

HCP2 has found "that the more point blank you are, the more impressive you are about getting a person to change their risky behavior." He also used concepts of identification or shared sense of closeness and said to patients:



Now all of us have been guilty. All of us have been guilty of being out there, being wide open. Then you pull your reigns in and say, no, I can't live like that no more. Because that is just the ole Russian Roulette thing that you're doing.

HCP2 was very concerned with preventing the positively diagnosed patient from spreading HIV/AIDS to their partner and used the following tactic to engage patients:

You still have to protect each other, if you don't protect each other, then you are not true lovers. You don't want your lover to get sick from something you caught on an error. Am I right?

This tactic is used for all of HCP2's patients as he recognized the complexity of relationships as male-to-male, female-to-female, and male-to-female where one partner is HIV/AIDS positive.

HCP2, HCP5, HCP6, and HCP7 acknowledged the importance of assessing family involvement and found that the more support a positively diagnosed patient has, the more likely the patient will remain in compliance. But for those who do not have a good support system, the doctor should be proactive and take charge, according to HCP2, HCP3, and HCP4. For example, HCP2 said,

If you act like you could care less, that is how you lose some people, and then you when you really worry about somebody. You pick the phone up, and you chase them down yourself.

Finally, HCP2 highlighted the importance of differentiating communication based on variables of age, sex, race, background, education, and sexuality. HCP2 said:

You improve on what you already actually know in medicine. These subjects are discussed, and people are being taught even more so on how to communicate with



folks. The last thing that we do in this society is teach people how to communicate with people. You can't talk to everybody the same way. You know, whether it's racial or whether it has to do with education level. Everybody can't be talked to the same way, and people have to be more patient and tolerant of people's short comings. Once you do that, then people are not afraid to communicate with you.

Developing and maintaining doctor-patient relationships within the HIV/AIDS interaction can be very challenging when other factors are present. Because every patient and each healthcare practitioner is an individual, the same tactics may not yield the same result. Yet, the effort is needed in order to gain the trust of the patient and to increase compliance. Failure to communicate or maintain a relationship with the patient and referred source (such as HIV/AIDS specialist) does not optimize care for the patient.

Conferring and negotiating. When patients and healthcare practitioners confer, referrals are made. HCP1 believes that referrals are necessary for her patients to receive the best possible care from specialists who deal with HIV/AIDS on a regular basis. HCP1 proclaimed:

I like to refer them to a HIV clinic because outcomes are best when someone is treated at a facility that treats HIV all day long every day. . . . I send my patients where they will get the best outcome.

Generally, healthcare practitioners immediately refer patients to HIV/AIDS specialists "to determine how far the disease has progressed," said HCP7. Only one healthcare practitioner (HCP6) did not refer all of his patients to other healthcare specialists. He provided HIV/AIDS treatment to patients but made referrals as needed (to



an infectious disease specialist, for example). HCP3's patient was referred to a social worker. This referral was not for counseling but for financial assistance. Financial assistance included getting funding for prescriptions for the treatment of HIV.

Referral to HIV/AIDS specialists, as HCP3 said, "is like a needle in the haystack. There are only two places I'm aware of." This comment highlights that HIV/AIDS specialists and clinics may be difficult to find or nonexistent in areas, which impedes the access of care and adds to the burden of having HIV/AIDS. Despite HCP3's recognition of the need for more HIV/AIDS specialists in the area, she has no intention of providing HIV/AIDS treatment.

No generated response or procedure existed to assure that patients went to the referred source. After referrals are made, HCPs in this study indicated that no follow-up procedure is present. Generally, healthcare practitioners do not know if the patient went to the referred source unless the patient follows up at a later date. However, HCP3 contacted the patient after the initial communication of the result because she was worried about her patient's welfare as a college student on a college campus. She feared that he would become depressed and not seek treatment.

HCP4 personally contacted the patient to find out if her patient visited the referred source. The patient did comply after negotiation of a preferred outsourced HIV/AIDS specialist. HCP4 acknowledged preferences for patients who receive HIV/AIDS referrals:

What I've learned is patients like to go away from where they are from instead of going to the HIV clinic that's closest to them.



Negotiation and conferring take place within the initial interaction of communication and sometimes after the initial interaction when healthcare practitioners make contact with the patients. The primary reason for patient negotiation is that patients want to go farther away from their home to avoid the likelihood of coming in contact with someone from their community. This avoidance signifies an HIV/AIDS identity evasion, at least in the presence of friends, family, and community.

#### Context

Research question two asked: What contextual factors are associated with the delivery of a positive HIV/AIDS test result? The interaction of delivering a positive HIV/AIDS test result to patients activates contextual factors for the patient or the healthcare practitioner or both. HCPs recalled having feelings ranging from nervousness, stress, calmness, shock, reluctance, to hope at different stages. The HCPs are reluctant and dread having to tell someone that he or she has an incurable stigmatized disease or infection. Three (HCP1, HCP3, and HCP4) of the seven HCPs recalled being more nervous than the patient and referenced themselves as being "freaked out."

# Calmness

The sense of calmness experienced by the practitioners was a result of the patient's composure. Patients who were aware of their risky behavior were also aware of the consequences and strong possibility of a positive test result. HCPs' shock was onset when the results came back positive. HCP3 said, "You do HIV testing, but you never anticipate it being positive."

Reluctance



HCP5 believes the experience of delivering a positive HIV/AIDS test result is similar to delivering any bad news to a patient. "There is reluctance," said HCP5.

Additionally, four HCPs felt the need to calm and comfort patients by hugging (HCP1, HCP3, HCP7) and crying (HCP1, HCP3, HCP7) with the patients.

Comfort

Seating arrangements were changed to help calm and comfort patients for HCP2 and HCP7. HCP2 recognized seating arrangements as a way to provide comfort as well as a way to remove potential communication barriers. HCP7 explained:

I try to be very laid back as I can. I say, let's sit back, relax, and go over all of your test results. I come from around my desk and sit next to the patient.

HCP7 emphasized the need for healthcare practitioners to sit at lower levels than the patient while HCP2 put emphasis on sitting next to the patient.

Hope

Five HCPs (1, 2, 5, 6, and 7) felt a sense of hope, acknowledging the modification of the state of HIV/AIDS from a death sentence to a chronic disease. HCP1 said:

When the first cases of HIV were diagnosed, I was an internal medicine resident So, I was in training. The first case was hospitalized multiple times during my residency. We only had one case. . . . so we knew a lot about him. But of course you know, he died quickly because we had no drugs to treat him.

Three of the five who felt hope recalled experiences of delivering the news to patients during the early years of HIV/AIDS onset. The HCPs recalled the dread and sense of helplessness that they experienced because little to no means of treatment existed that could be provided to patients.



# **Intervening Conditions**

Contextual factors of calmness, reluctance, comfort, and hope within disclosure gave precedence to intervening conditions. An intervening condition is anything that plays a part in the delivery of the news. Intervening conditions can facilitate or constrain the interaction. The third research question asks the following: What intervening conditions exist concurrent to the healthcare practitioner delivery of a positive HIV/AIDS test result?

Having HIV/AIDS, a chronic communicable disease, changes the identity of a person diagnosed significantly because of the stigma a newly diagnosed patient has to consider as compared to other chronic infections. HIV/AIDS-related stigma has been maintained in the social dynamics of everyday life, including, but not limited to, healthcare clinics and facilities, schools, businesses, and the general public. Therefore, stigma awareness is the major intervening condition for both the patient and healthcare practitioner.

Stigma awareness occurred early in healthcare clinics and facilities for healthcare practitioners who practiced medicine during the beginning of the HIV/AIDS pandemic. HCP1 recalled experiences during an internship at an emergency room of watching patients die from HIV/AIDS. This experience also brought to light HIV/AIDS-related stigma and treatment of persons with HIV/AIDS in healthcare. HCP1 recalled the following:

Construction worker . . . regular old redneck guy. Knowing he had it was very hard for him. . . . It was hard watching him die. . . . Oh, my God they were treated like lepers.



HCP5 acknowledged that stigma is not just a past issue; it remains a part of the healthcare environment among workers. He expressed his disgust about nurses who did not want to be in contact with a patient who had HIV.

HIV/AIDS stigma awareness causes discomforting conditions and has lasting effects. HCP3 recalled having sleepless nights afterwards and proclaimed, "It was actually the hardest thing I've ever had to do." HCP4 repeatedly admitted to being extremely nervous when disclosing a positive status to her patient. She compared her nervousness to that of the patient and concluded that she was more nervous than the patient. Her perceived high level of nervousness made the interaction very awkward.

Stigma awareness is the major intervening condition in this study because its impact on disclosure is dual. The awareness can thwart feedback obtained from interactive force and becomes a situated context in the interaction. In other words, the knowledge of stigma frames disclosure and causes reactions that need to be strategically handled.

Inaction may lead to major consequences, but due to other properties of stigma as context and an intervening condition, these effects are inseparable and not easily recognized. Identity crisis, sexual orientation, marital status, and the down-low culture are properties of the intervening condition of stigma present for the patient. The beginnings of this interaction have been found to be straightforward in a face-to-face encounter.

All healthcare practitioners interviewed believed that their communication of the result was simple. The term straightforward was used most, followed by terms or phrases such as straight up, go for it, and just tell them. Although the healthcare practitioners



considered their communication of this status as uncomplicated, they often mentioned the positive HIV/AIDS result in conjunction with the results from other tests performed. Instead of just giving the HIV/AIDS test result when the interaction with the HCP and the patient started, the HCPs communicated a deliberate attempt to offset the interaction by giving the results of other tests first. Healthcare practitioners communicated the result face-to-face. HCP5 emphasized, "This is not something you should do over the phone." HCP3 recalled having the nurse contact the patient over the phone to return to the clinic to receive the test result. HCP3 knew the patient personally and did not want to take the chance of disclosing the result over the phone.

# Identity Crisis

First, an identity crisis occurs immediately after a healthcare practitioner tells the patient that the HIV/AIDS test result is positive. HCP7 recalled a patient frantically saying,

I really didn't want to have sex with him but he said I was going to do it. I didn't know that he had AIDS, if I had known, I never would have had sex with him. So now look at me, look at my life. What am I going to do?

According to HCP7, another patient expressed denial and exclaimed, "You don't know what you are talking about." They also exhibit shock. Patients display the beginnings of their identity crisis by denying, blaming, and avoiding, which are also conditions that intervene with strategies used to manage the interaction.

Second, a patient's sexual orientation is significant because of HIV/AIDS' historical and stigmatized association with "gay men." If someone is homosexual or bisexual, he or she may already have expectations of rejection, especially the male due to



negative attitudes toward same gender orientation. HCP5 recalled, "One patient never wanted his family to know that he was homosexual and had HIV. He died of *pneumonia*." Further, some of these males reject or hide their sexual orientation prior to receiving a positive HIV/AIDS status.

Third, rejecting and hiding sexual orientation affects the identity of a patient who is diagnosed as HIV/AIDS positive. HCP5 referred to another case where he had a patient in ICU with an AIDS defining illness. The patient confided that he had a boyfriend in addition to his wife. He did not want his family to know his illness. HCP5 pronounced:

I can't tell him to tell the wife and children anything. If they ask what's wrong with him. He has pneumonia. That's not lying. But why? He wanted his family, for him to die, he wanted his family to never find out that he was homosexual and that he had HIV. And that is exactly how that went because he told us that when he was conscious.

Having a secret sex life directly impacts healthcare practitioner strategies and recognizes the impact of stigma. Some patients opted to die without disclosing their status to their spouses.

Fourth, HCP1 exclaimed, the *down-low* culture has contributed to the change in HIV/AIDS cases. Down-low culture refers to the practice of males who are married to females, or are in a relationship with females, engaging in secret sexual activity with males but do not consider themselves to be bisexual. What solidifies down-low as a culture is the shared set of behavior and practices. Women are not considered as down-low if the circumstances reversed.



# Consequences

Disclosure of a positive HIV/AIDS status has consequences. In other words, there are outcomes associated with delivery, whether positive or negative, intended or unintended. The fourth research question asks the following question: What are the consequences of the healthcare practitioner delivery of a positive HIV/AIDS test result? Consequences have been noted in patient response and communication change and the follow-up rate. Also, healthcare practitioners specifically recognized consequences related to experience or lack of experience on their part and an unawareness of a protocol for delivery.

# Follow-up Rate

Of the seven healthcare practitioners interviewed, only one (HCP7) had a 100% return rate; whereas, HCP6 said 80 - 90% of patients returned after being diagnosed. HCP3 and HCP4's patients did not return. However, because they knew the patient personally, either the patient or the HCP personally made contact with one another and inquired about compliance with the HIV/AIDS specialist. Patients diagnosed by HCP1 did not return. HCP5 did not recall the return of most patients diagnosed outside of the HIV unit, but did recall that few patients returned for health concerns other than HIV/AIDS. Lastly, HCP2 said some patients did not return, and those who did return were based on communication and relationship factors. HCP2 told patients:

I need to see you back in three weeks. Don't make me come looking for you.

When you establish that type of relationship people come back. . . . You pick the phone up and you chase them down yourself. You don't let it be dependent on that person's memory.



The results indicate a range of issues occurring within the initial interaction of disclosing a positive HIV/AIDS status. A primary concern is the need to create and foster doctor-patient relationships from the start. Maintaining the relationship increases return rates and compliance.

# Experience and Protocol

The healthcare practitioners interviewed have been practicing medicine from two to 39 years in their chosen specialty for practice. They have received training or practiced medicine in Alabama, California, Georgia, Massachusetts, Michigan, Mississippi, New Jersey, Tennessee, and the Bahamas. The results indicated that the length of time practicing medicine did have some bearing on the doctor-patient or healthcare practitioner-patient interaction.

Experience builds more confidence for HCPs. HCP1 has been practicing medicine for more than 25 years, HCP2 for more than 39 years, HCP3 for two years, HCP4 for three years, HCP5 for eight years, HCP6 for more than 30 years, and HCP7 for more than 30 years. HCP1, HCP4, and HCP7 believe that interactions get better. Yet, they asserted that communicating a positive HIV/AIDS test result is difficult now and believe that it will be in future interactions, while the remaining 4 HCPs believe that the interaction gets or will get better with experience.

Combined, the HCPs in this study delivered the news of a positive HIV/AIDS test result to over 80 patients. Generally, the longer HCPs practiced, the more patients the news was delivered to. In other words, an increase in experience increases the likelihood of having to disclose a positive HIV/AIDS status to patients.



Because, at the time, HCP3 had never delivered a positive HIV/AIDS test result, she asked for assistance from another "more experienced" healthcare provider in the clinic: "When I saw the lab results, I just freaked out. I wasn't really sure of what the protocol was in the clinic of how we deliver abnormal results." HCP3 communicated a positive HIV test result to one patient. She said, "It was really tough because I didn't even know what to do." HCP3 recalled that the more experienced assisting physician educated the patient by talking about T-cell counts. HCP3 indicated that she did not think the patient understood the education that was provided by the assisting physician. Further, the patient's educational level was not known by the assisting physician. However, HCP3 did know that the patient had some college education because the patient was known personally. Yet, HCP3 retrospectively revealed, "I don't think that he understood the educational aspect of the interaction."

HCP3 wished that a protocol for delivery of HIV/AIDS test results existed. She proclaimed that disclosing the result was the hardest thing she ever had to do; she also had sleepless nights. Her lack of experience and training in this area impeded the interaction. Yet, she believed that this experience would have a positive effect on future delivery of positive HIV/AIDS test results (although she hopes not to ever have to deliver this unfortunate result again). HCP3 stated that "having the first experience with someone known personally set the stage for treating everyone with the same sense of warmth and encouragement because it's nothing like when it hits home." None of the HCPs interviewed were aware of a protocol for delivering a positive HIV/AIDS test result. Thus, they had no tool specifically designed to help facilitate delivering this news. HCP4 looked forward to a protocol for delivery, "I wish there was a protocol and a



follow up procedure," said HCP4. Although HCP4 provides HIV/AIDS treatment to patients who were diagnosed by other healthcare providers, she did not feel she would ever be comfortable with delivering a positive test result saying: "It's not an easy thing to do. It doesn't matter how many times I would have to deliver this news, I don't think I will ever be comfortable with the situation."

HCP4 believes that the awkwardness and nervousness of the interaction caused her to make an unjustified assumption; she assumed her patient was gay. Additionally, she failed to mention prevention at all. However, the patient later confirmed her suspicion. HCP4 did not know if her patient only engaged in male-to-male sexual contact. "I didn't ask him if he was bisexual," said HCP4. Nevertheless, the patient told her he thinks that he contracted HIV from another male. Making assumptions and not asking questions that directly impact potential care and treatment for a patient can diminish the chances of optimal care. HCP4 was obviously uncomfortable with talking about sex and sexual orientation. She felt that a protocol would help guide the interaction and make sure that she had done everything in her power to provide the patient with the best care.

HCP5 discussed prevention when the diagnosed patient was married to a female but participated in sexual activity with males. Having a secret sex life directly affected prevention and disclosure efforts for HCP5 because patients do not want to tell their partner about their other life. Some male patients opted to die without disclosing their status to their wives.

HCP5 provided HIV/AIDS treatment to patients and contributes his comfort in dealing with HIV/AIDS to his experience. Yet, he recognized that not all people share



the same comfort, noting that some people in the profession are still afraid. He was furious because "the nurses in the hospital didn't want to go in the room. It's ridiculous."

HCP6 told people that he knew before the interaction and believed that the prior relationship helped with the comfort level, support, and compliance of the patient. HCP6 said:

One person that I knew personally, I have known her for my goodness, probably 20 to 25 years. I know her whole family. . . . In fact, that was more positive because they knew me and I knew them. They had the belief and confidence that I would treat them accordingly . . . if it was AIDS or high blood pressure or diabetes or cancer even.

HCP6 found that a support system is helpful for his patients. Patients with a support system are more likely to keep appointments and optimize health outcomes. He saw patients every three to six months and boasted about a follow-up rate of 80% to 90%.

The examination of healthcare practitioner communication of a positive HIV/AIDS test result revealed management strategies (interactive force and interactive facilitation) used by healthcare practitioners. These tactics help deal with contextual factors and intervening conditions that impede the interaction. Consequences of management positively and negatively affected both the patient and the provider. These effects range from patient compliance to relationship development. Additionally, healthcare practitioner experience, confidence, and unawareness of a protocol for delivery significantly impacted the interaction.



#### CHAPTER V

## CONCLUSIONS AND IMPLICATIONS

The results highlight the importance of exploring the initial communication of a positive HIV/AIDS test result. Further, they lend credence to the need for a protocol and for best practices for delivering a positive HIV/AIDS status to patients. Results continue to show that a protocol would give healthcare practitioners the sense of reassurance for the task before them while decreasing inconsistencies between provider disclosures. For example, only two doctors used strategic interactive force involving learning more about patients' sexual history and orientation. If healthcare providers are exposed to and use best practices within the protocol, more attention can be given to HIV/AIDS stigma.

The healthcare practitioners in this study, as a whole, experienced fear and reluctance when delivering the news of a positive HIV/AIDS status to patients because they were aware of HIV-related stigma and knew the patient would likely experience stigmatization as a result of this life-changing diagnosis. Goffman (1963) considered the framework of stigma as the public's attitude toward a person who has an attribute that is unfavorable according to societal expectations. Some of the healthcare practitioners in this study recalled instances where the patient who had just received a positive HIV/AIDS test result chose not to have his or her condition exposed (even unto death). The patients attempted to avoid being viewed as someone other than the person already known to family members, friends, and others. Avoidance was evident in that most patients informed the healthcare provider that he or she would not be disclosing his or her status to anyone. This behavior was especially true in instances where a married male engaged in secret sexual activity with someone other than his wife, especially when the



sex partner was another male. In this case, informing the wife would blemish the individual's character, exposing his dishonesty. The newly diagnosed patient may also fear judgment and rejection for living a secret life as a bisexual man. The intrusiveness of stigma as context and an intervening condition also make prevention and intervention efforts difficult to manage in this instance. Viewing stigma as both contextual and conditional allows the following conclusion: HIV/AIDS diagnosis damages a person's identity and causes one to become an outcast from personal relations and community. This exclusion may only be in the mind of the patient, but it may also be actual. Clearly, strategies for managing potential stigmatization are needed. Yet, in the initial interaction of disclosing a positive HIV/AIDS test result, an action or strategy solely for managing stigma did not exist.

Applying the Extended Parallel Process Model (Witte et al., 2001), healthcare practitioners would recognize the demonstrated behavior as fear control. The individual is attending to the fear by avoiding the disclosure of the status to others. Attending to fear by way of avoiding disclosure is troublesome when the avoidance is directed toward sexual partners who do not have HIV/AIDS. For example, one healthcare practitioner recalled a patient whose condition worsened. The patient's perception of the threat was obviously heightened because the patient sought hospital admission. The patient at this point was attending to the threat, thus enacting danger control. Yet, the patient's spouse was not aware of his HIV positive status. In other words, although the patient exercised danger control as it related to the direct threat of his health, the patient continued to exercise fear control as it related to the health of his spouse by failing to inform her of the likelihood of her HIV/AIDS status. Because EPPM assumes that individuals are either

exercising fear control or danger control but not both at the same time, HIV/AIDS extends this theory. When individuals are faced with health related issues of HIV/AIDS, individuals exemplify fear control and danger control simultaneously. The individuals attend to the health threat and their fear because both are salient for the individuals at that moment.

Healthcare practitioners recalled that most of the newly diagnosed patients contracted HIV/AIDS from sexual contact. Because sexual contact was the primary means of transmission, individuals may fear negative evaluation from others within the community because contracting HIV/AIDS could have been prevented. Yet, healthcare practitioners recalled patients blaming others for contracting HIV/AIDS. Blaming behavior exhibited by patients could be an effort to protect their identity with the healthcare practitioner who has delivered the news. An instance recalled by one healthcare practitioner of this study indicates that some healthcare practitioners stigmatize patients with HIV/AIDS. Healthcare practitioner disclosure interactions should seek to minimize stigmatization in the healthcare setting as well.

Even though newly diagnosed individuals try to avoid the social burden of HIV-related stigmatization when deciding not to disclose their status to others, they are still aware of the stigma. This awareness, whether the status is disclosed or not, is something that the individual will have to live with. Healthcare practitioners recalled their patients' reactions to this identity change. Patients displayed distress, nervousness, calmness, and shock. Most healthcare practitioners recognized a need for identity crisis intervention such as counseling; yet, counseling was not available for all patients. When someone's identity is challenged they may experience negative emotions and reactions. Potential



consequences of not having counseling can be severe (patients may not undergo treatment, may consider suicide, etc.). Thus, patients need to be connected with counselors.

This acknowledgment further highlight Freimuth et al.'s (2000) view that in the absence of a cure, communication theories and techniques need to be applied. At the time of delivering the bad news of a positive HIV/AIDS test result, nothing can be done to eradicate the status. The patient has to live with the results. The lack of a cure reinforces the importance of doctor-patient communication and relationship development. Thus, an important way to save lives and reduce suffering is by creating, implementing, and sharing communication techniques that will promote enduring doctor-patient relationships.

The first research question asked: How do healthcare practitioners communicate a positive HIV/AIDS test result? Healthcare practitioners communicate a positive HIV/AIDS test result by attempting to manage the interaction. The prevalent themes regarding communicating the result included strategic forced interaction and strategic interaction facilitation. During the disclosure of a positive HIV/AIDS test result to patients when healthcare practitioners experience disclosure apprehension, healthcare practitioners use interaction facilitation that leads to a greater likelihood of a decrease in anxiety for the healthcare practitioner. Healthcare practitioners allow patients opportunities to respond to the news. In turn, a reduction in anxiety may occur because the HCP has communicated the result, and the patient's response may reduce the immediate stress level of the HCP. Strategic forced interaction primarily includes asking questions about the patient's sexual history and orientation. Strategic interactive



facilitation involves information giving, conferring, and negotiating with the patient, monitoring patient reaction and response, and developing and sustaining healthcare practitioner-patient relationships. Both strategies combined help maximize doctor-patient or healthcare practitioner-patient relationship and management of the interaction of communicating a positive HIV/AIDS test result.

Some of the interactions recalled by the healthcare practitioners did not include all elements of the strategies; those that did not can be considered incomplete interactions. As mentioned earlier, an incomplete interaction would be communication that fails to use messages that will direct the patient and emphasize the critical elements of prevention, intervention, and treatment of HIV/AIDS. Communication strategies used by healthcare practitioners should mirror the goals of the National HIV/AIDS Strategy (reduce HIV incidence, increase access to care, optimize health outcomes, and reduce HIV-related health disparities).

A need exists to focus on the initial communication of a positive HIV/AIDS status to patients to better serve the patients. The context surrounding delivery must be understood. The second research question asked: What contextual factors are associated with the delivery of a positive HIV/AIDS test result? A range of feelings and emotions experienced by the patient and the healthcare practitioner surrounded the delivery of a positive test result. Yet, healthcare practitioners' feelings were evoked by fear of having to deliver this bad news, as well as reactions to their patients' feelings. This fear can be contributed primarily to the lack of a cure. Because no cure exists, the patient faces viewing himself or herself as a person with an incurable, stigmatized disease. During the disclosure of a positive HIV/AIDS test result when patients display fear, healthcare



practitioners could use strategic forced interaction. Disclosure of sexual history helps the healthcare practitioner find ways to best treat the patient, which then leads to strategic interaction facilitation where the patient can receive more personal guidance.

The results indicated that the experience of communicating the HIV/AIDS positive status occurred early in residence training for four out of the seven HCPs interviewed. The third research question was concerned with identifying the intervening conditions surrounding healthcare practitioner delivery of a positive HIV/AIDS test result; the following renders a response. The thought of HIV/AIDS disclosure never occurred to the other three healthcare practitioners until faced with the task. This acknowledgement emphasizes that educational courses in medical school should be implemented to prepare medical students for communicating a positive HIV/AIDS test result to patients before residence training. Because medical school had not specifically prepared the HCPs for communicating a positive HIV/AIDS status to patients, unpreparedness remained an intervening condition of delivery. In turn, preparation in medical school for communicating a positive HIVS/AIDS status to patients would enhance the delivery of a HIV/AIDS status, rather than disjointedly impede the interaction. For example, two newer HCPs only delivered the news to one patient but had not received any education on communicating the result. Their first and only experience left them feeling unsure about their communication skills. They also contemplated how they should have been more prepared for the initial interaction.

Intervening conditions that negatively interfere with healthcare practitioner strategies when delivering a positive HIV/AIDS test result to the patient as indicated within the results of this study are stigma, identity crisis, sexual orientation, marital



status, and culture. Healthcare practitioners tried to manage these intervening conditions. During the disclosure of a positive HIV/AIDS test result, when patients perceive a threat to their identity, healthcare practitioners try to control their psychological fear by way of strategic interaction facilitation, which leads to an increased likelihood of follow-up. For example, one HCP suggested that the patient bring his spouse to the next appointment. While another HCP tried to help a patient avoid an identity crisis by trying to get the patient to understand that contracting HIV/AIDS is possible for anyone who engages in sexual activity. Yet, these negative intervening conditions were difficult or unmanageable for some HCPs.

Because of the impact of the circumstances, the patient should be surrounded with supportive others when the bad news is disclosed. Counseling should be implemented to help minimize fear, to manage identity crisis, and to direct the patient to help achieve overall outcomes. Fear is inevitable primarily because the absence of a cure leads to premature death. HCPs and their patients want to be assured at every phase in the initial and follow-up interactions that everything within power is being done to keep the patient in an overall healthy state (physical, mental, and emotional being). In turn, healthcare practitioners who deliver the result, along with counselors, should help the patient manage an identity crisis. At the same time, the redirection of thoughts, patterns, and behaviors can be addressed.

Initial interactions are extremely important because the results have shown overall consequences that potentially affect prevention, intervention, and treatment. Referrals for HIV/AIDS treatment are made, but no active protocol is followed to assure that the referral was completed. The one healthcare practitioner who did have 100% follow-up



rate diagnosed pregnant females. The successes of healthcare practitioners' follow-up rates with patients were associated with communication and relational factors. Similar to the follow-up rate, knowledge of compliance with the HIV/AIDS specialist or internist is a result of communication and relational factors.

Having candid conversations, building trusting relationships, showing concern, recognizing and changing communication based on nonverbal displays, and being aware of culture are some communication and relational factors recalled by HCPs about their interactions. HCPs felt their interactions were more successful when the aforementioned factors were present. Consequently, a communication tool is needed to help facilitate the interaction of disclosing a positive HIV/AIDS status, as well as a follow up procedure.

# Directions for Future Research

In the initial communication of a positive HIV/AIDS test result, a patient is identified. Worthy of healthcare practitioners' attention is each newly diagnosed patient. Approaches should be put into practice that will maximize communication and sustain that patient's health in the absence of a cure. In doing so, not only will healthcare practitioners meet the goals of the National HIV/AIDS Strategy but they also will have greatly contributed to establishing and manifesting a strategy.

Future research should be undertaken to continue to unveil communication best practices as well as information that will add to collective knowledge and practice, thus a protocol for delivering a positive HIV/AIDS status to patients is needed. Scholars should test the protocol and make recommendations to be adopted for different types of facilities, areas of the country, and types of specialists. The goal of best practices is to consistently show better results than what can be accomplished by other means.



The intersection of identity research and health communication appears to provide fertile ground for future study. This study suggests that issues of identity are integral to moving individuals forward and hindering them from making reasonable decisions that impact their own health as well as others. Also, the Extended Parallel Process Model should be further extended to address identity preservation in attending to fear and danger control of HIV/AIDS related interactions.

#### Limitations

The basic limitations of this study included sample concerns and research design. First, the sample included any healthcare practitioner who had delivered the news of a positive HIV/AIDS test result rather than one type of healthcare provider such as Certified Nurse Family Practitioners. On the other hand, having a variety of healthcare practitioners add to better knowledge of healthcare practitioner disclosure in general, yet, the small sample size placed limitations on understanding and generalizability. Further, some healthcare practitioners had limited experience. For example, one healthcare practitioner disclosed a positive HIV/AIDS status only to pregnant females. Second, this research study was designed to include only the healthcare practitioners. All healthcare practitioners were briefly interviewed once. Data collection relied on recollections of the healthcare practitioners. Interviews were not conducted with patients. Actual interactions were not observed. Also, the demographic areas in which participants were recruited placed limits on this study.

### Conclusion

Changes regarding reactions to receiving HIV/AIDS test results since Christine Maggiore's rebellious path are few. Patients are still denying their status and blaming



others. Most patients are choosing to keep their status a secret from family and friends. Patients continue to show signs of distress, anger, and depression. Yet, 21 years have passed since Maggiore was first diagnosed. Although researchers and experts dismissed Maggiore's views, it is important not only to recognize the feelings that led to the views, but also to find ways to counteract these feelings and behaviors by implementing communication strategies designed to achieve the positive outcomes of intervention, prevention, and treatment. Strategic intervention and interaction should begin with the healthcare practitioner who discloses the positive HIV/AIDS test result because this moment marks the onset of an identity crisis—an identity crisis that can possibly lead a patient to dissension against HIV/AIDS management.

This study explored how healthcare practitioners deliver a positive HIV/AIDS test result to patients and found that the disclosure of HIV/AIDS test results causes discomfort and strain on the healthcare provider who delivers the positive status. Healthcare practitioners in this study experienced a range of reactions such as shock, nervousness, sleeplessness, and calmness. Immediately recognizable emotional reactions of the healthcare providers in this study included crying and hugging. The use of a protocol and best practices by healthcare practitioners would maximize the interaction for both the healthcare provider and the patient. Healthcare providers would be better prepared for disclosure. A protocol would minimize HCP reluctance and nervousness. Healthcare providers would also have available communication techniques to guide the interaction. Healthcare practitioner guidance of the interaction will help to create, promote, and foster lasting relationships in order to assist in patient compliance to standards of care for treatment, prevention, and intervention. Patients will significantly



benefit from the protocol and best practices implemented by the healthcare providers. Patient care remains the core of this communication tool. Thus, the chances of all of the patient's needs being met will increase considerably. Follow-up procedures will be in place for the specialists to maintain relationships with each other to optimize patients' health. The need for a protocol and best practices for communicating a positive HIV/AIDS test result to patients cannot be overstated.



# CHAPTER VI

# HIV/AIDS PROTOCOL

This protocol which includes some best practices for communicating a positive HIV/AIDS test result to a patient will aid in reducing HIV incidence, increasing access to care, optimizing health outcomes, and reducing HIV-related disparities. Furthermore, it will aid in the development of relationships, provide comfort, provide examples/stories/scenarios for patient understanding and engagement and will help the healthcare practitioner be attuned to verbal as well as the nonverbal communication of the patient. Combining the aforementioned concepts should contribute to a connected response and incorporation of treatment, prevention, and intervention.

The goal of best practices and protocol for delivery of a positive HIV/AIDS test result is to consistently show results of greater quality than what can be accomplished without a communicative tool. Now that HIV/AIDS is no longer novel, some careful and strategic best practices seem to be abandoned or no longer passed down such as the review of systems. Because healthcare practitioners are concerned with providing quality care to their patients, best practices and a protocol can serve as guidance for communicating a positive HIV/AIDS status. The following best practices and protocol represents collective knowledge and practice, which has been presented to aid in the increase in follow-up rates and the in development of healthcare practitioner-patient relationships.

Question patients using the Extraordinary Sexual Review System. Adjust communication and incorporate health needs and concerns based on the responses given by patient. The Extraordinary Sexuality Review System includes asking patients about



their sexual history in detail (knowing as much about your patient's sexuality is important and crucial to providing the best care and treatment, prevention, and intervention possible). Questions, such as, are you monogamous? In other words, do you only have one sex partner or multiple sex partners? Additional questions about patient's sexuality should be addressed. What is your sexual orientation? Do you consider yourself to be homosexual, bisexual, heterosexual, or other? Ask the patient to explain how he or she defines their sexual orientation to be sure an understanding is mutual. If male-to-male contact is made, distinguish who is the giver or the receiver. Are you the giver and/or the receiver during sexual intercourse?

Be straightforward with communicating the result. No justifiable reason to withhold this news is evident. Your HIV/AIDS test result is positive. (Confirmatory tests have been done to rule out false positive.). You are now a carrier of HIV/AIDS.

Educate the patient about the disease and its progression while defining medical terminology (such as HIV, AIDS, CD4 count, and CD8 count). Use terminology not exceeding the educational level of the patient that can be understood easily. HIV is a virus that attacks the body. You can get it in different ways (for example, by contact with blood, unprotected sex, and sharing needles). Explain how the virus works. The virus attacks the helper T-cells in the body which are the finder cells (known as CD4 cells) whose job are to find foreign objects in your body. HIV/AIDS does not affect the killer cells (CD8 cells) which can also be considered as the cleanup cells. When you are infected with HIV, your body cannot identify what is foreign because the helper cells have been attacked. Therefore, the body attacks and cannot identify the foreign things that should not be there. Your immune system is compromised and no longer works as it



should; it is now hard for your body to fight off infection. When your CD4 count falls below 200, your immune system is weak. HIV can progress to AIDS. Progression in the body is characterized by multiple infections at different levels. Sometimes, no signs are visible. When signs are visible, they often come in the form of flu-like symptoms.

Be candid throughout the interview/interaction. Honesty is very important. It sets the stage for building lasting relationships. Rearrange seating arrangements to help display concern during the interaction. For example, if the patient asks, "Will I die?", move closer to the patient and lower your chair. An honest response would explain the likelihood of death based on previous experience as well as reports from surveillance in the area. Many strides have been made to help deal with HIV/AIDS, but no cure exists. In the early years of diagnoses, contracting HIV/AIDS meant that patients died soon. HIV/AIDS is no longer an immediate death sentence. Instead, it is treated as a chronic disease like that of high blood pressure. In doing so, management of this condition will require treating you or sending you to someone who can give you the best treatment. If a patient asks, "Can I have children?" Explain the risks of the patient having children. Taking HIV/AIDS medication may help prevent HIV transmission to children if mothers take medication before and during birth. If the baby is given medication after birth, HIV transmission might be avoided (CDC, 2007). The CDC (2007) reports that one in four mothers will transmit HIV/AIDS to their children. Also, children born with HIV benefit from early diagnosis and treatment. Many are living longer and healthier lives due to these lifesaving drugs and other preventive measures.

Expound on prevention as a priority to prevent future partners from contracting HIV/AIDS and to prevent the newly diagnosed patient from compounding HIV/AIDS



with other diseases. Communicate the importance of prevention and intervention to prevent spreading HIV/AIDS to other individuals and reduce incidence. Encourage disclosure and sharing of status to partners. Ask questions such as, do you use drugs? Do you share needles or other drug paraphernalia? If so, explain the importance of not sharing needles or other drug paraphernalia. For example, tell the patient that using the same needles cannot only put you at risk of contracting other diseases and infections but will also put the other people at risk of contracting HIV/AIDS. Preventing others from contracting HIV/AIDS from you until a cure is found is a must. Continue to emphasize prevention. How often do you have sex? Does your partner(s) have HIV/AIDS? Has he, she, or they been tested? Try to make arrangements for him/her/them to come in to be tested as well. Will you inform him/her/them of your status right away? Disclosing your status is very important. This way, both or all of you can do what is necessary to prolong life and good health. As a final gesture of prevention and intervention, the patient should be given condoms.

Gauge patient's understanding of education by asking the patient questions.

Open-ended questions should be asked to get the patient's personal interpretation of the facts. For example, tell me in your own words the definition of HIV and AIDS. How can HIV/AIDS affect your body? Ask the patient to tell you in his/her own words his/her understanding of prevention, intervention, and other issues that would interfere or counteract with the diagnoses.

Know the patient's educational level and adjust communication as needed. Ask questions such as what is the highest grade level of school that you have completed?



After the patient has communicated understanding of HIV/AIDS progression, you will have some idea of the patient's level of comprehension as well.

Assess family involvement and other support systems to optimize health outcomes and to increase access to care. Encourage disclosure of status to family. Pose questions, such as who (family and friends) will you tell that you are HIV/AIDS positive? If the patient's response is "no one," ask why not? Knowing why the patient chooses to withhold his or her status will help you direct the patient to additional resources as needed. Additionally, the provider can take on the role of involvement by contacting the patient after the initial communication. Involvement beyond initial interaction will also communicate concern. If the patient will have family involvement, ask the patient if he/she will bring someone with him/her to the next visit? Family involvement will help the patient not feel alone but supported and will help increase the patient's chances of compliance.

Use different strategies to reach your patients. How strategies are used will depend on variables such as age, background, education, and sexuality. Tactics used to gain patient trust, develop good relationships, and aid in compliance are fear appeals, identification, logical reasoning, concern, emotional appeals, and ethical appeals. Examples of how healthcare practitioners can use these and other tactics are provided:

• Fear appeals are tactics that usually display worst case scenarios to get an individual's attention in hopes of bringing about a change in behavior and thought processes. As a healthcare practitioner, you can say, "You don't want to be like another patient that died quickly because he or she did not get



- treatment to increase his/her chances of survival." Fear appeals can be used when a patient has a history of at-risk behavior.
- Identification generally involves attempts to create a shared sense of connection. Infusing identification elements within the interaction will give the patient security in knowing that the healthcare practitioner understands and is not judging. For example, say to the patient, at some point, we have all done something that we have regretted, like take part in the risky behavior of having unprotected sex.
- Logical reasoning causes the patient to look at the facts and beyond sexual intercourse. If the patient is a teenager, you can say, "I know that young adults usually think and say that everyone else is having sex. But you have to make up your mind to do what's best for you and your health."
- Impart messages that are geared toward behavioral change. For example, the
  only way we can stop the spread of HIV/AIDS is if each individual takes a
  stand to make better choices. You are never too old or young to do this. It
  starts with you.
- Patients want to know that practitioners are concerned about them. Try to
  show concern by having a plan and communicating that plan. For example, I
  know that this is something that is very difficult to accept. I'm going to make
  sure that I connect you with a counselor.
- Emotional appeals include tactics that arouse feelings in order to have the patient be considerate of others. If you love your partner, protect them.



People love you and want to see you survive this. We as humans have sex to feel a sense of closeness among other reasons.

Ethical appeals challenge a patient's moral standards. Sexual intercourse is
not wrong, but diseases are present. You must make sure that you take
responsibility and protect yourself and others. You don't want anyone else to
contract HIV/AIDS. One way you can prevent spreading the disease is to use
condoms.

After strategies have been used to engage the patient, do not allow the initial interaction to be the last. Take charge by following up with the patient. Personally follow-up with the patient to help build and maintain a relationship with the patient as well and to make sure that the patient is compliant by visiting referred sources when needed. If you cannot make contact, designate a nurse or other personnel to follow up with patients. In other words, create and implement a follow-up procedure.

Clearly define the role of the healthcare provider (e.g., confidentiality). My role is to provide and direct you to the best care. Know that this interaction and results are strictly confidential. In other words, I will not tell anyone of your status (family members, friends, or partners). However, I do have to report this case as I must do with all infectious diseases to the U. S. Centers for Disease Control and Prevention or the state department of health.

Refer patients to additional resources. Refer patients to social workers or other resources that will reduce HIV-related disparities (socioeconomic status issues such as funding and travel). The resources provided by referrals should help lessen the burden of the disease.



Briefly explain treatment. Three different medicine combinations help stop the replication of the disease in the body and help the helper T-cells to start back working. If you are not comfortable with treating the patients, refer patients to HIV/AIDS specialists as needed. Prepare referrals and other resources options in advance.

Clinics should establish if the patient will be treated in-house or outsourced. For example, refer patients to treatment within the clinic before outsourcing services if and when available to increase access to care. Additionally, offer and review a list of options for treatment locations. Set up next appointment with the specialist and you. Refer all patients to identity crisis counseling. Bring counselor in for interview/interaction.

Seek assistance when needed. If you do not feel that you can adequately meet these objectives for disclosing a positive HIV/AIDS test result due to lack of experience, fear, or other factors, seek help from other healthcare practitioners.

# APPENDIX A

# ORAL PRESENTATION

<u>Purpose:</u> This research is designed to explore how doctors and other medical practitioners communicate a positive HIV/AIDS status to patients. Particular attention will be given to doctors and other medical practitioners' accounts of disclosing a positive HIV/AIDS test result to patients.

<u>Description of Study</u>: Face-to-face in-depth interviews will be conducted and audio-recorded (with verbal permission) by the researcher with doctors and medical practitioners. Participants will be recruited based on the purpose of the research, seeking individuals with experience related to communicating a positive HIV/AIDS status to patients. Interviews will be arranged with doctors and other medical practitioners. Participation will be secured face-to-face. The interviews should take about an hour to complete.

<u>Benefits:</u> The potential benefits include an in-depth understanding of the experiences of the disclosure of a positive HIV/AIDS test result from the medical practitioners' perspective and the revelation of best practices for disclosing a positive HIV/AIDS test result.

Risks: Anticipated risks associated with participating in this study are breach of confidentiality and anonymity. Doctors and medical practitioners are held to standards and procedures such as HIPPA that prevents them from disclosing certain information about their patients. Participants will be reminded and urged to refrain from providing any patient identifiable information to further safeguard



patient confidentiality. The disclosure of the doctors/medical practitioners' experiences also discloses the patients' experiences to some degree. Having any documentation leading to the identification of the doctors and medical practitioners could potentially cause discomfort and stress. Participants might experience stress while remembering a potentially negative experience. The researcher will remind all participants that counseling is available if needed. All healthcare providers directly or indirectly provide counseling. However, potential referral information will be readily available. The researcher has requested to waive the requirement to obtain a signed consent form as the potential risks would result in a breach of confidentiality and anonymity. In turn, the researcher and participants will engage in dialogue about the general purpose of the research and confidentiality measures. The confidentiality measures that will be undertaken are waiving of signed consent forms, audio recordings will only be listened to by the researcher and researcher's advisor, and transcriptions will not include real names or other identifiable information.

<u>Confidentiality:</u> Interview responses will be exclusively presented in aggregate form, without naming individuals. Data will be kept in the researcher's locked office. Only the researcher and researcher's advisor will have access.

Alternative Procedures: Participants may voluntarily terminate participation.

Participants may also refuse to answer specific questions while continuing participation.

Reasonable Limitations to Confidentiality: Confidentiality will be breached in instances such as participant disclosure of intent to harm self or others and abuse.



Participant's Assurance: This project has been reviewed by the Human Subjects Protection Review Committee, which ensures that research projects involving human subjects follow federal regulations. Any question or concerns about rights as a research subject should be directed to the chair of the Institutional Review Board, The University of Southern Mississippi, 118 College Drive #5147, Hattiesburg, MS 39406-0001, (601) 266-6820. Participation in this project is completely voluntary, and participants may withdraw from this study at any time without penalty, prejudice, or loss of benefits. Any questions about this research should be directed to Vikki Spann at (662)466-2084.

Vikki Spann

**Signature of Person Giving Oral Presentation** 

## APPENDIX B

# IRB APPROVAL LETTER



#### INSTITUTIONAL REVIEW BOARD

118 College Drive #5147 | Hattiesburg, MS 39406-0001 Phone: 601.266.6820 | Fax: 601.266.4377 | www.usm.edu/irb

#### NOTICE OF COMMITTEE ACTION

The project has been reviewed by The University of Southern Mississippi Institutional Review Board in accordance with Federal Drug Administration regulations (21 CFR 26, 111), Department of Health and Human Services (45 CFR Part 46), and university guidelines to ensure adherence to the following criteria:

- The risks to subjects are minimized.
- The risks to subjects are reasonable in relation to the anticipated benefits.
- · The selection of subjects is equitable.
- Informed consent is adequate and appropriately documented.
- Where appropriate, the research plan makes adequate provisions for monitoring the data collected to ensure the safety of the subjects.
- Where appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of all data.
- Appropriate additional safeguards have been included to protect vulnerable subjects.
- Any unanticipated, serious, or continuing problems encountered regarding risks to subjects must be reported immediately, but not later than 10 days following the event. This should be reported to the IRB Office via the "Adverse Effect Report Form".
- If approved, the maximum period of approval is limited to twelve months.
   Projects that exceed this period must submit an application for renewal or continuation.

PROTOCOL NUMBER: 13012906

PROJECT TITLE: Doctor Patient Communication about Positive HIV/AIDS Test

PROJECT TYPE: Dissertation RESEARCHER(S): Vikki Spann

COLLEGE/DIVISION: College of Arts & Letters DEPARTMENT: Communication Studies FUNDING AGENCY/SPONSOR: N/A

IRB COMMITTEE ACTION: Expedited Review Approval PERIOD OF APPROVAL: 03/01/2013 to 02/28/2014

Lawrence A. Hosman, Ph.D. Institutional Review Board

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