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## Human Touch: Perceptions of Self-Efficacy From a Non-Pharmacology Treatment for Individuals Living With HIV/AIDS

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HUMAN TOUCH: PERCEPTIONS OF SELF-EFFICACY FROM A  
NON-PHARMACOLOGY TREATMENT FOR INDIVIDUALS  
LIVING WITH HIV/AIDS

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# **Human Touch: Perceptions of self-efficacy from a non-pharmacology treatment for individuals living with HIV/AIDS**

By  
Anne E. Weisman

## **Abstract**

HIV/AIDS and a subsequent drug regimen can create many negative symptoms and side effects that lead those infected to seek out alternative and complementary therapies as treatments. Massage therapy is an ancient form of treatment that is now gaining popularity as part of the integrative medicine movement. A phenomenological, qualitative research study was conducted at Aid for AIDS of Nevada (AFAN). Participants received a massage and rich descriptive narratives were captured from the 12 participants, six female and six male, ranging in age from 30-67 years of age. The interviews were transcribed and coded for themes. For the purpose of this qualitative study, the research design included field observations and one on one interviews. Data was analyzed using a phenomenological lens. The data was coded for themes that emerged from the data and grouped. Four thematic themes resulted from this data analysis Self-efficacy, Human Connectivity through Touch, Physical & Mental Responses, and An Emotional Roller Coaster. Bandura (1993) states “perceived self-efficacy is concerned with people’s beliefs in their ability to influence events that influence their lives.” Many of the participants expressed statements that the non-pharmacology treatment of massage therapy assisted them in making a variety of positive decisions, thus alluding to the question of self-efficacy.

## Acknowledgements

The path that led me to this research has been one with many obstacles, suffering and growth. When I sustained a severe traumatic head injury in 1999, it was unclear how this injury would change my life. I am grateful today that this injury and the years before and after led me to learn more about healing and the human condition. It was my teacher of compassion, empathy and love.

Thank you to my husband and son for never letting me quit. Your love, continuous support and encouragement made this a reality. I would not have made it this far without each of you by my side. Thank you to my family for the love and laughter that got me through these years.

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## Key Terms

HIV-Human Immunodeficiency Virus

AIDS-Acquired Immune Deficiency Syndrome

CAM-Complementary & Alternative Medicine

Massage Therapy- defined as the manipulation of soft tissue by trained therapists for therapeutic purposes

Self-efficacy- the perceived capability of a person to perform a specific action required to achieve a concrete goal

IPA- Interpretive Phenomenological Analysis



## Chapter One

### Introduction

People living with HIV/AIDS face many challenges managing the multiple symptoms that accompany infection. In a clinical trial study among HIV-positive patients seeking relief from complementary and alternative therapies, the most commonly reported symptoms were nausea, insomnia, dermatological problems, depression and weakness (Sparber et al., 2000). To date, much of the research about living with HIV/AIDS focused on prevention and treatment, symptom management, and quality of life. There has been a surge in massage therapy research recently. However, no research exists to examine how receiving massage therapy could impact self-efficacy for people living with HIV/AIDS. Finch and Becker (2007), in preliminary work investigating changes in self-efficacy in MS patients receiving massage therapy, found significant improvement after an 8 week series of treatments. Self-efficacy has been found to be a predictor of health status (Riazi et al., 2004), and the concept is implicitly linked to psycho-emotional morbidity. Notably, a negative perception of control [a key component of self-efficacy] has been associated with both decreased optimism and increased hopelessness (Sinnakaruppan et al., 2010). These findings suggest that massage therapy has the potential to positively impact people with HIV/AIDS who receive massage therapy and will explore how self-efficacy is impacted.

A gap in the literature was identified concerning self-efficacy for individuals with HIV/AIDS who receive massage therapy as part of their treatment. Benefits with symptom management for people living with HIV/AIDS and massage therapy are known; however, we do not know why the individuals reported the changes or what they felt in response to the treatment.

Throughout the years of the HIV/AIDS epidemic, scientists, the medical community, and those infected have been searching for ways to alleviate the symptoms and manage the disease. HIV-infection presents individuals with multiple challenges which may overwhelm their coping resources and impair psychosocial adjustment to the ongoing demands of managing this stigmatized, chronic illness (Heckman et al., 2004 & Weaver et al., 2005). Prior to the invention of highly active antiretroviral treatment (HAART), without any curative treatment options available, patients relied heavily on complementary and alternative therapies for symptom management.

Since the beginning of the epidemic, almost 78 million people have been infected with the HIV virus and over 39 million have died, making it one of the most destructive viruses in recorded history (WHO, 2014). HIV/AIDS is the number one cause of death by infection worldwide (WHO, 2014). Last year HIV/AIDS claimed the lives of 1.5 million people around the globe (WHO, 2014). In the United States, more than 1.2 million people are living with HIV infection, and almost 1 in 7 (14%) are unaware of their infection (WHO, 2014). Southern Nevada has over 10,000 people living with HIV/AIDS (SNHD, 2015).

In 1996, HAART was approved by FDA and found to be an effective pharmacological treatment. Patients and researchers began to focus heavily on this new treatment. Western medicine provided (HAART), and where available and taken properly, great advances in mortality and morbidity have been recognized (UNAIDS, 2010). Patients who were taking HAART were living longer and different symptoms began to emerge that were thought to be side effects of either the drugs or the virus and patients began to return to the complementary and alternative healing methods as an additional way of treating or managing the disease. HIV-infected individuals use CAM therapies for relief from a variety of HIV-related symptoms.

In October of 1998, the National Institute for Health established The National Center for Complementary and Integrative Health (NCCIH). NCCIH is the Federal government's lead agency for scientific research on complementary and integrative health approaches. It defines complementary medicine as a non-mainstream practice that is used together with conventional medicine. Alternative medicine is defined as a non-mainstream practice used in place of conventional medicine. Complementary and alternative medicine are usually grouped together and known by the acronym CAM. In recent years, the use of CAM has been transitioning to the term "Integrative". NCCIH states that there are many definitions of "integrative" health care, but all involve bringing conventional and complementary approaches together in a coordinated way ([nccih.nih.gov](http://nccih.nih.gov)).

Massage therapy is one form of integrative care that has been found to be beneficial to individuals living with HIV/AIDS. According to Fairfield et. al., after learning that they were HIV-positive, 72.7% of the patients surveyed started visiting alternative providers in addition to the conventional therapies they were using, the most commonly reported CAM providers visited were massage therapists, acupuncturists and acupressurists (Fairfield, et. al., 1998.) Massage therapy has reduced the symptoms of the disease and the side effects from the medication, relieved pain, neuropathy, and has reduced stress, anxiety, and depression. Fairfield et. al. (1998) reported that those that used CAM providers found the treatments to be "extremely" or "quite a bit" helpful. Immune function, stress and HIV play a dangerous and delicate role with each other. According to the 2012 National Health Interview Survey, 33.2% of U.S. adults used complementary health approaches. The mind and body approaches most commonly used by adults include yoga, chiropractic and osteopathic manipulation, meditation, and massage therapy (NCCAM, 2015).

Throughout history, human beings have been laying hands on one another. The laying-on of hands has a long tradition, extending beyond recorded history, and has been a symbol of power in many cultures (Touch p.9 Field, 2014). As far back as 1553 BC, the Ebers Papyrus showed the early practice of healing by touch (Older, 1982). In the Greece of Hippocrates' time, around 400 BC, there were hand healers (comparable to today's internists) called *kheirourgos*. This is the origin of the word *surgeon*, even though the *kheirourgos* used the palm and the fingers, rather than surgical methods, to heal (Field, p.11, 2014). One of the most famous Roman healers, Galen (AD 130), used massage as a medical treatment (Field p. 11, 2014). Touch researchers offer several reasons why touch has fallen out of favor, including sexual taboos and the development of drugs and treatment technologies that dramatically changed the field of medicine (Field, p. 12, 2014). In his book, *Touching is Healing*, Jules Older claims, "Touch has become taboo and that is the reason it does not appear in medical textbooks or curricula."

During this past century, many new discoveries were made with diseases, their transmissions, and treatments. These discoveries led to great advances in the treatments of transmissible disease, but largely removed the human interactions that throughout history were part of the healer and patient relationship. As new and unknown pathogens emerged, new ways of treating and isolating patients became the standards of care. However, the patient's whose bodies were harboring these pathogens were also still human beings that require touch and care from other human beings for physical, mental, emotional, and psychological reasons. The advent of drugs was also a problem that negatively affected touch healing (Field, p. 12, 2014). As Voltaire said, "Physicians pour drugs, about which they know little, to cure diseases, about which they know less, into humans, about whom they know nothing (Montagu. (1986, 270))."

The greatest example of this isolation and its consequences in our lifetime is the HIV virus and

subsequent AIDS epidemic. Although touch is an effective healing agent, it is underused by healing practitioners, from neurologists to social workers, and has been generally ignored by institutions and neglected by researchers (Older. (1982).

During the past 30 years, researchers have looked at the ways in which patients manage HIV infection and some of the benefits of complementary and alternative therapies for patients. In a study of HIV-positive clinical trial patients who used CAM, 98% reported that they were feeling better, and 94% believed CAM therapies had improved their treatment outcome (Sparber et al., 2000). Moreover, 32% of the patients stated that CAM was equally or more effective than conventional treatment (Sparber et al., 2000). This is consistent with other research among HIV-positive individuals in that most (70%) of the sample reported that the use of alternative therapies had improved their quality of life (Duggan et al., 2001).

Up until the invention and FDA approval of the antiretroviral drugs in 1996, individuals infected with HIV had only palliative measures for their symptom management. Once the drug regimen was introduced, little attention was paid to the benefits of the treatments outside of the medications. This study will attempt to capture the phenomena of change that occurs in HIV positive individuals who receive massage therapy and study if it affects their self-efficacy.

Massage therapy is defined as the manipulation of soft tissue by trained therapists for therapeutic purposes (Field, 2008.) Massage therapy involves the application of combinations of specialized strokes, rubbing, and pressures applied in varying intensity to the soft tissues of the body and tailored to the individual's particular situation or condition. This therapy creates a broad range of psychological and physiological changes including improvements in blood and lymph flow, reduction of blood pressure, and relaxation of the mind (Ernst, 2008.) Currently,

massage therapy is one of the most used complementary and alternative therapies. According to Duggan, Peterson, Schutz, Khuder, & Charkraborty, a nationwide survey indicates that over the last decade the use of complementary and alternative therapies has increased 42% in the general population (Duggan et. al., 2001). The reasons cited for the use of complementary and alternative therapies by these patients are: expectation of a cure, reduction of symptoms, or reduction of the side effects from medicine, and a desire for increased control over the disease process (Duggan et. al., 2001).

Massage therapy and other integrative therapies use continue to be common practice among those living with HIV and this use may be reflective of the chronic, non-curative nature of this disease. The benefits from massage therapy could help to alleviate additional health care costs and burdens on the health care system by providing patients with an alternative, comforting option. According to Fairfield et. al., patients who visited complementary and alternative therapy providers made more visits to those providers than to their nurses and physicians combined. It was found that a single application of massage therapy reduced anxiety, blood pressure, and heart rate, but not negative mood, immediate assessment of pain and cortisol level (Moyer, Rounds, & Hannum, 2004). According to Whooten & Sparber (2001), early surveys of HIV-positive people identify the use of alternative and unapproved drug therapies. After 1995, surveys found an increase in the use of CAM such as relaxation techniques, massage therapy, diet, prayer and imagery (Whooten & Sparber, 2001). The increased use of CAM suggests that people are searching for alternatives to the traditional Western medical treatments prescribed by their physicians. This research will explore how massage therapy affects self-efficacy for people living with HIV/AIDS.

In the beginning of the HIV/AIDS pandemic, there were no pharmacological options for people who were fighting the disease. Misconceptions, fear and misinformation were pervasive and often those infected were also suffering from isolation and abandonment from physical contact with other people because of the lack of understanding and fear. As the treatments have changed, research has been conducted examining massage therapy and various other complementary and alternative medical options for people living with the virus. Currently, there is a lack of data about massage therapy and self-efficacy. The purpose of this research is to explore in depth the physical, mental, emotional, and spiritual changes that people experience by adding massage therapy to their care and see if these changes affect their self-efficacy.

A qualitative research design is preferred when questions about ‘what’, ‘how’ or ‘why’ a phenomenon exists rather than ‘how often’ or ‘how many’ are asked (Green & Thorogood, 2009). Social Cognitive Theory (SCT) addresses both the psychosocial dynamics influencing health behavior and methods for promoting behavioral change (Baranowski, Perry & Parcel). Within SCT, human behavior is explained in terms of triadic, dynamic, and reciprocal model in which behavior, personal factors (including cognitions), and environmental influences all interact (Baranowski et al.). Among the crucial personal factors are the individual’s capabilities to symbolize behavior, to anticipate the outcomes of behavior, to learn by observing others, to have confidence in performing a behavior (including overcoming the problems in performing the behavior), to self-determine or self-regulate behavior, and to reflect on or analyze experience (Bandura, 1997). Social cognitive theory produced the concept of self-efficacy as the perceived capability of a person to perform a specific action required to achieve a concrete goal (Bandura, 1997). This concept is competence-based, prospective and action-related (Bandura, 1997).

Human behavior has often been explained in terms of one-sided determinism (Bandura, 1986). In such modes of unidirectional causation, behavior is depicted as being shaped or controlled either by environmental influences or by internal dispositions. SCT favors a model of causation involving triadic reciprocal determinism (Bandura, 1986). In this model of reciprocal causation, behavior, cognition and other personal factors and environmental influences all operate as interacting determinants that influence each other bidirectionally (Bandura, 1986). Reciprocal causation does not mean that the different sources of influence are of equal strength.

Expectations, beliefs, self-perceptions, goals, and intentions give shape and direction to behavior (Bandura, 1986). What people think, believe and feel affects how they behave (Bandura, 1986; Bower, 1975; Neisser, 1976). The natural and extrinsic effects of their actions, in turn, partly determine their thought patterns and emotional reactions (Bandura, 1986). The personal factor also encompasses the biological properties of the organism. Physical structure and sensory and neural systems affect behavior and impose constraints on capabilities. Sensory systems and brain structures are, in turn, modifiable by behavioral experiences (Greenough, Black, & Wallace, 1987). Human expectations, beliefs and emotional bents and cognitive competencies are developed and modified by social influences that convey information and activate emotional reactions through modeling, instruction and social persuasion (Bandura, 1986).

In SCT, people are neither driven by inner forces nor automatically shaped and controlled by their environment (Bandura, 1986). They function as contributors to their own motivation, behavior and development within a network of reciprocally interacting influences. Self-efficacy is a major factor and research has shown the stronger the instilled sense of coping self-efficacy, the bolder the behavior (Bandura, 1982). According to Bandura, among the types of thoughts



that affect action, none is more central or persuasive than people's judgments of their capabilities to exercise control over events that affect their lives. The self-efficacy mechanism plays a central role in human agency (Bandura, 1982; 1986). People's judgments of their capabilities additionally influence whether their thought patterns are self-hindering or self-enhancing, and how much stress and despondency they experienced during anticipatory and actual transactions with the environment (Bandura, 1986). Seen from the perspective of SCT, human nature is characterized by a vast potentiality that can be fashioned by direct and vicarious experiences into a variety of forms within biological limits (Bandura, 1986).

### **Summary**

Chapter one provided the background to the purpose of this study. Chapter one also described the theoretical framework for the study. Chapter two provides a comprehensive review of research-based literature in the fields of early touch research, HIV/AIDS, massage therapy, complementary and alternative therapies, self-efficacy, & qualitative research. Chapter three will outline the methodological approach and design of the proposed study.

## Chapter Two

### Literature Review, Background & Significance

Massage therapy is one of the oldest forms of healing modalities and has been used for thousands of years to treat a variety of afflictions. Throughout the world, documents have been discovered that describe massage therapy. The first documented account of massage therapy as a healing treatment was found in China during the second century B.C. Similar writings have been found in India, Egypt, Greece, Rome, Arabian nations and Japan (Baxter, 2010). In 400 B.C., Hippocrates defined medicine as “the art of rubbing (Field, 1998).” Massage therapy disappeared from the American medical scene at approximately the same time as the pharmaceutical revolution of the 1940’s. Now considered an “integrative” therapy, it is becoming popular again as part of the integrative medicine movement.

Early research conducted about the impacts of touch on health were done following World War II when researchers & psychoanalysts John Bowlby and Renee Spitz noticed that infants who were not held or touched had significantly higher mortality rates than those who were held. The World Health Organization published a controversial report on this in 1951 authored by Bowlby. The report suggests a detrimental effect on human health with the absence of touch and is the basis of the research about touch via massage therapy that this paper will examine. During the 1940’s, one of the first researchers of child development found strong evidence of the importance of touch and human connectedness. Rene A. Spitz learned that infants, well fed and warm but not held or touched, tended to wither away and die. Of the 91 such babies observed, twenty-seven died within their first year of life, followed by 7 more in their second year of life. In other homes, he observed up to 90% died in early infancy (Cassileth

& Vickers, 2003). His observations and research was very important and helped to begin the understanding of the importance of human touch.

Studies were conducted around the same time Rene A. Spitz was working with touch using rats and monkeys as the subjects and these studies also support the use of touch as a therapy and show how detrimental a lack of touch can be. One study by Saul Schenberg had rat pups removed from their mother to investigate touch deprivation (Schenberg, 1994). The mother's behavior was simulated to restore the physiology and biochemistry of the rat pups to normal. It was noted that a decrease in growth hormones occurred when the pups were removed from their mothers. This decrease was observed in all of their body organs including the heart, liver, and brain and in all parts of the brain including the cerebrum, cerebellum, and brain stem. These values returned to normal when the pups were stimulated using techniques approximating the mother's behavior. One example of these techniques involved petting the rat with a paintbrush, simulating a mother's touch. Schenberg and his colleagues discovered a near immediate gene underlying protein synthesis that responds to tactile stimulation, suggesting genetic origins of this touch-growth relationship (Schenberg, 1994).

In a separate study of monkeys conducted during this same time period, it was shown that monkeys that had been removed from their mothers showed similar results, plus major dysfunctions as they developed and when they themselves became mothers. The author of this study, H. Harlow, was also a pioneer in this field and created his major work, "Touching: The Human Significance of the Skin," which clarified a major message: tactile stimulation is essential to normal development and even to survival (Cassileth & Vickers, 2003). The premise that touch is critical to development and survival is widely known but seems to be widely

underutilized. Perhaps with greater awareness and discussion, this will lead to an increased use and acceptance of massage therapy as a preventative and treatment tool.

According to the Touch Research Institute, massage therapy is older than recorded time and rubbing was the primary form of medicine until the pharmaceutical revolution in the 1940's (Field, 1998). Up until that time, massage was used and referenced as a medical therapy and faded away as the focus of medical care shifted to the biological sciences. Recently, massage therapy has become popular again as a part of the integrative medicine movement.

According to Moyer, Rounds, and Hannum (2004), massage therapy is an ancient form of treatment that is now gaining popularity as part of the complementary and alternative therapy movement. Several recent studies have studied the effectiveness of massage therapy as a treatment for HIV patients. Single applications of massage therapy reduced anxiety, blood pressure, and heart rate (Moyer, et. al., 2004). Multiple applications of massage therapy have been shown to reduce the delay in assessment of pain in HIV patients. The greatest effects of massage therapy are the reductions in trait anxiety and depression, which are similar in magnitude to the benefits provided to those that would undergo psychotherapy. Massage therapy helps HIV/AIDS patients in many different ways and had great potential as a treatment method. However, none of the available literature examined massage therapy and self-efficacy.

Over the past 34 years, massage therapy has been found to be beneficial to individuals living with HIV/AIDS. In the beginning of the AIDS epidemic, the only treatment options were palliative. Touch or human contact was reported as being one of the most comforting treatments and was often the only treatment available. When patients received massage therapy, they reported positive changes in the immune system, along with improved attitudes and feelings (Field, et. al., 2001). Massage therapy has also allowed them to feel they have more control of

the disease process. These changes are all important medically and to the quality of life. Many HIV-infected persons are exploring alternative medical therapies as a means to relieve HIV-related symptoms and in some cases, even to inhibit viral activity (Patrick, 2000; Wu, Attele, Zhang, & Yuan, 2001). Massage therapy has been used for thousands of years to help people with many different afflictions.

The individual use of massage therapy and other forms of integrative therapies are becoming widespread and its' effects on the recipients is often evident and immediate. The investigation into the use of complimentary therapies as a viable addition to the treatment of HIV-related infections arose in the mid-1980's. Since that time, these therapies have increasingly been used as adjuncts to medical treatment regimens for HIV-related illnesses (Ostrow, 1997). Evidence of physical, social, and emotional benefits from the addition of massage therapy into the care and treatment of HIV/AIDS patients has been observed by those that have treated patients. Primary reasons for seeking CAM therapies such as acupuncture and massage were pain, depression, and stress (Fairfield, et al., 1998). Most recent studies report CAM therapy utilization rates to be between 67% and 84% in the HIV-infected population (Knippels & Weiss, 2000; Sparber et al., 2000; Standish et al., 2001.)

Complementary and alternative therapy such as massage therapy continues to be a common practice among those with HIV, even if they have stable immune responses. This use may be reflective of the chronic, non-curative nature of the disease. Studies have shown patients with non-curative diseases such as cancer or AIDS tend to be high users of complementary and alternative therapies. Use among HIV-infected patients may not diminish even with the availability of increasingly effective medical therapy. Therefore, physicians should provide information to their patients about complementary and alternative therapy and its benefits. These

explanations are also found in HIV-specific research, which reports a number of barriers to using CAM: cost; access; the time, discipline, and energy connected with CAM use; the wide degree of choice involved with CAM; lack of scientific data; the fear of being associated with deviant groups; experiencing non-health-related life problems; and lack of effectiveness (Furin, 1995; Pawluch et al., 1998).

Research was conducted to examine changes in self-efficacy in multiple sclerosis patients following a series of massage therapy treatments (Finch & Bessonnette, 2012). This quantitative study was a small practical trial that investigated the effects of a pragmatic treatment protocol using a prospective randomized pretest posttest waitlist control design. Self-efficacy scores were obtained before the first treatment, mid-treatment, after the last treatment, four weeks after the last treatment and eight weeks after the treatment series ended. Self-efficacy was the outcome for the study, measured using the Multiple Sclerosis Self-Efficacy survey [MSSE]. Statistically significant improvement in self-efficacy was noted between treatment and control groups at mid treatment series, post treatment and at the four-week follow up. The eight-week follow up was not statistically significant. This study results support that massage therapy increases the self-efficacy of clients with multiple sclerosis, potentially resulting in a better overall adjustment to the disease and an improvement in psycho-emotional state (Finch & Bessonnette, 2012).

A pilot study using a quasi-experimental pretest-posttest design to examine if participation in a chronic disease self-management program improved self-efficacy, self-efficacy health, and self-management behaviors in an underserved, poor, rural population. Trained lay leaders with chronic illnesses worked with an interactive model based on Bandura's self-efficacy theory that included strategies for personal exercise program development, cognitive symptom management, problem solving, and communication skills. Significant improvements in self-

efficacy, self-efficacy health, and self-management behaviors occurred. Results underscore the need to evaluate intervention programs for specific populations and for a new paradigm that focuses on patient-provider partnerships that can improve health outcomes in underserved, poor, rural populations (Farrell, Wicks & Martin, 2004).

Research by Ho, Robles & Pawluch explored cultural resources for health participation. Their qualitative research was conducted using individual and group interviews. Participants reported that biomedical pills were an important context for understanding decision-making regarding neuropathy treatment. Peripheral neuropathy is not generally recognized by members of the lay public and is poorly understood even by medical professionals, yet it is the most common neurological disorder associated with HIV and is found in 30-38% of HIV-positive patients (Sadosky, McDermott, Brandenburg, & Strauss, 2008) and is often very difficult to treat, in part because certain regularly prescribed HIV drugs are believed to cause neuropathy (Sadowsky et al., 2008). Peripheral neuropathy manifests in a wide variety of ways, often as some combination of pain, burning, numbness, or pins and needles in the extremities that can range in severity from mildly irritating to constantly and permanently disabling. Some in this situation choose to use holistic therapies such as acupuncture and massage to manage their neuropathy. However, these “alternative” treatments are not always available, given public health and insurance funding that value a biomedical standard of treatment.

While most people spoke of the necessity of drugs for their survival, they also expressed deep resentment and frustration with biomedically prescribed pills. Complaints about the pills worked to frame the holistic alternatives of acupuncture and massage therapy as better options for neuropathy and to establish a foundation for understanding how participants made particular health treatment decisions. Through strategically refusing certain drugs and choosing holistic

treatments instead, participants asserted agency and control over their health decision-making. By choosing holistic therapies, these clients were able to make choices about their neuropathy treatment in light of the many issues surrounding drug toxicity and treatment efficacy.

This study used dialogue with patients to understand the culturally meaningful ways that patients made treatment decisions regarding their neuropathy and actively participated in their own health care process despite various forces of marginalization. Born out of a spirit of participatory health research (Cornwall & Jewkes, 1995) and aligned with a culture-centered approach (Dutta, 2008), this study was conducted in collaboration with staff and clients at a public health holistic therapy clinic called Healing Touch Clinic (HTC) in northern California.

Based on group and individual interviews, clients described their experiences with the use of biomedical drug treatments as a double-edge sword. On the one hand, all of the clients were or had previously been taking biomedically prescribed HIV medications and recognized the necessity of these drugs. On the other hand, because these drugs may have given them side effects like peripheral neuropathy, clients expressed feelings of betrayal by those same drugs and the doctors/medical system who prescribed them. This dialectical tension between the necessity and frustration aimed at pills established the health context for understanding how clients made decisions regarding the use of holistic therapies, specifically acupuncture and massage therapy.

Especially in the case of the elderly and people with multiple morbidities, studies found that patients often feel conflicted about their drug intake (Moen et al., 2009; Townsend, Hunt, & Wyke, 2003). On the one hand, patients recognized that taking the multiple pills that they take are keeping them alive (Moen et al., 2009; Townsend et al., 2003). However, at the same time, the drugs were also regarded as “unnatural” (Moen et al., 2009), poisonous (Moen et al., 2009; Townsend et al., 2003) and as a marker of illness (Townsend et al., 2003).



A review of qualitative studies of patient perceptions of treatments confirmed that neuropathy is a common side effect of antiretroviral treatments (ART) and has led to both fear and distrust in biomedicine (Pound et al., 2005). Despite an understanding that ART is also extremely useful for health and survival, these side effects often led patients to initiate HIV drug holidays and/or use alternatives because they are deemed to be less harmful and more natural (Pawluch, Cain, & Gillett, 2000; Pound et al., 2005).

### **HIV/AIDS Medical Information**

In May 1986, the International Committee on the Taxonomy of Viruses declares that the virus that causes AIDS will officially be known as *Human Immunodeficiency Virus* (HIV). It is the virus that can lead to the acquired immune deficiency syndrome (AIDS). HIV affects specific cells of the immune system, called CD4 cells or T cells. Over time, HIV can destroy so many of these cells that the body can't fight off infections and disease. The HIV virus establishes a latent infection at a very early stage and the T cell memory of the patient is rapidly destroyed. During HIV infection, a progressive loss of function and numbers of CD4+ cells reduces the host's immune capacity. The most effective way of improving the clinical course in HIV appears to be to reduce the viral load and thereby counter the deterioration of CD4+ cells (Gudmundsdotter et al., 2006).

Touch modalities are purported to increase circulation, alleviate pain, promote relaxation, and stimulate the immune system. Touch therapy involves manual manipulation of soft tissues, which is reported to have an effect on pain reduction and sense of well-being. Swanson et al., argue that increased blood flow, which maximizes oxygen and nutrients to pain sites, may be a possible mechanism for the therapeutic benefits of massage therapy. Additionally, massage and

other touch modalities lead to a reduction in muscular tightness and tension. Moreover, touch modalities can stimulate the release of endorphins. Ironson et al. reported that massage therapy significantly decreased anxiety in a small sample of HIV-positive persons (Ironson, et al., 1996).

In a study from the Touch Research Institute with HIV positive adults, Natural Killer cells (NK), and natural killer cell cytotoxicity activity increased following 20 days of massage therapy (Ironson, et al.) This suggests massage therapy as a strong addition to HIV/AIDS treatment. Several studies have suggested that stress and anxiety might over-activate the hypothalamic pituitary adrenal axis (HPA) resulting in the increased production of Cortisol and neuropeptides (Lutgendorf, 1996). This increase in hormones may further suppress the immune system, in particular Natural Killer Cells, the most aggressive of the white blood cells (Lutgendorf et al., 1996; Madhavan, & Shwartz, 1995; Zorilla et al., 1996). Integration of massage therapy can alleviate or break these cycles of stress in HIV/AIDS patients (Field, et. al., 2001). Patients with a greater desire for medical information and involvement in medical decision making and with a negative attitude toward antiretrovirals were more likely to use complementary and alternative therapies.

### **Complementary and Alternative Therapy Use & HIV/AIDS patients**

According to Whooten and Sparber (2001), early surveys of HIV-positive people identify the use of alternative & unapproved drug therapies. After 1995, surveys found an increase in the use of complementary & alternative therapies, such as relaxation, massage, diet, prayer, and imagery (Whooten & Sparber, 2001). These alternative methods not only increased within the HIV/AIDS community, but other groups began to use them. The increased use of complementary therapies in many different groups suggests that people would like alternatives to the traditional Western medical treatments. Limited research has been conducted on the efficacy of CAM

therapies for reducing HIV-related symptoms and delaying disease progression (Ozsoy & Ernst, 1999; Patrick, 2000; Swanson, Keithley, Zeller, & Cronin-Stubbs, 2000).

In another study with late-stage HIV/AIDS patients, the patients were evaluated with Metta Meditation, massage therapy and their effects on quality of life in people with AIDS (Williams, Selwyn, Liberti, Molde, Njike, McCorkie, Zelterman & Katz, 2005). It was found that the combination of meditation and massage therapy has a significantly favorable influence on overall and spiritual quality of life in late-stage disease. The use of complementary therapies in conjunction with HIV/AIDS medications appears to be most prevalent in young and highly educated individuals and to be associated with the debilitating and chronic nature of HIV disease (Williams et al., 2005). Across all of the studies examined in this paper, there are sets of common findings, depressed mood was decreased and anxiety levels and stress hormones (norepinephrine, epinephrine, cortisol) were reduced in all states.

Research that examines HIV patients' perceptions of their CAM use found that while there are distinguishable patterns, understandings of CAM are better studied as a dynamic process within an individual's particular social context (Pawluch et al., 2000). In a Canadian study of HIV-positive individuals who already used CAM therapies, Pawluch et al. (2000) found two ironic situations. First, unlike some studies that speculated that patients turn to CAM as a last resort, the participants in this study often turned to "Western medicine" as a last resort. Second, the reason people avoided Western medicine was because they felt that Western medicine was toxic and dangerous while CAM therapies were safer and more natural (Pawluch et al., 2000).

Mills, Wu & Ernst conducted a review of the studies about complementary therapies in the treatment of HIV and cited a nationwide survey of HIV+ individuals in the United States and

found that up to 68% of participants admitted to using some form of complementary and alternative medicine (CAM) within the previous 12 months. In addition, many of the reports reviewed have suggested that the HIV patients do not tell their physicians about their use of CAM. Reasons for CAM use include managing symptoms, medications and emotions; self-experimenting to evaluate disease progression; gaining freedom from medical regimens; and managing AIDS stigma (Mills et al., 2005).

### **Massage Therapy and Bodily Assessments**

It was found that a single application of massage therapy has been found to reduce state anxiety, blood pressure, and heart rate, but not negative mood, immediate assessment of pain and cortisol level (Moyer, Rounds & Hannum, 2004). This same study found that multiple applications reduced delayed assessment of pain. The two largest effects noted in this study were significant reductions of trait anxiety and depression with a course of treatment providing benefits similar in magnitude to those of psychotherapy (Moyer, Rounds & Hannum, 2004).

HIV-infected individuals frequently choose therapy that is outside the realm of traditional medicine (Alan, 1990; Sutherland, et al., 1990). Chronic anxiety and depression have been associated with immune suppression in otherwise healthy individuals. Corticosteroids such as cortisol, which is released in response to perceived stressful situations, may block the receptor on the T-and B-lymphocytes, which in turn impedes the ability of these cells to combat the infectious agent or antigen (Darko et al., 1988; Daurna and Morgan, 1990).

Relaxation and maintenance of positive mood have been associated with enhancement of immunological function. In a short-term study of healthy medical students during summer vacation, biofeedback-assisted relaxation produced increases in functional activity of CD4+ lymphocytes in the treated group in comparison to untreated controls (McGrady et al., 1992).

Relaxation-based interventions also have been correlated with improved mood state and decreased psychological symptoms of stress (Dillon et al., 1985; Green et al., 1988). Although some HIV public health clinics have begun to offer alternative therapies such as massage, yoga, acupuncture and Chinese herbs as an adjunct to conventional treatment, these services are costly and only available through private providers. Recent research reported only 26% of physicians discuss CAM during initial visits and only 5% at follow-up visits (Rose, O'Toole, Skeist, Pfeiffer, & Carlsen, 1998; Wynia, Eisenberg & Wilson, 1999.)

Poland, Gertsik, Favreau, Smith, Mirocha, Rao, & Daar conducted a study to determine whether massage therapy reduces symptoms of depression in subjects with human immunodeficiency virus (HIV) disease. Subjects were randomized non-blinded into one of three parallel groups to receive Swedish massage or to one of two control groups, touch or no intervention for eight weeks. Swedish massage and touch subjects visited the massage therapist for one hour twice per week. The touch group had a massage therapist place both hands on the subject with slight pressure, but no massage, in a uniform distribution in the same pattern used for the massage subjects. The Hamilton Rating Scale for Depression score was used along with the Beck Depression Inventory to assess the participants. Results showed that massage significantly reduced the severity of depression beginning at week 4 and continuing at weeks 6 and 8 compared with no intervention and/or touch. The results indicate that massage therapy can reduce symptoms of depression in subjects with HIV disease. The durability of the response, optimal "dose" of massage, and mechanisms by which massage exerts its antidepressant effects remain to be determined.

As with other serious illnesses, human immunodeficiency virus (HIV) infection often is accompanied by psychiatric complications, particularly depression. It is estimated that as many

as one in three HIV-infected persons suffer from depression. Not only is depression itself a leading cause of disability but also the combination of depression and HIV disease is an even larger and growing contributor to the burden of disease worldwide (Jewett & Hecht, 1993). Polypharmacy is common among those with HIV disease and the addition of another medication only increases the potential for serious drug interactions and adverse events. Accordingly, new, safe, and efficacious nonpharmacologic treatments for depression, particularly in subjects infected with HIV, are needed. One such treatment modality that has received increasing attention is massage therapy.

There have been several studies investigating the efficiency of massage therapy in psychiatric syndromes. As reviewed, extant data indicate that massage therapy decreases symptoms of anxiety and depression in a wide array of childhood and adult neuropsychiatric disorders. However, many of these studies only compared massage to a non-intervention (NI) group, which does not adequately address the possibility of a “placebo” effect. Using a novel dual-control group design, which included a light “touch” group to control for some of the nonspecific effects of massage and therapist-subject interaction, the efficacy of Swedish massage on symptoms of depression was assessed in HIV-positive patients with comorbid major depression. The hypothesis was that massage therapy would reduce depression in subjects with HIV disease. Post-hoc analyses showed that massage treatment was more effective in reducing HAM-D scores compared to both touch and NI, with the treatment effect emerging by week 4 and maintained through week 6 and 8.

Major depression and dysthymic disorders are particularly problematic among HIV-infected patients. Drug therapy in these patients can result in toxicity and important drug-drug interactions with other medications used to manage HIV or its complications. Because these

complications can be particularly troublesome for those in advanced stages of HIV disease, many individuals are utilizing complementary and alternative medicine (CAM) therapies for a variety of reasons, including the treatment of depression. This trial showed highly significant improvements in relief of depression in those receiving massage versus touch or NI.

The results from this study are consistent with other studies indicating that Swedish massage might be useful for the treatment of depression in HIV-uninfected individuals. However, rigorous trials of many CAM interventions including massage are somewhat limited and difficult to interpret because participants in the study are usually not “blind” to the interventions. Accordingly, two control groups were incorporated into the design of this study, a touch group and a NI group. The touch was utilized, along with an NI arm, to account for the potential effects associated with human contact independent of massage therapy. Although subjects were not told that the antidepressant response to massage might take weeks, this is what was observed. Since massage can produce a number of positive subjective effects acutely (e.g., reduced anxiety, peripheral vasodilation, muscle relaxation), one might expect an antidepressant effect earlier, but this did not occur (Poland et al., 2013).

Birk et al. designed a randomized, controlled trial to demonstrate the effects of massage therapy alone compared with massage therapy in combination with exercise on functional health status, mental health, symptom distress, and immune measures in HIV-infected persons. The massage-only group received a 45-minute whole-body using a Swedish technique massage once a week for 12 weeks. The second and third groups received massage paired with either aerobic exercise or stress management. The control group received the usual standard of care. Results from this study indicated no significant difference between groups in functional health status or symptom distress. The group that received massage therapy combined with stress management,

however, exhibited a decrease in medical care use and an increase in health perceptions when compared with the massage only group.

### **Massage Therapy and Quality of Life**

Major research and clinical initiatives are addressing prevention and cure strategies; issues of quality of life for survivors have received less attention (Hillier, Louw, Uwimana, & Statham). Massage therapy is proposed to have a positive effect on immune function through stress mediation. The objective of this systematic review was to examine the safety and effectiveness of massage therapy on quality of life, pain and immune system parameters in people living with HIV/AIDS. Studies were identified based on the trial design and participants. This review found that further studies are needed using larger sample sizes and rigorous design/reporting before massage therapy can be strongly recommended for people living with HIV/AIDS. People living with HIV/AIDS may experience a lower quality of life due to complications from the disease. Massage therapy may help people by improving their overall health and their ability to deal with stress.

Hillier et al., investigated studies that compared massage therapy with other forms of therapy or no therapy. Four randomized controlled trials were included that used children, adolescents or adults with HIV or late-stage AIDS. The review supports that massage therapy benefits people with HIV/AIDS by improving quality of life, particularly if they receive the therapy in conjunction with other techniques, such as meditation and relaxation training, and provide more benefit than these techniques individually. The review hypothesized that massage therapy may improve the body's ability to fight the disease, however, conclusive proof is still needed. Hillier et al., recommended further research to investigate this question and recommends that in the meantime, people with HIV/AIDS use massage therapy to improve quality of life.



Two of the trials investigated the primary outcome of quality of life, massage therapy in combination with other modalities, such as biofeedback stress reduction (Birk, 2000) and meditation (Williams, 2005) was reported to be superior to massage therapy alone, the other modalities alone, or the control group. The overall findings reflect the general conclusions of most other studies: there appears to be a positive effect on the quality of life of people living with HIV/AIDS particularly when massage therapy is delivered as a package of care, and that there is limited and conflicting evidence about the effects of massage therapy on immunological status. There are no other systematic reviews solely of massage therapy for people living with HIV/AIDS and the extant literature has mainly consisted of small studies of low methodological quality.

The other two systematic reviews evaluated complementary and alternative therapies, of which massage therapy is considered a part, in relation to effects on people living with HIV/AIDS (Ozsoy, 1999; Mills, 2005). Both studies reported that, despite the widespread use of complementary and alternative therapies by people living with HIV/AIDS, there is a paucity of clinical trials and a low level of methodological quality. Both reviews found more evidence for the use of complementary and alternative therapies in the “care” rather than the “cure” of HIV/AIDS, meaning that the overall effect of complementary and alternative therapies including massage therapy may lie mostly in improving quality of life. One (non-systematic) review article (Field, 2005) concluded that massage therapy does have physiological stress-reduction effects for a broad spectrum of people by decreasing cortisol and increasing serotonin and dopamine.

Holistic therapies, despite being called complementary and alternative medicine (CAM) or integrative therapies, are in fact used in quite mainstream ways in the United States. The most recent National Health Interview Survey report found that in 2007, 38.3% of adults and 11.8% of

children used some form of CAM in the last 12 months (Bares, Bloom, & Nahim, 2008). The high cost of both biomedical HIV treatments and holistic treatments often materially restricted participant agency in health decision-making. Equally important, the participants also had to negotiate their health decision-making given relevant cultural understandings of what treatments are appropriate and what are considered extravagant and/or ineffective.

### **Benefits of Massage Therapy**

HIV infection is commonly accompanied by psychological distress, often manifested as depression and anxiety, which may increase HIV symptomology (Jewett & Hecht, 1993). The psychological burden could be decreased with the integration of complementary or alternative therapies such as massage therapy into the plan of care. Several studies have suggested that stress and anxiety might over-activate the hypothalamic pituitary adrenal axis (HPA) resulting in the increased production of Cortisol and neuropeptides (Lutgendorf, 1996). This increase in hormones may further suppress the immune system, in particular Natural Killer Cells, the most aggressive of the white blood cells (Lutgendorf et al., 1996; Madhavan, & Shwartz, 1995; Zorilla et al., 1996). Integration of massage therapy can alleviate or break these cycles of stress in HIV/AIDS patients (Field, et. al., 2001).

Studies have demonstrated that 35% to 40 % of HIV-positive individuals use some form of complementary therapy in conjunction with traditional Western medicine regimens (Ostrow, et. al. 1997). Additional data suggest a more widespread use of complimentary and alternative therapies for individuals living with HIV/AIDS than for those individuals that do not have this disease. A study conducted through the University of Washington in Northern California from 1988-1990 found that of 2 groups of HIV –infected patients that 70% of those surveyed had used complementary and alternative therapies at some point. (Dwyer, et al., 1995). The large

percentages reported in these studies indicate that massage therapy is a welcome addition to treatment in HIV/AIDS patients.

According to Fairfield et al., (1998), “Massage therapists, acupuncturists, and acupressurists were the most commonly reported complementary and alternative therapy providers visited. Those that used CAM providers found the treatments to be “extremely” or “quite a bit” helpful. After learning they were HIV-positive 72.7 % of the patients surveyed started visiting alternative providers in addition to the conventional therapies they were using (Fairfield, et. al., 1998).”

An important finding from this survey is that patients who visited complementary and alternative therapy providers made more visits to those providers than to their nurses and physicians combined (Fairfield, 1998). These additional alternative therapy visits could provide a more comprehensive picture of HIV treatment and its’ effects for further research. Patients report substantial benefits from their use of complementary and alternative therapies, whether they used it alone or in combination with conventional treatment.

### **Improvements to Immune Responses**

HIV patients perceive differences in their health with the use of massage therapy and studies have demonstrated substantial improvements in HIV markers, like T-cell counts and viral loads (Ironson, 2001). It was found that the massage treatment group counts showed improvement when comparing the mean of the pre- and post- CD4 counts of the non-treatment control group to the treatment group pre- and post- CD4+ counts (Ironson, 2001). The treatment patients were interviewed and all reported a positive experience stating that massage had the greatest effect for pain-relief and improved sleep (Hendrickson, 2001).

A study from the Dominican Republic looked at HIV positive children that were not receiving ART but were receiving massage therapy and how massage therapy influenced behavior and development (Hernandez-Reif, Shor-Posner, Baez, Soto, Mendoza, Castillo, Quintero, Perez, & Zhang, 2008). It was found that the children in the massage therapy group improved in self-help abilities and communication. This suggests that massage therapy may enhance daily functioning for these children. The HIV infected children who were 6 or older showed a decrease in internalizing behaviors; specifically anxious/depressive behaviors and negative thoughts were reduced (Hernandez-Reif, et al., 2008). Due to these findings Hernandez-Reif et. al. suggests massage therapy as an alternative immune therapy for children without access to ART. Reif et al., studied forty-eight children (M age=4.8 years) infected with HIV/AIDS and living in the Dominican Republic were randomly assigned to a massage therapy or a play session control group. The children in the massage therapy group received two weekly 20-minute massages for 12 weeks; the children in the control group participated in the play session (coloring, playing with blocks) for the same duration and length as the massage therapy group. Overall, the children in the massage therapy group improved in self-help abilities and communication, suggesting massage therapy may enhance daily functioning for children with HIV/AIDS. Moreover, the HIV infected children who were six and older also showed a decrease in internalizing behaviors; specifically depressive/anxious behaviors and negative thoughts were reduced.

Dr. Tiffany Field, Director of the Touch Research Institute (TRI) at the University of Miami, Florida, is a pioneer for research about massage therapy and its' effects on human health. She conducted a study in 2001 with HIV- positive adolescents that showed improved immune function following massage therapy. In this study, HIV positive adolescents were recruited from

an outpatient clinic in a large urban university hospital. They were randomly assigned to receive massage therapy or progressive muscle relaxation two times per week for twelve weeks. To assess the effects of massage therapy treatment, participants were observed for depression, anxiety, and immune changes before and after treatment for the twelve-week treatment period. At the end of the twelve-week study, adolescents who received massage therapy were compared to those that experienced only relaxation therapy and they reported feeling less anxious & depressed. For the massage therapy group, immune changes included increased Natural Killer cell number (CD56 & CD3) along with an increase in the HIV disease progression markers (CD4+/CD8+ ratio and CD4 +/-) (Field, 2001).

In another study from Dr. Field in 1996, it was found that massage therapy was associated with enhancement of the immune system's cytotoxic capacity. Key HIV markers were selected that indicated progression of the HIV disease. A key marker of HIV progression is the decline of CD4+ positive (CD4+) T cells, which are the immune system's "helper" cells. HIV's propensity is to attach to CD4+ cells. These cells mobilize & replicate to fight infection causing more HIV copies to be made. These CD4+ cells are now infected and disarmed, causing other parts of the system to become disabled, such as the communication that stimulates B cells (antibodies) into action. CD8+T cells, cytotoxic or suppressor cells, are also thought to be involved. Research has shown that these cells are mobilized into defense mode against HIV replication (Field, 1996). Another marker of HIV is the ratio of CD4+ to CD8+ cells, which are indicators of immune status. A healthy ratio is about one to two CD4+ cells to every CD8+ cell. Although values range from one individual to another, typically in HIV infection there is a dramatic drop in CD4+ count and also in the CD4+ & CD8+, which indicates a serious depletion of T-helper cells (Geijtenbeek, 2000). CD4+ cell counts normally range from 500 to 1,600 but

average around 1,000 per mm<sup>3</sup> of blood (Geijtenbeek, et al, 2000). According to the Centers for Disease Control and Prevention (CDC) 2010 standards, a CD4<sup>+</sup> count > 200, along with other symptoms, define the progression to AIDS and is considered the most advanced stage of HIV-infection. At this stage, immune depletion is set and life-threatening opportunistic infections like pneumonia and cancer take over. The TRI has conducted research proving the power of massage therapy to induce relaxation, decrease anxiety, and decrease stress hormones. These effects are a large part of TRI's HIV research and the following article explores massage therapy in context with the specific markers of HIV cellular activity.

In 1996, 29 gay men (20 HIV+, 9 HIV-) received daily massages for one month. A subset of 11 of the HIV + subjects served as a control group, they received massages for one month followed by one month without massage. Major findings after a month of massage included an increase in natural killer cell numbers, natural killer cell cytotoxicity, soluble CD8<sup>+</sup> cells, and the cytotoxic subset of CD8<sup>+</sup> cells. There were no changes in HIV disease progression markers such as CD4<sup>+</sup> cells and CD4<sup>+</sup>/CD8<sup>+</sup>, Beta-2 microglobulin or neopterin). Major endocrine findings, measured through 24-hour urinalysis include a noticeable decrease in Cortisol, and a slight trend toward a decrease in catecholamines. There were also noticeable decreases in anxiety along with increases in relaxation. These have a direct correlation with increases in natural killer cell numbers. This study shows that there is an increase in cytotoxic capacity associated with massage therapy (Field, et. al., 1996).

### **Summary**

The overwhelming benefits from massage therapy could alleviate additional health care costs and burdens on the health care system by providing an alternative option for infected

individuals. Findings from the literature review include that HIV patients most commonly used CAM for nausea, insomnia, dermatological problems, depression and weakness (Sparber, et.al., 2000). This same study reported that 98% of the respondents that used CAM reported feeling better and 94% believed CAM improved their treatment outcome (Sparber, et al., 2000). Duggan et al., 2001 reported that 70% of HIV positive people reported that the use of CAM had improved their quality of life. Fairfield et.al., 1998 reported that 72.7% of HIV patients surveyed reported starting to visit CAM providers.

The psychological and physiological changes reported from the literature review include improvements in blood & lymph flow, reduction of blood pressure, and relaxation of the mind (Ernst, 2008). It was reported that a single application of massage therapy reduced anxiety, blood pressure, and heart rate, but not negative mood (Moyer, Rounds & Hannum, 2004). When patients received massage therapy, they reported positive changes in the immune system, along with improved attitudes and feelings (Field, et.al., 2001). Swanson et. al., argues that the increased blood flow, which maximizes oxygen and nutrients to pain sites, may be a possible mechanism for the therapeutic benefits of massage therapy. Ironson reported a significant reduction in anxiety from massage therapy for HIV patients. Ironson et al., reported natural killer cells (NK), and natural killer cell cytotoxicity activity increased following 20 days of massage therapy. Massage therapy appears to have a positive effect on the quality of life for people living with HIV/AIDS (Williams, 2005). Research by Hillier, Louw, Morris, Uwimana, & Statham recommends people with HIV/AIDS use massage therapy to improve their quality of life.

Medical schools in the United States are increasingly involving complementary and alternative therapy education as part of elective and required curriculum. This recognizes the continued public interest in alternative therapies along with the continued patient use of

complementary and alternative medicine. Until HIV infection is eradicated, it seems likely that patients will continue to use complementary & alternative medicine. Physician awareness and acceptance of this treatment also appears to be increasing. The increasing use & questions to physicians about complementary & alternative therapies along with the increase in curriculum training to new doctors suggests that massage therapy could become more mainstream in the prescribed treatment of HIV/AIDS. Further research and a comprehensive plan to implement more complementary and alternative therapies into the care of HIV/AIDS patients is necessary in order for more patients to be aware of and receive this treatment.



### **Chapter Three-Methods**

The primary purpose of this study was to explore how massage therapy affected self-efficacy for people living with HIV/AIDS who received it. This was explored through the lens of Social Cognitive Theory using qualitative methods. This study attempted to identify the changes in self-efficacy that occurred for the patients who received massage therapy using the Social Cognitive Theory as the framework. This study intended to document and better understand the relationship between massage therapy for people with HIV/AIDS and how it affected their self-efficacy. This study gained insight into how self-efficacy was impacted by massage therapy and how beneficial this therapy can be for people living with HIV/AIDS.

As a public health professional and massage therapist, the researcher began her massage therapy research with AFAN twelve years ago after volunteering there while a student of massage therapy. The researcher voluntarily massaged clients of AFAN for a school project when she began to notice significant changes with the clients who were receiving massage therapy and the clients were expressing many changes they were experiencing. She became interested in how the addition of massage therapy could impact the client's health and self-efficacy. As a result of the researcher's work and the research presented in this literature review, it is imperative to find out more about how massage therapy affects the self-efficacy of this population, the members of which are often marginalized.

#### **IRB**

A research protocol proposal was filed and approved by the University of Nevada, Las Vegas Institutional Review Board (IRB). The IRB protocol number for this study is 804375-1. Immediately following the IRB approval, participant recruitment began. Recruitment was conducted by placing copies of the IRB-approved fliers on the community resource table in the

lobby of AFAN as well as hanging up fliers around AFAN. Clients of AFAN who were interested in participating in the study picked up the flier and then called to become a participant. When calls were received the researcher explained the study to the interested participant and the time commitment. An explanation of the participant inclusion criteria was discussed to ensure that the interested participant fit the criteria. Interestingly, the recruitment began before Thanksgiving and by Christmas, saturation was close to occurring. Data was collected using observations, journals & interviews.

### **Site of study**

The study was conducted at an HIV/AIDS agency in southern Nevada; Aid for AIDS of Nevada (AFAN). AFAN is well established in the Las Vegas and Henderson areas. Aid for AIDS of Nevada (AFAN) provides support and advocacy for adults and children living with and affected by HIV/AIDS in southern Nevada. AFAN works to reduce HIV infection through prevention education to eliminate fear, prejudice and the stigma associated with the disease. AFAN is committed to a system that nurtures personal growth and dignity of persons served, which is emphasized during orientation, ongoing staff trainings and the culture of our organization.

Founded in 1984, Aid for AIDS of Nevada (AFAN) is the oldest and largest AIDS service organization in the state of Nevada. Over four thousand men, women and children infected with HIV are registered as clients. AFAN provides direct client service programs, food programs, prevention and education programs, and community outreach. It is the mission of AFAN's client service programs to enhance the physical health and psychosocial wellness of the individuals served, while promoting their dignity and improving the quality of their lives.

## Qualitative Methods

In order to better understand the affects of massage therapy and self-efficacy for people living with HIV and AIDS, this study utilized qualitative methods. The term qualitative research is used to refer both to techniques (of data collection and analysis) and to a wider framework for conducting research, or paradigm (Brown & Clarke, 2013). Qualitative approaches including feminism (Crawford & Unger, 2004), post-structuralism (Gavey, 1989), hermeneutics (Schwandt, 2000), and phenomenology (Langdrige, 2007) in different ways questioned or rejected the idea of an observable, independent (singular & universal) reality, where humans understood as responding to external and internal influences (Braun and Clarke, 2013). One thing absolutely fundamental is that it tends not to assume there is only one correct version of reality or knowledge (Braun & Clarke, 2013). A quantitative research design is appropriate when questions about ‘how many’ or ‘how often’ are asked while a qualitative research design is preferred when questions about ‘what’, ‘how’ or ‘why’ a phenomenon exists are asked (Green & Thorogood, 2009).

A good qualitative research design is one in which the method of analysis is appropriate to the research question, and where the method of data collection generates data that are appropriate to the method of analysis (Carla Willig, 2001 p. 21). There are four types of qualitative data collection methods: “observations, interviews, documents, and audiovisual materials” (Creswell, 2013, p.159) For the purpose of this study, the methods most appropriate were observations, interviews and documents. Documents included the interview questions, answers to the questions, notes from the massage therapy sessions, final interview questions and the journals. Data collection included the transcribed notes, interview notes, observation notes,

participant generated documents, document analysis and semi-structured interviews all related to the study.

### **Phenomenology**

The research design most appropriate for this study was phenomenology.

Phenomenology is the study of lived experiences (Creswell, 2013). Herbert Spiegelberg explained phenomenology as “the name for a philosophical movement whose primary objective is the direct investigation and description of phenomena as consciously experienced, without theories about their causal explanation and as free as possible from unexamined preconceptions and presuppositions.” Phenomenological research is a strategy of inquiry in which the researcher identifies the essence of human experiences about a phenomenon as described by participants (Creswell, 2009). Understanding the lived experiences marks phenomenology as a philosophy as well as a method, and the procedure involves studying a small number of subjects through extensive and prolonged engagement to develop patterns and relationships of meaning (Moustakas, 1994).

In this process, the researcher brackets or sets aside his or her own experiences in order to understand those of the participants in the study (Nieswiadomy, 1993). Phenomenology lets the researcher “enter another’s world and to discover the practical wisdom, possibilities, and understandings found there” (Polit & Beck, 2008, p. 229). An advantage of the phenomenological approach is that it focuses on how the individual experiences the world and how this human experience is lived (Dowling, 2007).

## **Social Cognitive Theory**

Social Cognitive Theory (SCT) addresses both the psychosocial dynamics influencing health behavior and methods for promoting behavioral change (Baranowski, Perry & Parcel). Within SCT, human behavior is explained in terms of triadic, dynamic, and reciprocal model in which behavior, personal factors (including cognitions), and environmental influences all interact (Baranowski et al.). Among the crucial personal factors are the individual's capabilities to symbolize behavior, to anticipate the outcomes of behavior, to learn by observing others, to have confidence in performing a behavior (including overcoming the problems in performing the behavior), to self-determine or self-regulate behavior, and to reflect on or analyze experience (Bandura, 1997). Social cognitive theory produced the concept of self-efficacy as the perceived capability of a person to perform a specific action required to achieve a concrete goal (Bandura, 1997). This concept is competence-based, prospective and action-related (Bandura, 1997).

### **Self-efficacy**

To date, much of the research about massage therapy and HIV/AIDS has been quantitative and focused on symptom-specific findings such as those mentioned previously. Only a small number of the studies were done with a qualitative methodology and of all of those, none of them have examined the benefits of self-efficacy for people living with HIV/AIDS. Self-efficacy is defined as "the conviction that one can successfully execute the behavior required to produce the outcomes" (Bandura, 1977b). Bandura and colleagues (Bandura, 1977b, 1978, 1982, 1986, 1997) proposed that self-efficacy is the most important prerequisite for behavior change because it affects how much effort is invested in a given task and what level of performance is attained. Bandura moved SCT from the domain of mechanistic theories of human behavior to the views of the person as an agent in control of his or her own life. A growing body of literature

supports the importance of self-efficacy in accounting for initiation and maintenance of behavioral change (Bandura, 1995, 1997).

### **Research Question**

The primary question that guided this study was: *How does massage therapy affect the self-efficacy of people living with HIV/AIDS?* The goal of this qualitative study was to identify how massage therapy might affect the self-efficacy for people living with HIV/AIDS.

### **Sampling Method**

For the research study, convenience sampling was used from AFAN. Convenience sampling is a very common approach in participant-based research (Patton, 2002), both qualitative and quantitative, and refers to a sample selected because it is accessible to the researcher. This was done by hanging up fliers inside AFAN and by leaving fliers on the community resource table. The fliers consisted of the information regarding the study, the contact information for the principal investigator and researcher and the IRB protocol number. Potential participants called the researcher to discuss the study and schedule the appointments after inclusion verification.

Fourteen participants called the researcher and of those, 12 completed the study. Of the two that did not complete, one received massage and never came back to be interviewed. This participant did not respond to any phone calls to try to reschedule. The other participant scheduled and never showed up or answered any follow up telephone calls.

The study had a couple of interesting components to contend with. Once the researcher received IRB approval, recruitment began at AFAN by placing copies of the IRB-approved fliers at AFAN as well as on the community resource table in the lobby. This happened to coincide with the beginning of holiday season and the researcher was anticipating a slow start. The

opposite occurred, with ten of the participants completing before the Christmas holiday. A systematic recruitment strategy for inviting participants from a sampling frame was employed to obtain enough participants to answer the research question (Green & Thorogood, 2014). Of the fourteen inquiries, twelve completed the study.

**Table 1.** Demographics of study participants

<b>Participant</b>	<b>Gender</b>	<b>Age</b>
Participant 1	Male	67
Participant 2	Female	N/A
Participant 3	Male	55
Participant 4	Female	30
Participant 5	Male	57
Participant 6	Male	40
Participant 7	Male	54
Participant 8	Male	N/A
Participant 9	Male	48
Participant 10	Female	60
Participant 11	Female	51
Participant 12	Female	55
Participant 13	Female	48
Participant 14	Female	36



## Summary

Convenience sampling was effective for this study. The participants were self-selected with the exception of the participant who was referred to the study by his social worker. Recruitment was not difficult and many of the participants noted that the offer of a free massage was their reason for participating.

## Data Collection

AFAN was supportive about the request to conduct this research from the initial interaction. The researcher met with the patient education supervisor, Andrew Evanski to explain the research design and process. He was receptive to the study and introduced her to the director, Antiocho Carrillo. He agreed to allow AFAN and its' clients to participate in the research; once IRB approval was obtained and participants were recruited and scheduled, the researcher was provided a designated massage therapy treatment room at AFAN. The researcher set up the room to create a relaxing and tranquil space where the participants could relax and unwind. A portable massage therapy table was in the center of the room with a couple of chairs and a small table in corners of the room. The researcher carried the IRB at all times, related documents, participant journals, and a researcher journal for participant observation field notes.

As each participant was picked up, the researcher would introduce herself and speak with the participant asking the intake questions approved by the IRB and again obtain verbal consent. The participants would tell the researcher how they were feeling as well as where they were experiencing pain. Once they reached the massage room, the participants often expressed surprise that the room was so different from the rest of the building and some were surprised that it was a full-body massage.

A pre-assessment was conducted with each participant by the massage therapist to determine the client's needs on the day of the massage so the massage therapist could provide the best care. The therapist wrote down what the participant told her and performed the massage accordingly. The researcher spoke with the participants about where to place their belongings, and how to lay on the table for the massage. As the researcher stepped out of the room, to wash hands, jot down a couple of notes from the observations and intake questions and mentally and physically prepare for the session. The researcher had various relaxing spa-like music selections to listen to and would ask the participant if they wanted music and would play those as the massage began. Each massage followed the protocol approved by the IRB and concluded with the researcher thanking the participant and stepping out of the room.

### **Data Collection Observations**

The researcher arrived at AFAN and there was a man in the lobby in a wheelchair and all of his belongings fell off of his lap as the researcher entered the lobby. The researcher stopped and picked up the belongings and began speaking with the man. They introduced themselves and his speech was difficult to understand. He wondered if he could participate in the study? The researcher scheduled him for a massage and interview and proceeded into the back to set up for appointments.

Participant one and two showed up early and expressed positive remarks about the massage, the treatment room and how differently they felt coming out of the massage than they did coming in. When the massage had ended and each participant was finished, they were given a bottle of water, the journal and instructions about how to use it. The interview date and times were confirmed. Both participants agreed to return on the scheduled date and time for the interview.

Participant one returned for the interview and had a lot to say about this experience and his experiences from his former home because massage therapy was offered as a standard part of care. Participant two did not return for her interview and never returned the phone calls or messages left for her trying to reach her. This was surprising to the researcher as this participant expressed that she was unaware that the massage would be a full-body massage. During the treatment and following the treatment, she expressed such gratitude and told the researcher how much better she felt.

In between the first day of data collection and the date of the interviews for the first two participants, the third participant called and we were able to schedule her massage on the same day as the first two participants completed their interviews. The third participant was quite interested in the study and was verbose. She spoke throughout most of the massage and expressed many thoughts about her body, the disease and how long it had been since she had experienced a professional massage.

When she turned over and was supine on the table, she became very quiet and seemed able to relax into the remainder of the treatment. As the treatment ended, the researcher closed the session and thanked her for participating and left the room. When she was dressed, the researcher came back in with a bottle of water and spoke about how she was feeling. In the course of the discussion, the researcher forgot to give her the journal. The interview date and time were confirmed and the third participant thanked the researcher and left.

The day the researcher was interviewing the third participant one of the social workers at AFAN approached her and asked if she would be willing to work with a client of hers. A flier was given to pass along to him as they spoke about what he was going through and how he might benefit from massage therapy. The third participant arrived early for her interview and the

researcher apologized for forgetting to give the participant the journal. The third participant laughed and said that she had told her mom and friends all about the experience and said that she could have stayed on the table for hours and that the researcher could have just worked on her back the whole time because she has so many problem areas there.

The researcher made the third participant a cup of hot chocolate and the interview began. The third participant had been a massage therapy student when she was younger and expressed how much this could help her. The interview went very well and the participant spoke at length about her experiences and how she thinks regular massage therapy could help her and others.

The fourth participant referred by the social worker called several days later and we were able to schedule his appointments for the following week. On the day of his massage, the researcher picked him up from the lobby and they spoke briefly on the way back to the treatment room. He appeared skeptical and uneasy. The researcher explained exactly what she would be doing and asked him about his body and pain.

He expressed a long history of trauma and seemed to relax more as he spoke. The researcher left the room as he got onto the table and returned with the relaxing music on and began the massage. The fourth participant expressed some relief during the treatment and when the session ended, he appeared visually more relaxed. He said he did not realize how much pain he was carrying. The researcher gave him a bottle of water as well as the journal and we confirmed the interview date and time.

The fourth participant arrived early for the scheduled interview and said that he was in a lot of pain on this day. The researcher asked him where he was hurting and he said that his head hurt him. As we entered the massage treatment room, the fourth participant asked the researcher if she could turn the lights out during the interview because of the pain in his head. The

Himalayan salt lamp to provide some soft lighting. Not having the overhead light provided some difficulty in reading the questions and the interview was conducted. The fourth participant expressed his isolation and his unwillingness to let anyone be close to him. Throughout the interview, the fourth participant expressed pain in all areas of his life and an overwhelming detachment from others. He thought the massage might have helped, but that his life just was the way it was. He was unsure if this treatment could help him if it was provided regularly but said he would try it.

The fifth and sixth participants called during the week of Thanksgiving and the researcher scheduled them for their massage therapy appointments and interviews. The fifth participant ended up cancelling his appointment time and rescheduling for another date and time as there was a death in his partner's family. The sixth participant showed up for the massage and was early. The researcher picked up the sixth participant from the lobby and conducted the pre-assessment questions.

The sixth participant stated that he felt alright but just wanted to have massage. The researcher and sixth participant spoke for a bit about what his body has been through and then the researcher left the room while the sixth participant undressed and got onto the table. The massage protocol was followed and the sixth participant expressed relief throughout the massage. When the session ended, the researcher closed the massage session and left the room while the sixth participant got dressed. When the sixth participant was dressed, she gave him a bottle of water and a journal. They spoke about his experience during the massage and he felt really good.

When the sixth participant left the treatment room and returned to the front lobby, there was a man seated in the lobby who inquired about the study. The researcher spoke with the man

and he asked if he could participate. They set the dates and times up for both the interview and massage the following week and he became the seventh participant. The seventh participant never showed up and did not return phone calls to attempt to reschedule. However, the sixth participant arrived for his scheduled interview and spoke about how different he felt the day he received the treatment.

The eighth participant called and scheduled for massage and the interview. The first participant for this day was the first gentleman that met the researcher in the lobby when his belongings dropped off his lap a couple of weeks earlier and is listed as the third participant. He is wheelchair bound and requested the massage be done without him transferring to the table and the researcher agreed.

The protocol was followed with modifications for the third participant and he seemed to relax with the treatment. When the session ended, he expressed gratitude and said he felt much better. The researcher left the room and got him a bottle of water and a journal and then confirmed the interview date and time.

The third participant expressed trouble with transportation, so it was decided that they would do the interview by phone at the same time and date they had agreed upon. The third participant was happy to not have to come so far again. The researcher thanked him for his time and efforts and went with him to the lobby where the ninth participant was seated. After the introduction and allowing a few minutes while the room was changed the massage began.

When the researcher returned and picked the ninth participant up, they went through the pre-assessment questions and he said that he had been having some trouble with his back. When asked which part of the back he was referring to, he said the whole thing. The researcher explained the study again and the massage protocol and left the room while the ninth participant

undressed and got onto the table. The massage went well and the participant seemed to relax. When the session ended, the researcher closed the session and left the room. Once the client was dressed, the researcher gave him a bottle of water and a journal. He thanked her and said how much better he felt and that he had never had a massage before. He then asked for a hug and left. The researcher walked him to the lobby and thanked him for his time.

About 30 minutes after the session ended and the researcher had left AFAN, the phone began to ding with the indication that text messages were coming in. The researcher parked and read through the messages and they were from the ninth participant and were sexually explicit. The researcher promptly wrote back that this massage is for research and contacted her Principal Investigator, Dr. Carolee Dodge-Francis, to let her know what was happening. Dr. Dodge-Francis advised the researcher to either not interview this participant in person or to drop him from the study. The researcher wrote back to the participant and asked that they interview by phone at the same date and time the in-person interview was scheduled and he agreed.

When the scheduled phone interview date and time occurred, the ninth participant did not answer his phone. Later that evening, the ninth participant sent the researcher a text message stating that he was ill and that is why he did not answer the phone. He wrote that he had lost his voice but would do the interview by text. The researcher agreed and immediately proceeded through the questions. The ninth participant answered each of the questions and as the message was ending, asked the researcher if she was flirting with him. The researcher wrote back no and the ninth participant said he was going to bed and ended the interview.

The third participant's interview was on the same day as the ninth participant was scheduled. He answered the phone and the interview was conducted. The third participant's speech was difficult to understand but the researcher and participant were able to get through the

interview. The third participant was very disappointed about his living situation, the lack of services in Las Vegas and hoped that massage would be able to be added to the care. He said that he slept much better in the days following the treatment and was able to relax.

Participants ten, eleven and twelve called and their massages and interviews were scheduled. The first two, ten and eleven, were scheduled for their massages at the end of the week before Christmas. Participant ten was in the lobby and the researcher went to pick her up and they had a good conversation and intake questioning prior to the massage.

Participant ten expressed how long it had been since she had been able to have a massage and said her body needed this. The researcher left the room while she undressed and got onto the table. When the researcher returned the tenth participant was all ready for the treatment and seemed to relax during the treatment. There was one point during the session that the client began to cry and told the researcher that she has been dealing with so much since moving to Las Vegas.

The researcher held her hands on the client's back and listened while she cried and spoke. When the session ended, the participant was tearful and spoke of the isolation and stress of the disease. She said how much she thought massage therapy would help people feel better and handle their stress. The researcher listened and gave the tenth participant some water and a journal. The researcher and tenth participant agreed and confirmed the date and time for the interview.

The eleventh participant was in the lobby when the tenth participant and researcher returned to the lobby. The researcher said goodbye to the tenth participant and then introduced herself to the eleventh participant. The researcher let her know that she needed a few minutes to change the room over and would be up to pick her up as soon as she finished. As the researcher



picked up the eleventh participant, they discussed the pre-assessment questions and the eleventh participant did not have any major problem areas and told the researcher it had been a long time since she had her last massage.

The eleventh participant was looking forward to this treatment and the researcher explained the process and left the room while the eleventh participant undressed and got onto the table. As the researcher returned, the eleventh participant said she already felt better just being in the room. The massage protocol was followed and the eleventh participant did very well and relaxed. When the massage ended, the eleventh participant and researcher confirmed the interview date and time.

The twelfth participant was scheduled for her massage on the same day as the previous two were scheduled for interviews. She arrived on time and completed the pre-assessment with and said sometimes it hurts in her legs when she is walking and said she stated that her stress levels are very high. The researcher followed the protocol and adjusted some of her techniques to help the client relax. The session went very well and the twelfth participant expressed relief when the massage was over. The researcher left the room and returned with water and the journal for the participant. The twelfth participant thanked the researcher and confirmed the date and time for the interview.

The tenth and eleventh participants both arrived for their interviews on time. The tenth participant's interview went very well and the participant addressed how much better she felt following the treatment and how much more connected to her emotions she felt on the days following the treatment. The eleventh participant had never experienced massage before and spoke of her life and the struggles she is having. She expressed anger at the person who knowingly infected her and at the person who she and her son are currently living with. She

spoke about how this massage was something different, something where she didn't feel like, "a rat in a lab." The thirteenth participant was interviewed by phone due to the holiday. The interview was conducted and the participant expressed relief from the pain in her legs and reported feeling more peaceful.

A couple of weeks passed between the holidays and no potential participants had called. The researcher went over to AFAN to check the fliers to make sure they were still there. The researcher brought more of the approved fliers to leave out on the community table and then left. Several days later, the thirteenth and fourteenth participants called and the researcher discussed the study with each of them and as they agreed to participate, they were each scheduled for the massage sessions as well as the interviews.

The thirteenth participant arrived for her massage and the pre-assessment questions were asked. She did not have any physical complaints and just said she gets stressed and has some anxiety. The researcher explained the massage and then stepped out of the room while she got ready for the massage. When the researcher came back into the room and did the massage, the thirteenth participant stated how relaxed she felt. When the session was over, the researcher left the room while the participant got dressed. She returned with water and a journal for the participant. The participant told the researcher that she felt so much better and thanked her for the massage. They returned to the lobby and confirmed the interview date and time.

The thirteenth participant and researcher's schedules conflicted so they agreed to interview by phone. The interview with the thirteenth participant went well and she told the researcher that one of her good friends commented on how her energy was so different following the massage. She was interested in this research and hopeful that it will continue for the clients at AFAN.

The fourteenth participant was sitting outside smoking when the researcher arrived. The researcher and participant introduced themselves and the researcher let the participant know it would be a few minutes while the room was set up for the treatment. When the researcher was finished with the preparations, the participant came up from the lobby and they went back to the treatment room and discussed the pre-assessment questions.

The fourteenth participant said that her muscles are tense and she has a lot of anxiety. The researcher left the room while the participant undressed and got onto the massage table. When the researcher came back in, the participant said that she already felt better and the massage began. The participant was relaxed throughout the session. When it was over, the researcher thanked the participant and left the room. When the participant was ready, the researcher gave her a bottle of water and confirmed the interview date and time. The interview with the fourteenth participant was done by phone and the participant answered all of the questions. She felt much more relaxed following the treatment and reported less anxiety.

The study followed the four types of qualitative data collection methods: “observations, interviews, documents, and audiovisual materials” (Creswell, 2013, p. 159). This study utilized observations, interviews and documents. The field observations were especially helpful in collecting data with each participant that could have been missed without the documentation on the day of the intervention.

### **Data Collection-Interviews**

Each participant was asked to participate in a 50-minute massage, to journal that week about the experience and to be interviewed at the end of the week. The massage was administered for 50 minutes and followed the protocol listed in the appendices. Following the massage, the participant spoke with the therapist briefly to describe their experience and was

given a journal to record thoughts. At the end of the week, the massage therapist interviewed the participants. The researcher wanted the interviews conducted with a week so that the participant had a strong memory of the experience. The data was recorded, transcribed and coded. This continued for each of the participants until saturation occurred. The participants' privacy was of utmost importance and in alliance with IRB and HIPPA regulations.

### **Interviews**

Interviews were utilized as a data collection tool for this research study after each participant received an hour massage one-week post. An interview is defined by Braun & Clarke as a one-on one method of collecting qualitative data, where a participant responds to a researcher's questions. Interviews are traditionally conducted in person, but can also be conducted virtually (Braun & Clarke, 2012).

According to US sociologists Gubrium & Holstein, 2002, we live in an, 'interview society'. The social prevalence of interviewing means that interviews are perhaps the most familiar data collection tool both for new qualitative researchers and for participants (Braun & Clarke, 2012). Interviews are certainly one of the most common methods of data collection within the social and health sciences (Briggs, 1986), and the most common qualitative method of data collection (Braun & Clarke, 2012).

We define interviewing as a 'professional conversation' (Kvale, 2007), with the goal of getting a participant to talk about *their* experiences and perspectives, and to capture *their* language and concepts, in relation to a topic that *you* have determined (Rubin & Rubin, 1995). This study used the semi-structured interview. The semi-structured interview is an approach in which the researcher has prepared an interview guide before the interview, but does not rigidly adhere to it, either in terms of precise wording or questions, or to the order in which questions

are asked (Braun & Clarke, 2012). This technique proved to be valuable and many of the participants shared experiences that helped shape the understanding of their experiences living with HIV/AIDS. Question wording and order are contextual and responsive to the participant's developing account (Braun & Clarke, 2012). Often, while listening to the interviews during transcription, the researcher's thoughts would echo those of the participant with regard to tone, inflection and wording. In the words of US sociologists Rubin & Rubin (1995:42), the ideal qualitative interview is 'on target while hanging loose.'

In semi-structured interviews, participants are given the opportunity to discuss issues that are important to them and that the researcher has not anticipated and are not on the interview guide, the researcher needed to be flexible (Braun & Clarke, 2012). The semi-structured format sometimes led to very long interviews that would veer off topic. This researcher learned while transcribing some of the earliest interviews to try to get the participants back on track a bit sooner. Partly because the qualitative interview arose as a method in response to critiques about the 'depersonalization' of (then) standard social scientific methods of data collection (Oakley, 1981), face-to-face contact between researcher and participant was typically viewed as the ideal way to collect interview data; the 'gold standard' (Novick, 2008).

The interviews that were conducted in person tended to be longer in duration, deeper in subject matter and much more personal. In a qualitative interview, the researcher asked the participants a series of (ideally) open-ended questions, and the participant responded using their own words. When interviewing face-to-face, the researcher and participant had a conversation, which was audio-recorded and the recording then transformed into written text, narrative transcripts, ready for analysis (Braun & Clarke, 2012).

## Written Documents: Journaling

Journaling is used in phenomenological research studies to record participant experiences in their natural contexts. Research conducted by Hayman, Wilkes, & Jackson, (2012), identified the challenges associated with using journaling as a method of data collection and offered strategies for effectively managing the challenges. Journaling was defined in this paper as referring to the process of participants sharing thoughts, ideas, feelings and experiences through writing and/or other media. Haymen et al., found three main challenges that affect journaling as a method of data collection: poor participation, feeling exposed and staying on track.

They identified six strategies to promote participation in journaling as: coaching participants, limiting the journaling period, providing follow-up contact, promoting comfort, ensuring safety and providing clear content expectations. Journaling as a method of data collection has long been accepted as a valid method of accessing rich qualitative data. The authors noted that by acknowledging the common challenges associated with the process of journaling that are experienced by the participants, researchers employing this data collection method can promote constructive and valuable participation.

Researcher-directed (or solicited) diaries are diaries produced for the purpose of research (Braun & Clarke, 2013). They require participants to record their thoughts, feelings, experiences and/or practices over a specified period of time. Researcher-directed diaries can take many formats: hard copy, handwritten diary; typed online or emailed electronic diary; audio-recorded diary; 'performed' video diary; or a (creative) 'scrapbook' diary in which participants write, draw, and cut and paste in mementos, pictures from magazines, postcards, etc. (Thompson & Holland, 2005). Video (and email, online and audio) diaries are thought to be particularly

‘empowering’ for participants because they can edit their entries before submitting their diaries, giving them control over what they submit as data (Holliday, 1999).

Diaries require regular entries over a period of time. Participants can be asked to make entries once (or more) a day, a week or a month, for periods as short as a week and as long as several months (Braun & Clarke, 2013). Diaries range from very structured, which specify exactly what information participants should record, and when, to very unstructured, which specify little more than the topic (e.g. Holliday, 1999). Phenomenological theoretical position, which is concerned with lived experience, this provides an umbrella under which certain types of questions (about lived experiences), methods (interviews), diaries and IPA analysis and answers fit.

U.S. ethnographers Zimmerman and Wieder (1977) pioneered the ‘diary-interview method’, where participants keep a diary for a particular period of time and then discuss and elaborate on their entries in an interview. The diaries are used to stimulate and enrich the interview method or as an additional data form. Journals were given to each of the participants following their massage treatment, with the exception of one participant. Of the fourteen participants, only one used the journal that was provided.

This data collection technique was not very useful for the study. Many participants shared that they had thought about using the journal, but then forgot or did not know what to say or how to say what they were experiencing.

Poor participation in journaling has been identified as a common barrier to the success of the method (Richardson 1994, Stone et al 2002, Taylor et al 2006, Välimäki et al 2007). Failure to participate can be attributed to participants lacking the confidence to write, the length of time it takes to complete a journal compared with a single interview, and anxieties associated with the

participant writing his or her feelings and experiences as possible permanent records (Hayman, Wilkes, Jackson, 2012).

### **Data analysis & interpretation**

The researcher listened to the audio recording of the interviews before beginning transcription. As the transcription began by the researcher, each interview was transcribed word for word. Once the transcription was completed, the researcher listened to the interview again to ensure accuracy.

Data was analyzed using a phenomenological lens. This study utilized Interpretive Phenomenological Analysis (IPA). IPA was developed by British health psychologist Jonathan Smith and his colleagues; it focuses on how people make sense of their lived experiences; it can be used to analyze individual cases to generate themes across a small group of participants (Cresswell, 2012). IPA is phenomenological because it is concerned with how people make sense of their lived experiences (phenomenology is focused on how people perceive and talk about objects and events); it is interpretive because understanding how people make sense of experience is achieved through interpretive activity on the part of the researcher (Creswell, 2012.)

Data was coded for themes that emerged throughout the interviews and grouped by prevalence. Initially, there were themed by categories. These were condensed to four main themes. Dr. Dodge-Francis assisted as the intercoder and notes were compared for themes. The transcriptions were then sent to the participants for their review and any revisions or additions. None of the participants had any changes to the data set. The themes were agreed upon by the researcher and Dr. Dodge-Francis.



### **Data Storage**

For data storage, pre-assessments, interview transcripts, journals and observational field notes were kept on a password-protected computer or in locked file cabinet with Dr. Dodge Francis. In accordance with a UNLV IRB protocol all interviews transcripts gathered in this study were kept confidential. Each participant was given a pseudonym for the interview data and then numbered in order of participation for the dissertation. The interviews were audio recorded and deleted following the transcription. All information will be kept for five years after completion of the study and the audio and transcriptions will be destroyed.

### **Role of the Researcher**

As one of the researchers in this study, the custodian of all data, and the data analyzer, researcher responsibilities included developing and implementing all aspects of the study. These aspects included developing the massage therapy protocol, participant recruitment and consent, creating all interview questions, conducting the massage therapy, conducting the participant interviews, and transcribing the interviews. Data analysis occurred with the phenomenological approach. To ensure objectivity and validity of data analysis, the assistance of an experienced research faculty member through an intercoder agreement with Dr. Dodge Francis was used.

### **Gaining Access**

Gaining access to the participants was not an issue for this study as the researcher has a long-standing relationship with the organization and this is where the researcher interests began twelve years ago while volunteering as a massage therapy student. The researcher's involvement with AFAN began fifteen years ago while she was an undergraduate student of communications. The researcher volunteered at AFAN and provided help with their public relations. Following the years of volunteering in a public relations capacity, the researcher began to study massage

therapy and then volunteer as a massage therapist at AFAN as part of her work for a Pathology course. That course began the researcher's journey back to UNLV to learn how to conduct this research.

### **Making Contact**

Participants had a telephone contact printed on the recruitment fliers that were posted at AFAN as well as on those that were on the community table. Participants initiated the contact by calling and then we would discuss the purpose of the study and what was required of them. If they agreed to participate, an appointment was scheduled for massage and interview.

### **Inclusion Criteria**

Participants were recruited from AFAN's sites as convenience sampling. The inclusion criteria included adults 18 years and older that were HIV-positive and willing to participate in all three parts of the study including the massage, journal entries and interview. Each step was discussed with the participants when they called to inquire about participating in the study and then again at the massage session.

## Timeline & Data Collection Sources

In order to secure sufficient data to answer the research question, a timeline and data collection process were outlined and followed.

Start Date	End Date	Steps
08/28/15	09/08/15	Complete IRB.
08/24/15		Starting date for fall semester.
10/01/15	10/30/15	Introduction to proposed research to AFAN clients and recruitment.
11/02/15	11/23/15	Participants will receive massage therapy, questionnaire and interviews.
11/23/15	01/04/16	Analyze, organize and transcribe data by themes.
01/04/16	03/15/16	Work with data to write chapters 4 & 5
04/04/16	04/08/16	Present research findings and dissertation to committee

## Reliability

Several strategies were employed to ensure study reliability. Reliability in qualitative research refers to the strength of findings of data sets among more than one coder (Creswell, 2013; Merriam, 1998). To ensure the reliability for this research, this researcher employed an intercoder agreement. Intercoder reliability refers to the degree in which two or more independent coders agree on the coding of the data while using the same coding strategy

(Armstrong, Gosling, Weinman, & Marteau; Creswell, 2013). Dr. Carolee Dodge-Francis, an experienced qualitative research faculty member was in the position of intercoder.

### **Ethical Considerations**

Confidentiality is an ethical responsibility in social research (Green & Thorogood, 2009). Every participant's identity was protected by using password protected computers and software. Each participant was given a pseudonym for the interview data and then numbered in order of participation for the dissertation. All the interviews were audio recorded. Transcriptions and written materials were locked and stored on campus at the University of Nevada, Las Vegas. All aspects of the research abided by the IRB and HIPPA regulations. There was a safeguard in place for participants if needed. While AFAN gave permission for the study, some of their services were available if physical, mental or emotional responses arose.

### **Limitations of the study**

This study was conducted with a sample population of AFAN clients. Because this study was limited to AFAN clients in care, the research could not make conclusions for all people living with HIV/AIDS. Furthermore, because this study was limited to AFAN clients in care, the researcher could not make generalizations about people living with HIV/AIDS that are not in care.

The topics and themes in the research study may also be a limitation. Self-efficacy changes can be difficult to understand, acknowledge and discuss, especially with only a one time massage intervention. Since this research study began with massage therapy provided from the sole researcher, AFAN clients may feel differently discussing how their experiences with the

practitioner. However, as the sole researcher and massage therapist, it was a honor to create a safe, healing environment where clients would feel safe to relax and unwind.

The academic connection to the proposed research study can also be viewed as a limitation.

### **Biases**

As a current doctoral student in Public Health and practicing massage therapist with twelve years of experience caring for terminally ill patients as well as those with HIV/AIDS, implicit biases are foremost. This awareness of biases was utilized in the approach for the proposed research study. Plus it provided an opportunity to address any biases that may have affected data collection and research.

This study was conducted using qualitative research where the interview responses were transcribed and coded by the researcher and an additional faculty member. Every effort was made to ensure neutrality from the biases of this researcher and how that could impact the interpretation of the results.

### **Summary**

This research sought to know how receiving massage therapy affects self-efficacy for the people living with HIV/AIDS who received the care. This research will fill a gap in the current research about the self-efficacy benefits of massage therapy for people living with HIV/AIDS. This research also fills a gap where a strong link has yet to be made that would help establish touch as one of the ways to treat HIV/AIDS as well as to provide care.

## Chapter 4 Results

The research question that informs this study and provides reflection of the literature. *How does massage therapy affect the self-efficacy for individuals living with HIV/AIDS?* The qualitative data collected from this study attempts to answer the above research question. Four themes emerged from the narrative data analysis: self-efficacy, human connectivity through touch, physical responses, and emotional release.

### Self-efficacy

Bandura (1993) states “perceived self-efficacy is concerned with people's beliefs in their ability to influence events that affect their lives. This core belief is the foundation of human motivation, performance accomplishments, and emotional well-being. Many of the participants expressed within their narrative statements that were a reflection of these self-efficacy characteristics.

Participant 6 discussed how he keeps entirely to himself because he doesn't trust anyone he has met in Las Vegas.

I don't want to make any friends. People here just want to take, take, take.  
(Participant 6, 11/30/2015)

He went on to tell stories about kind deeds unreturned or unnoticed.

Vegas has the weirdest people. It brings around a weird side of humanity. I have given people clothes, and no one calls to say how are you doing? What's going on? So you know, I don't need no friends out here.  
(Participant 6, 11/30/2015).

His narrative portrayed him as the most detached person socially from his environment. He did say that he thought massage therapy made a difference and if it were offered regularly, he would like to participate. His statements strongly correlate to Bandura's Social Cognitive Theory in which he states that people are neither driven by inner forces nor automatically shaped and

controlled by their environment (Bandura, 1986). They function as contributors to their own motivation, behavior and development within a network of reciprocally interacting influences. Baranowski et. al., explain that within SCT, human behavior is explained in terms of triadic, dynamic and reciprocal model in which behavior, personal factors and environmental influences all interact. His statement of returning for massage therapy again contrasted the isolated person reflected in his statements about not needing friends or people. His commentary highlights this dynamic of SCT and his experience with receiving the massage contributed to his willingness to return and participate in more massage therapy when offered.

Moyer, Rounds & Hannum's (2004) found that the greatest effects of massage therapy are the reductions in trait anxiety and depression, which are similar in magnitude to the benefits provided to those that would undergo psychotherapy. Diego, Field, Hernandez-Reif, Shaw, Friedman & Ironson (2001), wrote about massage therapy affecting anxiety and depression in their research. Participants who received massage therapy versus those who experienced relaxation therapy reported feeling less anxious and they were less depressed and showed enhanced immune function.

Yes, I mean I am kind of shy about saying this but I felt very loving, my normal loving self. I wasn't angry or cranky or anxious, or nervous or depressed. Yeah, I felt like a surge of love. (Participant 13, 01/22/2016).

She continued to say that her change in mood and energy was noticeable to a friend of hers that she was communicating with on the day of the massage. A friend wondered what was different and she told them that she had just had a massage.

The willingness to be part of his environment was expressed by Participant 7, when he spoke of the following:

Oh yes! I never want to go out. When I do things, I just want to go back home and watch television, get in the bed and take off my clothes. But

when I left here, I went shopping. I had the energy, I had the attitude, you know, I was just talking to people. You know, I was just taking my time, enjoying myself and it felt really good. Then after that, I went and treated myself to Cane's. The Caniac. And I used to have to drive through the drive through and I thought no, I just want to sit and relax and eat and you know, so and it was just good and I just sat there and I just ate (Participant 7, 12/04/15).

These responses reflect how the experience of massage therapy might impact the self-efficacy for the participants. Massage therapy has also allowed them to feel as they have more control of the disease process. These changes are all important medically and to the quality of life.

### **Human Connectivity Through Touch**

Since the beginning of the AIDS epidemic, massage therapy has been beneficial for those with the virus. In the beginning, the only treatment options were palliative. Touch or human contact was reported as being one of the most comforting treatments and was often the only treatment available. When patients received massage therapy, they reported positive changes in the immune system, along with improved attitudes and feelings (Field, et. al., 2001

One of the major themes that emerged was the sense or feeling of human connectivity through touch. The narratives substantiated previous literature with regard to massage therapy and HIV/AIDS. The early touch research by Spitz found strong evidence of the importance of touch and human connectedness. Spitz's research clearly demonstrated that while infants had the "necessary" elements of survival such as shelter and food, but with the absence of touch and human contact, many infants suffered increased mortality rates (Cassileth & Vickers, 2003). Research shows that human beings require touch to function and thrive.

Participant 11 spoke of an awareness and self-care realizations that she had following the massage. Her words illustrate the findings of Price, Diana, Smith-DiJulio, & Voss (2013) in



which they stated that self-care skills for persons living with HIV are needed to better cope with the common symptoms and emotional challenges of living with this chronic illness.

Yeah, its like you know you are the first person who has been able to touch me in like, 2 years.(Participant 11, 12/18/2015).

Her awareness of human touch and how she feels unable to do anything for herself is an important part of how human touch can change behavior outcomes. She expressed deep frustration and resentment about her condition.

Another pioneer in the touch field, H. Harlow, speaks of, “Touching: The Human Significance of the Skin, “ which clarified a major message: tactile stimulation is essential to normal development and even to survival (Cassileth & Vickers, 2003). Without human touch, human beings suffer and do not thrive. The Touch Research Institute produced research supporting this and cites how massage therapy is older than recorded time and rubbing was the primary form of medicine until the pharmaceutical revolution in the 1940’s (Field, 1998).

The following quote correlates with research conducted by Ho, Robles, & Pawluch that discussed the deep resentment and frustration HIV/AIDS patients feel about their medical care:

I mean, everything I do is I feel like a test rat, I feel like a rat in a lab.  
(Participant 11, 12/18/2015).

Participant 11’s comments reflect the de-humanization of health care and offered an insight as to how patients feel as they are being treated. Birk et al., (2000), found that massage combined with stress management favorably alters health perceptions and leads to less utilization of health care resources.

Participant 12 expressed sentiments that echoed Bowlby & Spitz’s early research about the importance of human touch

Physically, mentally, even with my sleep and waking up with a positive mood and you know I guess the connection you have with the

human touch you know like a hug, you know how a hug makes you feel good, it puts you in the same kind of thing (Participant 12, 12/24/2015).

Many of the participants expressed feelings of reconnection in various forms, how the years of living with HIV infection have affected them, the essence of humanness, the importance and various meanings of human touch and how massage therapy helped them release emotions, states of mind and experiences.

Participant 10 expressed the experience of being touched that is an echo of what the early touch researchers had discovered. Research from Spitz (1940) showed that babies, well fed and warm, but not held or touched, tended to wither away and die:

Just having your body, just by being physically touched all over your body it just created what's the word, I am trying to think of the word, of humanness, of humanness (Participant 10, 12/21/2015).

Participant 5's quote also expressed how the human contact made him feel. His words reflect the same sentiment as Bowlby & Spitz and the many others who followed in their research footprints about human touch:

You know you just need to have some laying of the hands on you. (Participant 5, 12/05/2015).

He went on to say;

Oh, I felt wonderful. It's been 30 years of all of this shit (Participant 5, 12/05/2015).

Years of living with the disease and all of the hospitalizations this participant had been through left him tired but upbeat. He expressed that his life is his to create.

These responses all speak to the need for human touch, wanting to experience a sense of belonging and to be able to participate in research. They speak of feelings of acceptance through human contact and reconnection.

A 67 year-old male expressed that massage therapy was one of the treatments he received while living and receiving HIV treatment in another state. Like the research from Fairfield et al., (1998), which identified that after learning that they were HIV-positive, 72.7% of the patients surveyed started visiting alternative providers in addition to the conventional therapies they were using. He spoke about massage being part of his care:

I had inquired when I first got here, was there massage therapy because I knew massage therapy first hand, I knew the benefits of it. (Participant 1, 11/13/2015).

Many of the participants expressed how they wanted massage therapy and how they were open to trying other treatments for HIV.

### The Cost of Touch

Gillett, Pawluch, & Cain (2002), discuss cost as a barrier in their research. The expression of no cost for the massage was articulated by several participants. They stated that cost was by far the greatest barrier to accessing complementary and alternative therapies. This one factor was unanimous among the participants from Gillett, Pawluch, & Cain (2002), and also this research group.

Oh my God! I haven't had one in years so I was like yeah, that sounds good. I was like, oh my God! I am going for a free massage. (Participant 5, 12/07/15).

Overall, many participants stated that without cost as a barrier, it made participation in the study advantageous.

Participant 10's comment also echoed what Gillett, Pawluch & Cain's research presented about cost being the biggest barrier to accessing complementary and alternative therapies.

Quite simple, I wanted a massage for free because you know financially, I don't have the finances and I know how they make you feel. (Participant 10, 12/21/15).

Cost was a factor for many of the participants and they spoke about the financial hardships that HIV-infection entails. When asked if they would continue participating in a massage therapy program, every participant was interested and said that they would.

Complementary and alternative approaches to caring for people living with HIV/AIDS and the symptoms associated with it have been a part of the treatment since the beginning of the epidemic. Research by Pawluch et al., (2000) presented findings that those interviewed viewed Western medicine as a "last resort" and relied on complementary and alternative methods before Western approaches.

Authors also stated that they viewed these approaches as safer and more natural. Research from Ho, Robles & Pawluch echo these same findings and expand to discuss the importance of community-based participatory research as well as how the participants in their study wanted to have options for treatment beyond just pharmaceutical options:

I believe in the pharmaceutical and holistic part of medicines. So when I heard of it, there were all these plusses. (Participant 7, 12/04/2015).

His belief in both ways of healing helped him to participate in the study. Ho, Robles & Pawluch address how the participants want to be involved in the care and treatments that affect them.

### **Physical & Mental Responses**

Physical gratification from massage therapy was expressed as being relaxing, changing awareness and decreasing stress for the participants. His words strongly supported the research by Moyers, Rounds & Hannum (2004) in which they spoke about the benefits of massage therapy being similar in effect to those from psychotherapy:

It just, I just feel so much more relaxed. When I walk through the door, my stress level might have been a nine and a half or an eight. When I walk out of the door, it's like a five or six, so obviously I am approaching the situation entirely differently than I would have if I was so in the moment (Participant 1, 11/13/2015).

His sense of relaxation was evident from the end of treatment through the interview process. In the observation notes from his session, I noted that he expressed relaxation and was visibly relaxed leaving the treatment. He went on to talk about spiritually and mentally the differences he noticed:

Spiritually and mentally it was just like a freedom. Like shaking off the shackles of this world and just the ability to just remove yourself and just go someplace where there's just no bills, no people, no bosses, no this, no that and just you know. Yeah...you just kind of drift away (Participant 1, 11/13/2015).

Moyer, Rounds, & Hannum's (2004) research discussed how just a single application of massage therapy can affect anxiety and depression. Participant 4's statements correlated to their findings and she commented on her feeling more relaxed:

Um, I think I felt more at ease, my muscles felt more relaxed, less tense, less tension. Yeah and once the dog stopped barking, I think the, like, I don't know, even the...maybe I stress up, maybe when I am going through something, you just get tense, but I felt more relaxed, and soothed. (Participant 4, 11/16/2015).

Her sense of being more relaxed is something that affects all of the systems in her body and is a significant response. Her sense of relaxation could also help her manage her stress in a different way and reinforce positive lifestyle choices.

The fourth participant's statement correlates with Poland et al., (2013) which stated that massage could produce a number of positive subjective effects acutely:

When I texted you, I had not peed that night. I pee like four times a night. Guaranteed and I didn't because it helped (Participant 4, 11/16/2015).

Participant 5 expressed his sense of relaxation and how he wanted to experience something totally different from his normal routine following the massage:

I just, I wanted to go to a park or something. I just wanted to go relax. Come home and do some incense and yoga...I would have just went home and meditated (Participant 5, 12/07/15).

This comment from him was a polar opposite from his previous statements of wanting to be out and about shopping and being busy. His feelings of relaxation also could have beneficial positive behavioral implications.

Participant 4 spoke about how the massage helped her with her emotions and mentally. Her statement correlated with Moyers, et. al., 2004 about her relief from the massage. She expressed:

I said bipolar too, in addition to, so the massage, oddly enough, slowed my head down a little (Participant 4, 11/16/2015).

The sensation of feeling her head slowing down following the massage is a powerful statement of the benefits of massage therapy. It demonstrates how massage therapy affects both the physical and mental bodies.

Two participants expressed similar feelings:

I think that it would help people to relax their bodies physically relax their minds emotionally and mentally and this that it would things that you think about would not necessarily be so dire, so serious (Participant 10, 12/21/2015).

Participant 11 expressed how she always feels dirty and how she did not feel that during the treatment.

You didn't make me feel like, some people just make you feel dirty. And I already feel dirty, and I can't clean myself enough, I can't douche enough, shower enough. I just feel dirty. So I don't need somebody making me feel like I have this creepy crud (Participant 11, 12/18/2015).

Her expression of not feeling dirty while she was receiving the massage is an important piece of the results. Stigma is a huge part of living with HIV/AIDS. Some HIV-positive women have reported underutilizing health and supportive services because of negative experiences with providers where they have felt unsafe, unwelcome or discriminated against (Carter et al., 2013).

Whooten & Sparber (2001) discuss how complementary and alternative therapy use including massage therapy increases feelings of relaxation. She expressed a sense of emotional relief and a good feeling accompanying it.

Yeah, it was a little different. I felt relaxed and at peace and I was able to pretty much let go of everything outside. Almost like, just very at peace and like not emotional, but a good emotion, like the touch or something about it...it was like a surge of relief or a good feeling inside (Participant 13, 01/22/2016).

### Sleeping Again

In addition to the sense of relaxation many participants expressed, most of the participants spoke of how their sleep was impacted positively following the massage therapy session. Eight out of the twelve participants reported benefits to their sleep.

The fourth participant's comments about her improved sleep relates with Hendrickson's research (2001) that found significant improvements in sleep for the participants who received acupuncture and massage therapy. Her statement about her lymph correlated with the research by Ernst (2008), which listed changes in lymph flow among the physiological changes from massage therapy:

Yeah, that's why I was so happy when I actually could get some sleep, sleep, because I was like I don't know what the heck. I guess the lymph system got pushed into working the way it was supposed to? (Participant 4, 11/16/2015)

While not explicitly stated in Field (2001) and Sparber's (2000) research, it falls under the same umbrella of improved attitudes and feelings and feeling better with improved outcomes:

Participant 13 expressed her sleep was affected as well which correlated to Gamaldo, Spira, Hock, et. al. (2013) in which they discuss how HIV positive individuals are suffering with under diagnosed sleep disorders that are negatively impacting quality of life and functional capabilities:

I usually have trouble getting to sleep usually and I just fell asleep around 9 which is not a usual thing for me and I didn't need to knock myself out of anything which was nice (Participant 13, 01/21/2016).

Gamaldo et al., (2013), discusses how the lack of sleep negatively impacts quality of life and other functional capabilities and discuss how mounting evidence is linking sleep disorders to conditions associated with increased morbidity & mortality They discuss how amongst HIV positive individuals, sleep complaints have been common and debilitating but have rarely been formally assessed.

Yes, I slept really well. I have been sleeping really well ever since (Participant 12, 12/24/2015).

Participant 10 also experienced changes in her sleep and stated:

Yeah, I think I slept like a baby Friday night. Plus the massage that enabled me just to sleep like a baby that Friday night (Participant 10, 12/21/2015).

The changes in sleep are especially significant because the lack of quality sleep is widely known to negatively impact health outcomes.

Field (2001) that stated that massage therapy positively impacted the immune systems of people living with HIV/AIDS who received massage:

I think it is just a great thing cause it is great for the immune system, I have read about it and I just think it is a positive thing and I want to be a part of it. (Participant 13, 01/22/2016).

Participant 13 understood that people like to be touched and also that massage therapy would help her immune system:



I feel like just the touch part of it, even that, you know, people like to be touched. I think that people would really feel better and it would help their immune system obviously (Participant 13, 01/22/2016).

Her statement about touch helping the immune system has been shown in Diego et al., (2001), which found decreased anxiety and depression following massage therapy along with enhanced immunity.

### **An Emotional Roller Coaster**

Many emotions were expressed throughout the duration of this study.

Participants' emotions ranged from anger, anxiety, depression and isolation to feelings of happiness, sadness, love and gratitude. The wide range of emotions and feelings and the catharsis that sometimes occurred for the participants' was incredible to witness.

Many of the participants spoke about their anxiety. The thirteenth participant's comments correlated to Moyers, Rounds & Hannum's (2004) and Ironson et al., (1996) findings of decreases in anxiety for participants that received massage therapy:

Immediately. Yeah, cause I was very...cause I get stressed and I have anxiety and different things in my body, you know, the muscles and this and that I just felt clear, I had energy and was ready to tackle the day, I felt peaceful, I felt really, really, amazing (Participant 13, 01/22/2016).

The thirteenth participant went on to say:

They were like, I feel your energy. Well it was actually one of my friends. We were texting a little and then we were talking before I went in for my appointment and he was like, I can feel you right now, your energy is so...and I was like, I just had a great massage, so...(Participant 13, 01/22/2016).

This change in her energy was meaningful to her and she continued to say how different she felt following the massage. The decreases in stress and anxiety could positively impact health outcomes for this population as well as many others.

Participant one expressed less feelings of stress, which correlates to Moyer et al., (2004) and Field (2001) whose research noted decreases in stress and anxiety levels for participants that receive massage (expand more):

During the course of the day I know whatever was going on, I was in a whole different frame to deal with it. Because it didn't seem as stressful, it didn't seem as for lack of a better word, provocative. (Participant 1, 11/13/2015).

One participant expressed feelings of gratitude following the massage:

You know, oh I think I think this it made me realize after that massage how much gratitude I need to have I need to be more grateful for what I have in terms of not looking at what I don't have (Participant 10, 12/21/2015).

She spoke at length about this newfound gratitude and how she was moved following the massage to be more grateful and felt very empathetic and aware of those she was encountering post-massage.

### **Results Summary**

Four main themes emerged from this study: self-efficacy, human connectivity through touch, physical and mental gratification, and the emotional roller coaster. All of these themes suggest that massage therapy can be a powerful addition to the care and treatment for people living with HIV/AIDS. These changes and themes could also assist the participants' to feel more empowered about their health and treatment of their health.. As far as medicine has come in the care and treatment of disease, the very basic human needs remain and one of the most important of those is human contact. Integrated approaches are being taken in medicine more often as patients request more holistic care.

## Chapter 5

### Discussion, Correlations, Limitations, & Conclusion

#### Discussion

This study is the conclusion of twelve years of exploration and study for the researcher. It began from a pathology project in massage therapy school, which led the researcher to providing massage in several area HIV/AIDS community organizations in Las Vegas. She began noticing changes within the clients that were coming in for massage treatment. The clients themselves told her about various changes they were noticing as well. The researcher then contacted individuals at the University of Nevada, Las Vegas to find out how to express what she was observing. Thus the journey of a Ph.D began.

The findings from this study and the implications for the care and treatment for individuals living with HIV/AIDS could also be extrapolated into the care and treatment of many other chronic diseases. The proposed recommendations for further exploration and implementation of massage therapy as a treatment to be included in the plans of care could provide further evidence of the effectiveness of human contact to provide meaningful change for influencing human behavior. The first part of the chapter, the findings from the interview questions are discussed and how they assisted in answering the research question. The connecting relationships from this study and the literature presented create a strong foundation to conduct more research on this topic.

The purpose of this phenomenological study was to explore how massage therapy affected the self-efficacy for individuals living with HIV/AIDS that were in care at AFAN in Las Vegas, Nevada. The phenomenological approach was used for this study because the researcher was interested in the participant's lived experiences in order to better understand how massage

therapy could affect their self-efficacy. The convenience sample included 14 participants, 7 male and 7 female. Four of the participants were African-American, 8 Caucasian, and 2 Latino. Of these 14 participants, 12 completed the study.

One of the most striking revelations from this study was how disenfranchised many of the participants felt. Many of the participants spoke of how this experience of receiving massage therapy helped their feelings of isolation, anxiety, how it allowed them to sleep better, how it reminded them of their “humanness,” and how long it had been since they were touched by another human being, as well as the frustrations of accessing care and services in Nevada.

One participant spoke about how the anticipation of getting a massage was almost as good for him as the actual massage. The anticipation of looking forward to massage was a powerful part of the experience. Many of the participants expressed that receiving massage therapy reminded them that they needed to do more of self-care in addition to their daily routines. Another participant spoke of how it reminded her to be grateful and have gratitude for her life. Other participants’ spoke of how living with HIV still continues to hold a strong stigma and that the world sees and treats you differently. They stated how the massage experience was a positive note and allowed them to transform past the disease during the session.

This sense of isolation and the ensuing anxiety are contributing factors to depression and harmful health behaviors. If massage therapy was able to be a regular part of individual care for people with HIV/AIDS, it is possible that the positive effects could be maintained. The changes in self-worth, self-esteem and increase in awareness and healthy behaviors could dramatically enhance their quality of life and potentially change their behaviors. Many of the participants from this study spoke of such an awareness and how they made different choices following the

massage that were health-enhancing behaviors. This researcher believes that this provides answers to the research question about massage therapy affecting self-efficacy.

### **Correlations of Findings to the Current Literature**

The results of this study related to other research findings in regards to reasons participants tried massage therapy including reduction of symptoms, stress relief, help with anxiety, to help the pain in their bodies and relaxation (Duggan et al., 2001, Moyer et al., 2004, Field et al., 2001, Patrick, 2000, Wu, Attele, Zhang, & Yuan, 2000, Fairfield, et al., 1998, Ironson, et al., 1996, Poland et al., Jewett & Hecht, 1993, Hillier et al., 2010). All of the participants expressed that they wanted to participate in the study so that they could receive massage therapy and many were interested in the changes it could make for them. Interestingly, a majority of the participants noticed positive changes in their minds, bodies and spiritually. This finding suggests that massage therapy could be a useful addition to plans of care for individuals living with HIV/AIDS.

The effects from Bandura's Social Cognitive Theory and self-efficacy theory were evident throughout the interviews with the participants in the days following their massage therapy session. Many of the participants spoke of a new awareness of their actions, bodies, and behaviors. This correlates directly to Bandura's definition of self-efficacy where he states:

“Among the crucial personal factors are the individual's capabilities to symbolize behavior, to anticipate the outcomes of behavior, to learn by observing others, to have confidence in performing a behavior (including overcoming the problems in performing the behavior), to self-determine or self-regulate behavior, and to reflect on or analyze experience (Bandura, 1997).”

The experience of having a massage seemed to help many of the participants reintegrate themselves with themselves and some would speak of making changes to their lifestyle or behaviors.

Another finding that emerged from previous studies and to the extent people think and believe and feel affects how they behave (Bandura, 1986; Bower, 1975; and Neisser, 1976). Many of the participants reported behaviors that differed from their norms following the massage therapy session. According to research cited previously from Bandura,

The natural and extrinsic effects of their actions, in turn, partly determine their thought patterns and emotional reactions (Bandura, 1986). The personal factor also encompasses the biological properties of the organism.

This effect could have the potential to change the individual thoughts and emotions, which could lead to better overall health and well-being.

The data results from this study runs parallel with the findings from Finch and Bessonnette, 2012:

This study results support that massage therapy increases the self-efficacy of clients with multiple sclerosis, potentially resulting in a better overall adjustment to the disease and an improvement in psycho-emotional state (Finch & Bessonnette, 2012).

The data from this study show the improvement in psycho-emotional state and suggest further research is necessary to show the long-term effects of regular massage therapy for individuals living with HIV/AIDS and could expand even further to any chronic disease.

Another finding from this study that related within the research was that the many of the participants were frustrated by the drug regimen that they had to take and all of the side effects that they caused. They felt that the pills were a constant reminder of their illness (Moen et al., 2009; Townsend et al, 2003). Many of the participants were seeking out other ways to manage their disease and symptoms associated with it. They expressed relief from the anxiety, stress, bodily pains and isolation from the one massage therapy session.

### **Limitations of the study**

This study encountered some limitations. These limitations included the participants only being able to receive one massage before being interviewed. The second limitation was the sample of participants was limited to clients of AFAN who are in-care and did not provide a representative sample population of HIV/AIDS patients living in Southern Nevada. The third limitation was that the participants were limited to AFAN clients who were inside the building during the months of November-January. Plus this excluded clients who did not physically come into AFAN as the recruitment tools were fliers left on the community resource table. The fourth limitation was that there was no way to ensure saturation had occurred. The final limitation was that the researcher was also the massage therapist and interviewed so the participants may have answered the questions differently.

### **Conclusion**

This study provided a glimpse into the lives of individuals living with HIV/AIDS in Las Vegas and how one massage therapy session affected their feelings of self-efficacy. The subsequent interviews with each participant provided data that strongly supported the use of massage therapy as an additional treatment method that could help enhance each participant's sense of self-efficacy. Every participant in this study reported positive benefits following the massage therapy session and many expressed a newfound awareness of their bodies and their overall well-being.

This awareness is pivotal in initiating meaningful behavioral changes. The feelings of being cared for created a ripple effect where the participants begin to think about their decisions in a different light. Due to the limited time frame and study design, a longitudinal research study with HIV/AIDS patients would be an excellent tool to continue gathering data to see what the

long-term effects of regular massage therapy could be. Additionally, there are numerous other methods that fall under the integrated medicine umbrella that could be tested and utilized to help improve the quality of life and provide better care for people living with HIV/AIDS.

Integrating massage therapy into the plans of care for individuals living with HIV/AIDS is the next recommendation. This research shows how beneficial massage therapy is and the addition of massage therapy into the plans of care and services offered by the organizations could also be very effective in assisting clients manage the overwhelming emotions, symptoms and management of their disease.

This research could be applicable to individuals living with other chronic diseases. The symptoms and emotions that the participants expressed echo those of patients this researcher worked with in her years working with hospice patients. The human emotions and the experience of being ill create a different dynamic for the affected individual as well as those who love them. The introduction of touch through the method of massage therapy can provide a meaningful human connection that helps to provide comfort in ways that words cannot.

I strongly believe from this study and from my years of working as a massage therapist that touch is the missing link in our cycle of health and illness. Modern medicine has created miraculous discoveries and ways of extending our life cycles, yet our most basic human needs are being overlooked in the “busy” or hectic pace of medicine. At our most basic human level, human beings are complex organisms that require food, air, water, shelter and human contact to thrive. Many of us have the first four necessities but the lack of human touch is destroying our health, physically, mentally and spiritually. I believe that with more research and education about the importance of human touch, we can reverse many of the modern day afflictions that are impacting our health.



## **Implications for Public Health**

The implications for the field of public health are evident from the findings of this study. Massage therapy programs are needed to help members of the community who have HIV/AIDS to reduce anxiety and stress as well as to help reconnect bodies, minds and spirits. Several participants spoke of prior drug or alcohol abuse and this addition into the plans of care could also help decrease usage and create a new way of mediating stress and manage emotions. Massage therapy can help the mental, physical, and emotional problems that further impact the health of individuals living with HIV/AIDS.

The addition of massage therapy could begin to expand HIV/AIDS treatments in Las Vegas to a more integrated model of care in which patients could receive a more comprehensive plan of care. The lack of the integrated model further contributes to the health disparities for this population as well. Many of the participants in this study expressed exceedingly high levels of stress and a lack of a cohesive and supportive community. The introduction of massage therapy to HIV/AIDS care could provide more support and exponential health benefits to those who receive it.

The addition of massage therapy to HIV/AIDS care could also create a pathway for more integrated health methods to become accessible to those infected in the community. As shown in the literature of Ho, Robles & Pawluch, those living with HIV/AIDS understood the necessity of the drugs and expressed deep resentment & frustrations about the medications. Their research also showed that the participants were able to assert agency and control over their health care choices when given options. This is important so that individuals are empowered to take charge of their health. Massage therapy and other integrative methods are effective ways to help individuals recognize their role in the health decisions made everyday.

## Appendix 1

### Discussion Guide & Questions:

#### How Does Massage Therapy Affect Self-Efficacy for People Living With HIV/AIDS?

1. Introductions are made between the participant and researcher.
2. Introduction to the study
  - a. Discuss current knowledge on HIV/AIDS & massage and explain the lack of knowledge about HIV/AIDS, massage therapy & self-efficacy
3. Informed Consent
  - a. Discuss the project with the participant and get an oral consent.
4. Discussion Protocol
  - a. Explain the parameters of the study and that the participant is going to be asked questions about their thoughts on massage therapy, self-efficacy, & touch.
5. Face to face
  - Have you ever had a massage?
  - If so, how was your experience?
  - If not, why not?
  - How did you feel while receiving the massage?
  - Did you notice any differences in your body following the treatment?
  - Did you notice any differences mentally following the treatment?
  - Did you notice any differences emotionally following the treatment?
  - Did you notice any differences spiritually following the treatment?
  - Did you experience any changes in sleep?
  - Did you experience any changes in appetite?
  - Did you experience any changes in other areas?
  - How do you think massage therapy could change the plans of care for individuals living with chronic diseases such as HIV/AIDS?
6. Discussion Ends

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## Curriculum Vitae

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### Education

Ph.D. in Public Health, University of Nevada, Las Vegas	2011-2016
Master of Public Health, University of Nevada, Las Vegas	2007-2011
Bachelor of Arts Communications, University of Nevada, Las Vegas	1999-2002
Certification Nevada School of Massage Therapy	2005-2006

### Professional Experience

Director of Integrative Medicine & Wellness UNLV School of Medicine	Current
Massage Therapist Caesar's Palace	2010-2011 2014-current
Graduate Research Assistant University of Nevada, Las Vegas	2011-2015
Massage Therapist Nathan Adelson Hospice	2006-2014
Founder/Massage Therapist Healing Hands Foundation	2005-current

### Poster Presentations & Abstracts

American Public Health Association	Washington, D.C. 2011
Implementing Teen Pregnancy Prevention In African American Churches: A Review of Partnerships & Pilot Sites	

American Public Health Association

San Francisco, CA  
2012

The Benefits of Massage Therapy in the Treatment of HIV/AIDS Patients

American Public Health Association

Boston, MA  
2013

American Public Health Association

New Orleans, LA  
2014

Lessons Learned from Implementing Teen Pregnancy Prevention Interventions in African American Faith Based Organizations

### **Oral Presentation**

Nevada Public Health Association Annual Meeting

September 2015

Integrating Massage Therapy into the Prevention and Treatment of Chronic Disease

### **Honors & Awards**

Nevada Representative Hugh O'Brien Youth Leadership Conference

1996

Nevada Winner of the Jefferson Award for Public Service

2007

Nevada Representative Clinton Global Initiative University Miami

2011