DO CHRONIC DISEASE SELF-MANAGEMENT PROGRAMS FOR INDIVIDUALS LIVING WITH HIV/AIDS PROMOTE SELF-EFFICACY AND DO THEY IMPROVE HEALTH OUTCOMES?

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DO CHRONIC DISEASE SELF-MANAGEMENT PROGRAMS FOR INDIVIDUALS LIVING WITH HIV/AIDS PROMOTE SELF-EFFICACY AND DO THEY IMPROVE HEALTH OUTCOMES?

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Adán Carlos Gómez
June 2019
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Approved by:

Dr. Carolyn McAllister, Faculty Supervisor, Social Work

Dr. Janet Chang, M.S.W. Research Coordinator
ABSTRACT

The purpose of this study was to analyze and measure the short-term and long-term impacts of a chronic disease self-management program (CDSP) for individuals living with HIV/AIDS. This study was a follow-up study on an HIV/AIDS Organization in Southern California’s (HAOSC’s) CDSP programs in 2007 and 2008 called “Newly Empowered Women” (NEW), a six (6) week CDSP for women diagnosed with HIV/AIDS which sought to promote self-efficacy through education and self-management skills. A retrospective longitudinal study on the female clients who participated with this program in 2007 and 2008 determined whether clients retained the skills taught in the CDSP and if they attained self-efficacy through improved behavioral changes in better overall self-management that were influenced as a result of their participation. Behavioral changes were examined and measured in the areas of self-rated health, anxiety and stress, social activities, communication with physicians, and the client’s overall self-confidence in managing symptoms related to the disease. The measurement of change in these areas informed the study on the effectiveness and practicality of the skills being taught in the CDSP and their effectiveness in the promotion of self-efficacy. It also highlighted which skills seem to be most helpful and impactful to clients, and if the skills they learned were retained over time. The study measured the short-term impacts from completion of the CDSP to the 6-month follow-up period and also measured the long-term impacts the CDSP had on client health outcomes three (3) and four (4) years after the initial
program was implemented to see if there was a correlation between increased self-efficacy and improved health outcomes. Participant CD4 and viral load counts were analyzed, as these are determinant biological markers in measuring the immunological impacts of the disease. Measuring these variables over time for individuals that were in a CDSP gave the study insight into the CDSP’s short-term and long-term effectiveness in the promotion and sustainment of self-efficacy for individuals living with HIV/AIDS and how the effective management of their chronic illness can lead to overall better health outcomes. Additionally, this study sought to better understand the experience of the women who participated in the CDSP through incorporating a mixed methods qualitative approach, by interviewing some of the women who had participated in the CDSP to identify common themes or lessons learned, best practices of the program, and areas for improvement.

Although this study was not able to show that changes in behavior and increased self-efficacy impact health outcomes, more complex analysis should be done in this area, as this study highlighted the positive impacts a CDSP can have on increasing self-management skills and promoting self-efficacy over the short-term and long-term for individuals diagnosed with HIV/AIDS.
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DEDICATION

First and foremost, I dedicate this project and the completion of my degree to my God, Lord and Savior, Jesus Christ. Thank you God for never giving up on me and for seeing me through this entire process. I know that you always hear me and I know that you have a plan for me to use this degree for good. I am forever humble and loyal to you as one of your soldiers of this profession in doing the work that needs to be accomplished to assist, serve and to empower others.

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CHAPTER ONE

INTRODUCTION

Introduction

This chapter gives a historic overview of the HIV/AIDS epidemic in this country and how the U.S. government’s slow response to address the issue immediately and comprehensively, may have led to the additional contraction of the disease by unknowing individuals and subsequently may have led to more individuals being infected. It also highlights the stigma around HIV/AIDS which influenced and perpetuated the government’s slow response in acknowledging that the illness existed and the stigma that continues in accessing services and in creating visibility to a public health epidemic which still exists. Finally, the need to develop comprehensive and specialized programming for individuals impacted by HIV/AIDS is discussed and reviewed as the rational and motivation behind conducting this research study.

The world was first introduced to the illness termed as Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) in the early 1980’s as hospitals, primarily in California and New York, started reporting rare forms of cancer and/or pneumonia that were affecting young men who had been relatively healthy prior to these illnesses. The one element that connected all of these cases, however, was that all of these patients were homosexual men. The first official documentation of the condition was
reported by the U.S. Centers for Disease Control (CDC) in 1981 in a report entitled, “Pneumocystis Pneumonia-Los Angeles.” The report focused on the cases of five (5) young gay men that were hospitalized at various hospitals in Los Angeles, California with serious Pneumocystis Pneumonia Carinii (PCP), cytomegalovirus (CMV), and disseminated candidal mucosal infections (Center for Disease Control [CDC], 1981). The patients described in this report exhibited symptoms including daily fevers ranging in duration from two to four (2-4) months, had esophageal or oral candidiasis (or both) and had all been healthy with no previous immunodeficiency which was unusual for PCP. These men were also between the ages 29-36 years and all identified as being homosexual. Shortly thereafter, in July of 1981, the New York times published an article titled, “Rare Cancer Seen In 41 Homosexuals,” reporting that a total of 41 homosexual men had been diagnosed with Kaposi’s Sarcoma (KS), “a rare and often rapidly fatal form of cancer”, and that eight (8) of them had died less than 24 months after the diagnosis was made (Altman, 1981). Not understanding the illnesses’ mode of transmission or treatment, the article also served to alert other doctors treating homosexual men, in an effort to identify more cases so as, “to reduce the delay in offering chemotherapy treatment” (Altman, 1981). As dark-blue or purple-brown plagues or nodules associated with KS were visible on the extremities of these patients, chemotherapy was initially used to treat these clients exhibiting symptoms related to HIV. In another early study documenting the outbreak of the HIV disease, Haverkos and Curran (1987) identified that
immunosuppression appeared to be the common link between the Kaposi Sarcoma (KS) and Pneumocystis Pneumonia Carinii (PCP) cases (p.334) that were being identified and reported in Los Angeles and New York City. They also identified, that at least 47 percent of these patients had another opportunistic infection (OI) in addition to KS or PCP and that PCP patients were more likely to have an OI than KS patients (Haverkos & Curran, 1987). As immunosuppression was the common link among these patients and it was believed that the disease was underdiagnosed, specific attention was noted to being alert to OIs and assessing for this and to the rise of OIs as a result of this epidemic (Haverkos and Curran, 1987, p.334). By 1981, there were 270 reported cases of severe immune deficiency among gay men of which 121 of them had died (U.S. Department of Health and Human Services, 2016). By June of 1982, the CDC reported a total of 593 reported cases of Kaposi’s sarcoma, Pneumocystis carinii pneumonia (PCP) and/or serious opportunistic infections in the United States, with a mortality rate of 41% and exceeding 60% for cases that were diagnosed more than a year ago (CDC, 1982). The difference in these new reports however, was that they were now not solely isolated to homosexual males, 20% of these cases now included heterosexual men and women (CDC, 1982). In September of 1982, for the first time the CDC described this illness as Acquired Immune Deficiency Syndrome (AIDS) and noted that it was, “A disease at least moderately predictive of a defect in cell mediated immunity, occurring in a person with no known case for diminished resistance to that disease”
(CDC, 1982). By the beginning of 1983, the CDC identified heterosexual women who had contracted the disease from their male partners, suggesting that it could be transmitted via heterosexual sex (CDC, 1983a). Later that year, reports of AIDS in children started to be reported in infants born to mothers who had the disease raising concerns for in utero or perinatal transmission (CDC, 1983b). Additionally, approximately fifty-six percent of the persons who had the disease and who identified as heterosexual or whose sexual orientation was unknown, were reported to be intravenous drug users (Haverkos & Curran, 1987, p.335). G’dali Braverman, an AIDS activist living in San Francisco during this time, summed it up best by stating that, “By mid-1982 it was clearly different. People were starting to shake in their pants. It was clear at this point that it was more than just isolated incidents” (Avert, 2018, p. 2). The identification of AIDS cases across the U.S. in 34 states, 15 countries (CDC, 1983b) and reports that this illness was now affecting heterosexual men, women, and children awoke not only the nation, but the world to the stark reality that this disease was indiscriminate. By the end of the year, there were a total of 3,064 reported AIDS cases in the U.S., of which 1,283 or 43% had died (CDC, 1984). It could no longer be viewed as a disease just associated with the homosexual community (as originally thought) as it was now affecting many, regardless of their age, culture, gender, or sexual orientation.

From the onset, the AIDS virus was associated with a high level of stigma and discrimination, as it was originally perceived as a disease that only affected
homosexuals and intravenous drug users. The fact that there was little if any evidence-based information on the transmission of this disease led to false reports by the media regarding its transmission. This fear translated into society developing its own theories regarding how this virus was contracted, despite that by the end of 1983, the CDC had already identified all major ways of transmitting the disease and ruled out transmission by casual contact, food, water, air or surfaces (CDC, 1983c). The issue of bringing this national epidemic to the forefront was also stagnated by the U.S. government which further perpetuated the stigmatization of this disease, by failing to acknowledge CDC reports of AIDS as a national epidemic. This adamant indifference was highlighted in a press briefing at the White House when a journalist asked a spokesperson for President Reagan, “does the President have any reaction to the announcement by the Center for Disease Control in Atlanta, that AIDS in now an epidemic and we have over 600 cases?” The spokesperson responded by stating, “What AIDS?” When the journalist asked if the white house was aware of the epidemic, the spokesperson replied, “I don’t think so” (Lopez, 2016). The stigmatization of this disease further led to the reluctance of some legislators, medical professionals and researchers to investigate the causes of AIDS and as a result caused a major public health crisis to go unaddressed for a long period of time.

In August of 1983, a congressional subcommittee held hearings to review the government’s involvement and response to the AIDS epidemic. In a report titled, “Federal Response to AIDS”, the congressional subcommittee criticized the
government’s response to this epidemic noting that, “Far too long our collective response, societal as well as governmental, to the crisis was haphazard and inexcusably slow” (Committee on Government Operations, 1983, p.1). In essence, this committee recognized that the U.S. government’s response had been uncoordinated, insufficient, and inadequate in supporting public health education and in funding healthcare for AIDS patients. Through this hearing, the committee sought more knowledge and information on this illness by hearing from those living with AIDS and from the subject matter experts in this field, in an effort to mobilize a comprehensive response to this epidemic. In 1985 the U.S. government funded the development of a HIV test and later that same year researchers finally developed a test for identifying antibodies to HIV. It was in September of the same year that President Reagan publicly mentioned AIDS for the first time, and highlighted it as one of his “top priorities”, although he had failed to address it for almost four (4) years. It wasn’t until 1988, through the Health Omnibus Programs Extension (HOPE) Act which authorized the use of Federal funds for AIDS prevention, education, and testing that the first national, coordinated AIDS education campaign was launched. By the end of 1988 there were 82,764 cases of AIDS that had been identified in America, and over 45,602 people had already died (CDC, 1989).

The government’s slow response to dealing with the AIDS epidemic fostered a slow response from the medical community in addressing and dealing with HIV patient concerns. This slow response also delayed research from
pharmaceutical companies to produce antiretroviral drugs to treat those with AIDS. Although there has been some progress in AIDS research development and therapy over the last decade, the progress to address the needs of this underserved population have been slow and insufficient to deal with this growing epidemic. In 2010, the CDC reported that as of 2009 there were an estimated 476,732 people in the United States living with AIDS and 784,701 people living with HIV (CDC, 2012). The CDC also estimates that there are approximately 1.1 million adults and adolescents living with HIV in the U.S., including those not yet diagnosed, and those who have already progressed to AIDS (CDC, 2012). In 2010, the CDC also reported that in 2009 there were an estimated 7,505 people in San Bernardino and Riverside Counties who live with AIDS (CDC, 2012).

Although HIV infection rates have declined or stayed the same for some age groups, for persons aged fifteen through nineteen and twenty through twenty-four infection rates have increased. In 2010, the largest percentage of all diagnoses nationally (16%) and the highest rate per 100,000 population (36.9) were those for persons aged twenty to twenty-four (CDC, 2012). The fact that HIV infection rates have failed to decline consistently and collectively for all age groups and ethnicities since it first came into the medical spotlight in the early eighties highlights the need for more funding, research, structured therapy, to adequately address the needs of those impacted with this illness and preventative services to educate the public in an effort to reduce stigma and to lower HIV infection rates.
Another area of concern in addressing the needs of this population are the disparities in access to healthcare services for racial and ethnic minorities. From 2007 through 2010 black Americans accounted for 43% of AIDS diagnoses in the United States and 46% of all diagnoses of HIV infection. (CDC, 2012). Almost half of the HIV/AIDS diagnoses reported to the CDC are among black Americans, even though blacks represented only 13 percent of the population and that rates for other minority populations is also disproportionately high. This is discouraging and raises the need for more outreach and education to be done to minority groups that have historically been unserved, underserved, or inappropriately served. The lack of effective AIDS outreach, education, and preventative services to minority populations has created a racial disparity in access to services and treatment. This is further compounded by the cultural implications of how AIDS is perceived in an individual’s given culture which may at times endanger the person or put them at greater risk if it is not accepted by exposing them, in not addressing prevention an individual is at greater risk of HIV infection, or by not providing resources or guidance which further creates barriers to treatment and care.

Problem Statement

Do Chronic Disease Self-Management Programs (CDSPs) for individuals living with HIV/AIDS promote self-efficacy, and do they improve health outcomes?
It was hypothesized that individuals who participated in CDSPs would have increased self-efficacy which will lead to improved health outcomes.

**Purpose of Study**

The purpose of this study was to measure the short-term and long-term impacts that a chronic disease self-management program (CDSPs) have on the promotion of self-efficacy, if this knowledge is retained over time, and if there is a correlation to improved health outcomes (increased CD4 and decreased viral load counts). For the purposes of this paper, it is understood that chronic disease self-management courses (CDSC) and chronic disease self-management programs (CDSP) are interchangeable and represent the same type of training and programming for the client that works to educate the client to help facilitate self-efficacy. They are referred to as either CDSCs or CDSPs throughout this paper according to how they were originally presented by the given author(s) of a referenced study. In the study that an HIV/AIDS Organization in Southern California (HAOSC) conducted relating to chronic disease self-management, they referred to their program as a CDSP.

The HIV/AIDS Organization in Southern California (HAOSC) used in this study, was founded by a group of concerned individuals who saw many of their friends and family members stricken with this disease with nowhere to turn. As the HIV/AIDS epidemic evolved, so did the HAOSC. This particular HAOSC currently has three (3) offices in Southern California that service clients residing
in Los Angeles, San Bernardino and Riverside counties. Most of the clients at this HAOSC are on Social Security Disability Insurance (SSDI) and many fall at or below the federal poverty guidelines (HIV/AIDS Organization in Southern California, n.d.). In 2007, the HAOSC developed a chronic disease self-management Program (CDSP) at two (2) of its Southern California locations through funding from the Pfizer Corporation's, "ConnectHIV" Initiative. The goal of the Pfizer study was to fund comprehensive, evidence-based approaches to HIV prevention and access to care and treatment. The HAOSC chose to call their CDSP program, the "Newly Empowered Women" group (M. Francois, personal communication, September 14, 2010). Through the Pfizer grant, the HAOSC was able to secure a license to adopt Stanford University's "The Chronic Disease Self-Management Workshop" curriculum for their CDSP, using an evidenced based approach. The study conducted by Stanford University in the development of this curriculum spanned a total of five (5) years and involved more than 1,000 subjects. What the Stanford researchers were able to find in their study was that, "people who took the program, when compared to people who did not take the program, improved their healthful behaviors (exercise, cognitive symptom management, coping, and communications with physicians), improved their health status (self-reported health, fatigue, disability, social/role activities, and health distress) and decrease their days in the hospital" (Lorig, Sobel, Ritter, Laurent, & Hobbs., 2001, p. 259). The “Chronic Disease Self-Management Workshop” curriculum was administered in conjunction with the
book, *Living A Healthy Life with Chronic Conditions*, by Lorig, Halsted, Sobel, and Laurent (2006), which was used as an instructional guide in guiding the concepts of the program. This guide was coupled with descriptive overviews of chronic illnesses and also offered practical self-management activities, techniques, and workshops that allowed clients to explore and understand the concepts presented in each training. The trainings for these workshops was facilitated by a staff member from the HAOSC and co-facilitated by a peer-educator who was also a HAOSC client who had received training in administering this curriculum. The goal of implementing a CDSP for clients at the HAOSC was done in an effort to promote better self-management and to foster client self-efficacy in managing the complexities of the HIV/AIDS disease.

In 2007, the HAOSC implemented a six (6) week CDSP with some of its female clients from the two (2) of its Southern California locations and found that the individuals who participated in this plan increased their knowledge and self-efficacy in managing the disease after completing the program (pre and post tests were administered). At follow-up (six [6] months after completing the program) the study also showed that these women's self-efficacy continued to develop and that their health continued to improve both in terms of their self-management behaviors and also in terms of their immunological measures as it pertained to increased CD4 counts and decreased viral loads counts. These women also experienced better overall outcomes in their access to medical services, medication adherence, improved diets, were more knowledgeable
about their illness and reported a better overall quality of life as compared to other female clients who were not a part of this group (M. Francois, personal communication, September 14, 2010). Due to the program’s success, the CDSP was re-funded in 2008 and the HAOSC re-administered the program using the same curriculum, guide, and evaluation instruments from the previous study. A total of 55 clients participated in the HAOSC’s study (from two [2] of their Southern California locations) from 2007-2008, of which 35 (16 in 2007 and 19 in 2008) of these clients were from one (1) of the two (2) locations of the study. This study focused on the clients from one (1) of the two (2) Southern California locations that participated in the original CDSP studies.

This study sought to expand on the outcomes the HAOSC initially identified through their CDSPs. The HAOSC utilized a structured empirical assessment tool in evaluating its results as it pertained to increased self-efficacy, but the increases that they saw in these patients’ overall improvement specifically in the areas of CD4 increase and viral load decrease were noteworthy. Like the HAOSC study, this study also measured the short-term impacts of a CDSP, but more importantly, the long-term impacts a CDSP has on increasing client self-efficacy through the application of self-management techniques, the retention of these skills, and how the application of these self-management skills not only improves client self-efficacy but also impacts overall health outcomes. A retrospective longitudinal study on the female clients who participated with this program in 2007 and 2008 determined whether any clients retained the skills
taught in the CDSP and if they attained self-efficacy through behavioral changes in better overall self-management that were influenced as a result of their participation. As this study sought to specifically measure the attainment of self-efficacy and self-management skills attained through the CDSP, only five (5) of the original eight (8) measures that were used in the HAOSC’s initial study were analyzed. Behavioral changes and responses were examined and measured in the areas of self-rated health, health distress, social activities, communication with physicians, and the client’s overall self-confidence in managing symptoms related to the disease. The measurement of change in these areas informed the study on the effectiveness and practicality of the skills being taught in the CDSP and their effectiveness in the promotion of self-efficacy. It also highlighted which skills seem to be most helpful and impactful to clients, and if the skills they learned were retained over time. The study also measured the impact the CDSP had on client health outcomes at 6 months to assess the short-term impacts related to health and then at three (3) and four (4) years after the initial program was implemented to assess the long-term impacts and to see if there was a correlation between increased self-efficacy and improved health outcomes. As it pertains to changes in biological health, the two (2) key areas of most concern for people living with HIV and AIDS are those that pertain to CD4 and viral load counts, as these are determinant biological markers in measuring the immunological impacts of the disease. Measuring these variables over time for individuals that were in a CDSP gave the study additional insight into the CDSP’s
long term effectiveness in the promotion and sustainment of self-efficacy for individuals living with HIV/AIDS and how educating a client toward the effective management of their chronic illness can lead to overall better health outcomes. Thus, the research question that was proposed was, “Do Chronic Disease Self-Management Programs (CDSP) for individuals living with HIV/AIDS foster self-efficacy, and do they improve health outcomes?” It was hypothesized through a directional hypothesis that individuals who participated in CDSP will have increased self-efficacy and that there is a positive correlation to improved health outcomes.

Significance of the Project for Social Work Practice

From a macro perspective, the findings of this study help to contribute to the overall understanding of HIV/AIDS service delivery in Riverside and San Bernardino counties and further our understanding of how chronic disease self-management programs (CDSPs) are an effective way of improving program and service delivery by empowering, and improving the conditions of those who are impacted with this illness. The findings of this hypothesis were substantiated through research data, and if implemented could help influence and enhance the delivery of services to those affected with HIV/AIDS. Policy and service delivery changes in Riverside and San Bernardino Counties could mandate the implementation of CDSPs for all HIV/AIDS programs that are funded through federal monies like the Ryan White Act. From a micro perspective, this change
in policy could improve the overall quality of life for individuals with HIV/AIDS in that it would foster better overall self-management skills, promote self-efficacy, and lead to improved behavior and health outcomes. The promotion of client self-efficacy could also empower the client and change the communication process between the client and practitioner/therapist and influence the way practitioners/therapists work with their clients in empowering them by having them give input into their case or treatment plan. Their involvement in the case or treatment plan would further foster the promotion of self-efficacy by not only having the client involved in its development but it also would have them play a major role in its implementation. A program’s effective use of peer educators could also strengthen outreach efforts by making them more targeted and more successful in capturing and engaging clients into this continuum of care. This approach could help to decrease infection rates in the community by quickly identifying affected individuals, bringing them into care, and educating and empowering them on how to better care for themselves, thereby reducing the likelihood of the disease being re-transmitted. In a study assessing the effectiveness and impact of peer education interventions targeting active drug users in disseminating general HIV education and other modest incentives, it identified that peer educators have better access to harder to serve or hidden populations that may have limited interaction with more traditional programs (Sergeyev, et al., 1999). As HIV/AIDS is a relatively new illness to the medical community and one where affected individuals have historically been stigmatized
(making it difficult to identify those affected to bring them into care) utilizing a peer driven method of outreach and education is key in early identification and treatment. Engaging and retaining people in care will also have an impact on the community viral load as collective transmission rates will be reduced as a result of this intervention, which serves in empowering not only the individual but the community at large. Ultimately, the results of this study could be used to positively drive macro and micro changes in service delivery for individuals living with HIV/AIDS in Riverside and San Bernardino counties.
CHAPTER TWO
LITERATURE REVIEW

Introduction

This chapter will look at other studies and literature which have researched and explored CDSP programs and their impacts on behavioral and health outcomes. Identified themes or outcomes highlight the attainment of self-management skills in the promotion of self-efficacy and the impact of these behavioral changes on health outcomes. The application of these interventions on individuals who have HIV/AIDS is supported and discussed. Follow-up methodologies of these studies will also be highlighted and these follow-up periods will be compared to the follow-up points used in this study to measure the short-term and long-term impacts and outcomes of CDSPs. In exploring components of CDSPs, the use of peers as outreach workers and educators is also discussed and their impact on these activities given their lived experience is also highlighted. The concept of a mutual aid is also discussed and its role and impacts as a strength-based application in CDSPs is discussed. Finally, this chapter will discuss the theoretical framework that guides the principles and application of CDSPs.
Self-Management Skills and the Promotion of Self-Efficacy

In the literature reviewed, in relation to chronic disease self-management and specifically to the self-management of HIV/AIDS services, some similarities and differences were found in the chronic disease management program that was observed and researched in this study. In both studies by Wright, Barlow, Turner, and Bancroft (2003), and Barlow, Bancroft, and Turner (2005), similar intervention strategies for individuals with chronic illnesses were evaluated after the completion of a six (6) week chronic disease self-management course (CDSC) where participants met once a week for approximately two (2) hours for each session. These CDSC's were then evaluated at follow-up, to measure for behavioral changes over time as a result of this intervention. Both studies also used similar follow-up measures in that they both checked-in with participants at specific intervals after the completion of the CDSC. The Wright and colleagues (2003), study implemented a single follow-up at four (4) months and the Barlow and colleagues (2005), study implemented two (2) follow-up tests at four (4) months then at twelve months after the completion of the CDSC. In effect both studies also sought to measure behavioral changes in anxiety, health distress, self-reported exercise, self-efficacy, fatigue, health care utilization, and communication with a physician. As Wright and colleagues (2003) notes, there are "broad similarities in the type of self-management approaches developed for people with chronic diseases, particularly in terms of the course content with many of the most effective approaches using cognitive behavioral techniques to
facilitate change” (p.466). Additionally, like the study being examined, both of the studies by Wright and colleagues (2003) and Barlow and colleagues (2005), examined chronic disease management programs in community settings where the chronic disease management course was administered by lay tutors who had been trained in course delivery. The study by Barlow and colleagues (2005), was also similar to this study as it used a qualitative approach to gather information on the process of perceived change and the usefulness of the CDSC through client interviews.

In the study by Wright and colleagues (2003), the researchers found a significant reduction in depressive and anxious mood states for female participants (p.470). This information was gathered from quantitative research that contrasted the participants' pre-test and post-test follow-up scores. They also found small to moderate increases and improvement in self-efficacy disease and symptoms, cognitive symptom management, and increased communication with physicians. The researchers in this study were also able to see moderate decreases in the areas of anxiety, fatigue, and depression (Wright et al., 2003). Similarly, in the study conducted by Barlow and colleagues (2005), qualitative findings revealed greater client compliance in the areas of medication adherence, improved diet, confidence in communicating with their physicians and others, and they "felt more in control of their disease and expressed confidence in their ability to manage their condition despite no improvement in their symptoms" (p.868). The Wright and colleagues (2003), and Barlow and colleagues (2005) studies are
similar to this study in that they incorporated a mixed methods approach in
gathering the results of their projects. Like both studies, this study also assessed
client change towards self-efficacy by using a quantitative approach in measuring
client pre and post-test follow-up scores and like the Barlow and colleagues
(2005) study, this study also incorporates a qualitative approach via client
interviews to learn about the client experience and to assess client learning,
through this type of program, specifically the promotion of self-efficacy and
adherence in key areas of psycho-educational interventions that are commonly
utilized with individuals with HIV/AIDS.

Both of these studies, however, differ from this study in that the
interventions that were implemented in the Wright and colleagues (2003), and
Barlow and colleagues (2005), were not disease specific as it relates to
HIV/AIDS. The interventions that were introduced in this study however were
disease specific and related specifically to interventions and themes that affect
individuals living with HIV/AIDS. Wright and colleagues (2003), and Barlow and
colleagues (2005), acknowledge the limitations of their study in not being disease
specific and cite the work of Lorig and colleagues (1999), that notes that there
are, "Few studies have dealt with more than one disease or the problems of
comorbidity" (as cited in Wright et al., 2003, p.466). Additionally, the authors of
both these articles seek to understand not the direct impact of disease specific
interventions, but the impact of CDSC’s that provide participants with a set of
generic skills common to many chronic diseases and can be used and designed
to meet the specific needs of specific diseases (Wright et al., 2003, p.474). In their studies however, the authors acknowledge that, "The possible drawback of a generic course is that by including participants with very dissimilar conditions the opportunity for making relevant and informative comparisons may be compromised" (Barlow et al., 2005, p.870). Wright and colleagues (2003), also acknowledge the need for CDSC's that are designed to meet the needs of specific diseases by noting, "Hence the ideal scenario may be to encourage people with chronic diseases to attend a generic self-management package in combination with disease-specific, education interventions" (p.474). Another key area that differentiates both of these studies from this study is the length in follow-up periods to measure behavioral changes after the completion of a CDSC. The study by Wright and colleagues (2003), incorporated a follow-up at four (4) months and the Barlow and colleagues (2005) study incorporated follow-up periods after the completion of the CDSC and then again at four (4) and twelve months. In the results of each study, the researchers acknowledge a need for longer term follow-up measures to assess the retention of these behavioral changes over time. As Wright and colleagues (2003) notes, "Longer-term follow-up is needed to determine whether the changes reported here are maintained, and whether other changes become apparent over time" (p.474). This study sought to assess and measure the short-term as well as the long-term impacts of these programs as it relates to the retention of self-management skills in the promotion of self-efficacy and improved health outcomes by assessing
these changes at three (3) follow-up periods, to assess and compare the differences in the attainment and retention of self-management skills between these periods. The follow-up periods in this study encompassed follow-up at the completion of the CDSC, follow-up at six (6) months, and then follow-up at three (3) to four (4) years (depending on whether the participants completed the program in either 2007 or 2008). This study also differs from the two (2) studies by Wright and colleagues (2003), and Barlow and colleagues (2005), in that this study includes client health measures as it pertains to their CD4 and viral load counts that were measured at the three (3) noted follow-up periods, to assess the overall impact behavioral changes have on the actual biological measures associated to a given disease, which in this study included measuring client health changes over time for those affected with HIV/AIDS. Finally, the implementation and collection of qualitative data in this study differs from how data was gathered in the Barlow and colleagues (2005) study. In the Barlow and colleagues (2005) study, qualitative information was gathered from participants through telephone interviews rather than through face to face contact. The researchers acknowledged the limitations of this format by noting that, "telephone interviews have certain limitations compared to face-to-face interviews for establishing rapport and observing non-verbal signals" (Barlow et al., 2005, p.866). In this study, all interviews were conducted via a face-to-face format to allow for the establishment of rapport between the interviewer and the client and
in an effort to observe non-verbal communication which is paramount in the communication process.

**Chronic Disease Self-Management Programs for individuals living with HIV/AIDS**

The research associated to specific self-management strategies for HIV/AIDS cites the importance of specific HIV/AIDS interventions and skill sets that allow individuals to better self-manage the daily functions related to the disease, and the importance of social supports that reduce the anxiety and stigma often associated to the disease, which often impacts access to services and treatment of the illness. In the study by Gifford & Sengupta (1999) the researchers noted that, "Patients with HIV/AIDS need a wide range of self-management skills, including skills for using and adhering to complicated medical regimens, for monitoring symptoms and acting on them appropriately, and for participating actively in medical decisions with a good understanding of the risks and benefits" (p.116). In another study that addresses needed self-management strategies for individuals with HIV/AIDS, Kemppainen and colleagues (2006), identified specific interventions and self-management strategies for individuals with HIV/AIDS in an international study conducted in Norway, Taiwan, and the U.S. to examine the frequency and effectiveness of commonly used strategies for self-management of anxiety among individuals with HIV/AIDS. In this study, researchers found that the scores for each self-care strategy by country reflected a wide variation. One particularly relevant finding is that participants from the
U.S. had the highest ratings of all three (3) countries in the areas of attending support groups (42%) (Kemppainen et al., 2006, p.605). The overall harmful effects of anxiety in impacting the management of the HIV/AIDS disease have been noted by Tucker and colleagues (2003), which found that persons with generalized anxiety disorder were more likely to be non-adherent with HIV medication regimens than those without a diagnosis of anxiety disorder. These studies further cite the need to create disease specific chronic disease programs that provide education on specific self-management techniques and strategies to address the multiple complexities associated to this illness. The elements of self-management for individuals living with HIV/AIDS, encompasses the psychological component in accepting and dealing with the illness amidst the social factors and the relationships that exist in our support network, and the biological component in understanding the impacts this illness has on the body and how these changes can be self-monitored and improved through empowering individuals through education and self-management techniques. This research study specifically looked at some of the disease specific skill sets and self-management skills noted by Gifford & Sengupta (1999) and Kemppainen and colleagues (2006), in their studies and assessed the impact these skill sets and self-management techniques have in a chronic disease self-management program (CDSP) training that is specific to HIV/AIDS clients and how this training influences and promotes the attainment of self-efficacy to assist clients in better managing their illness. It is this disease specific knowledge and
the skills sets that an individual with HIV/AIDS must possess to properly manage their disease that makes the need for disease specific interventions and trainings all the more critical. It is also through the structure of these programs that family members and individuals with HIV/AIDS can come together through education, social understanding and support to become aware of how to access resources and services they may need without fear of being discriminated or stigmatized.

**Self-Help Mutual Aid Model**

In the review of the literature, other important components in the successful implementation of a chronic disease self-management program (CDSP) was the use of the self-help/ mutual aid model, which allows clients to connect to others that have similar shared experiences and the use of peer educators to disseminate information. The goals of the self-help mutual aid model are to foster client support and empowerment and to encourage clients to share best practices and coping strategies that improve overall self-management techniques. In the study by Gifford and Sengupta (1999), the value of support groups is recognized, as many of the participants noted how they "were impressed by the connectedness and camaraderie felt among the group members" (p.124). The respondents of this study noted the importance of the group in allowing them, "to support, educate and share experiences with others" (p.125). These findings were also further supported by Barlow and colleagues (2005) in the qualitative component of their study where individuals with a chronic
illness were interviewed to assess their experiences of being in a chronic disease self-management course. An important factor that was noted by clients who participated in this program was, "The experience of being with similar others and sharing and comparing common experiences" (p.867). Wituk, S.A., Shelly, T., Commer, A., Warren, M., and Meissen, G. (2003) note that self-help groups are started, "because people believe they could be helpful to others who share their concern" and because, "they are motivated to help others who may be in a similar circumstance" (p.85). The underlying motivation to this therapeutic process is found in an individual's ability to connect with others they can relate to, and in the sharing of similar experiences, individuals can work together to empower and help one another. Finn (1999) highlights the engagement of dialogue that occurs between clients in these groups as they are able to discuss "taboo" ideas, and are able to share common experiences through the "being in the same boat" analogy (p.221). The study by Wituk and colleagues (2003) further notes the importance of this model to the profession of social work in noting that, "The ideas and principles of self-help groups are consistent with social work, including a strength-based approach, recognition of participant's experiences and empowering others" (p.84). The importance of the self-help mutual aid model for the HIV/AIDS population is instrumental in the development of self-efficacy in that it draws its strengths from the collective experiences and subsequent knowledge of the group. The self-help mutual aid model is based on the principles of empowerment, inclusion, nonhierarchical decision making,
shared responsibility and it promotes a holistic approach to meet individual needs as they relate to cultural, economic and social needs (Steinberg, 2004, p.15). Through this process, individuals come to acknowledge their strengths and are motivated and challenged to exert control over the issues that impact their lives. This intervention also fosters and encourages empowerment in that clients are able to accept personal responsibility for the management of their illness. Through the self-efficacy process that is nurtured in self-help groups, individuals are able to see that they do in fact have control over their treatment and that they can implement strategies that allow them to effectively manage their illness and ultimately their overall health.

Peer Educators

Finally, the use of peer educators is also a prevalent topic in the review of literature when it comes to HIV/AIDS education and the importance of a cultural, grass roots dissemination of information for the prevention and treatment of this illness. Changing an individual’s beliefs plays an important role in changing their behaviors as it pertains to sex, getting tested and seeking treatment. Changing the stigmatization and perception of HIV/AIDS is also an important goal of peer educator programs in changing how those that are infected and affected are viewed and treated in the communities and cultures they are a part of. The underutilization of services is also impacted by the illness’ public perception, which in turn can impact the accessibility to services. Dickinson and Deutsch
(2009) highlight the effective use of peer educators in the context of culture by looking at a peer educator’s ability to understand the web of social relationships that exist within a culture and as a result their position and ability to be able to communicate in a horizontal rather than vertical communication process (p.6). This study is similar to the research by Dickinson and Deutsch (2009), in that it incorporates the use of peer educators in conducting outreach to educate and enroll individuals into the program and as peer educators were also used as the instructors in the delivery of information. In addressing the communication process in the delivery of information aimed at educating others towards behavioral change, what is unique about the peer educator process is that through the horizontal communication process, it allows “embeddedness in local cultural contexts; dialogue, especially among similar individuals, rather than information delivered by experts; individuals as change agents, rather than as targets for change; and the importance of face-to-face, personal communication channels” (Dickinson & Deutsch, 2009, p.6). Through this unique relationship, peer educators are often able to address difficult situations in the delivery of sensitive information by understanding the gender, community, family, and workplace relationships that exist. The research study that Dickinson and Deutsch conducted differs from this study in that the study by Dickinson and Deutsch utilized peer educators who had been impacted or affected by the disease (community member, friend, family member, etc.) and did not have a positive HIV/AIDS diagnosis, as to where the peer educators in this study had a
positive HIV/AIDS diagnosis. The peer educators in the Dickinson and Deutsch study were also employees of large corporate companies in South Africa that specifically ran peer educator programs for their employees from a prevention standpoint and those in attendance at these trainings did not have a HIV/AIDS diagnosis as to where the clients in this study all had a diagnosis of HIV/AIDS and were clients of the HAOSC.

The use of peer educators is also highlighted in the study by Cupples, Zukoski, and Dierwechter (2010), which looked specifically at the recruitment and development of male peer educators in a male-focused peer based sexual health program. In this study the researchers not only focused on the recruitment, selection, and the training of peer educators but also looked at how peer educators can be instrumental in shaping attitudes and normative beliefs about performing healthy behaviors (Cupples et al., 2010, p. 20). Through an eight (8) year study that evaluated the use of male peer educators, what the researchers discovered is the positive impact and influence that the peer educators had on recruiting and engaging youth in sexual reproductive discussions and also in that they were able to deliver prevention methods in a manner that was hip and relevant to youth culture while still being medically accurate and comprehensive (Cupples et al., 2010, p.22). This study is similar to the Cupples and colleagues (2010) study in that it used peer educators that were gender specific to educate and share information to the clients in an effort to change their attitudes and beliefs and to promote healthy behaviors and a healthy lifestyle. The study by
Cupples and colleagues (2010) differs from this study in that this study utilized peer educators that were female to educate an all-female client group as to where the study by Cupples and colleagues (2010) used all male peer educators to educate and train other males. Although there are gender differences in the application of each study, what is similar is the impact peer educators have on shaping beliefs and customs with clients who are of the same gender. The peer educators in the studies being reviewed, and in this study, could relate to the clients, as they had experiences that were gender specific and relatable to the clients. These shared experiences through gender allowed the peer educators in both studies to have a positive impact on shaping clients’ beliefs and customs towards healthier behaviors and healthier lifestyles that were gender specific and in the case of this study disease specific as well.

Theories Guiding Conceptualization

In the review of the literature associated to chronic disease self-management courses (CDSC) and chronic disease self-management programs (CDSP), the overriding theoretical approach incorporates a behavioral theory framework. Behavioral intervention models emphasize positive learning experiences, focusing on helping clients acquire new skills, improve communication or learn to break maladaptive habits (Lesser & Pope, 2007, p.65). Bandura's (1977) Social Learning Theory, an extension of behavioral theories, is grounded on the premise that behaviors are learned through imitation, modeling,
and observation. Social learning theory draws on the foundation of understanding that there are three (3) major types of learning which include classical conditioning or learning behavior through association or through a conditioned response to a stimulus, operant learning which looks at how an individual chooses to respond to a stimulus based on their environment and the consequences of that behavior, and modeling which is the basis of Social Learning Theory, in which individuals learn through observation and through observing the outcomes of those behaviors. In Social Learning Theory, it is this continuous interaction with cognitive, behavioral, and environmental influences which shape behavior. Social Learning Theory can be applied to understanding and informing the effectiveness of psychoeducational learning models in that they serve to change behavior patterns through education and through the modeling of appropriate behavior. Social learning theory draws on the notion that individuals are able to learn or change their behavior by identifying effective ways of managing their disease through observing others and in identifying the positive impact that behavior has on them and then modeling that behavior to produce the same positive results. This approach is conceptualized in chronic disease self-management programs where individuals are educated about their illness, taught coping and self-care skills, and are continuously empowered toward acquiring new skills as they work towards the attainment of self-efficacy. This practicing of behavior leads to the desired behavioral changes that ultimately lead to self-efficacy. Chronic disease self-management programs that
are specific for individuals with HIV and AIDS provide the opportunity for clients to learn how to manage various aspects of the HIV disease as it relates to exercise, diet, medication adherence and treatment, management of disease specific symptoms, and strategies to cope with the stigma that is often associated to individuals with this disease. Self-help groups in general further the concept of social learning theory in that they allow group members to share and model new ideas and techniques amongst individuals that share similar traits or experiences. These positive shared learning experiences are reinforced and strengthened not only through results, but also through the creation of relationships, positive interactions and through the acknowledgement of others. Through information sharing in a self-help mutual aid format, clients are empowered though the acquisition of new knowledge and through learning from the experience and knowledge of others, as they continue to work towards self-efficacy.

Self-efficacy theory and the belief that an individual has their own self-determination and is capable of acting and exercising control over their own lives is an empowering perspective, fundamental to the profession of social work. The power and the importance of self-efficacy for individuals with HIV and AIDS is further exemplified in a study by Ironson and colleagues (2005), where self-efficacy was used to measure the impact of health outcomes for individuals with HIV and AIDS. The researchers found that self-efficacy was related to better overall health outcomes as it related to viral load decreases and CD4 count.
increases (p.232). Barlow and colleagues (2005), further acknowledge self-efficacy as grounding the theoretical framework of chronic disease self-management courses (CDSCs) by noting that the goals of these programs are, "to enhance self-efficacy through skill mastery, role modeling, persuasion, re-interpreting of symptoms, problem solving, decision making and action planning" (p.864). In essence, self-efficacy or beliefs about one's capabilities, and potential to meet situational demands is known to influence effort, perseverance perception of control, personal choices, thought patterns, depression and perception of stress, are all essential to individuals with HIV and AIDS (Bandura, 1995).

The self-help mutual aid model will also be used to inform this study, as it seeks to understand how the interventions of the chronic disease model makes way for the sharing of information and mutual support, which is critical for the success of chronic disease self-management programs. As Steinberg (2004) notes, "Mutual aid requires that they [clients] exercise and extend their strengths to help other as well as themselves" (p.15). The exchange and fostering of information in the mutual-aid model as members come to share common feelings, needs, and concerns is further illustrated in the research of Barlow and colleagues (2005), Wright and colleagues (2003), and Wituk and colleagues (2003). These studies were able to identify the benefits associated to the self-help mutual aid model, as it pertains to disease specific or population specific demographics, in articulating how it allows individuals to connect and help each
other through the sharing of similar experiences and as Steinberg (2004) notes, "it is most easily actualized in groups that are formed around a common cause" (p.16).

Summary

In the review of the literature as it relates to the treatment of individuals with HIV/AIDS, the evidenced based practices and interventions that have had positive outcomes, identify the use of chronic disease self-management courses (CDSCs) and chronic disease self-management programs (CDSPs), as they serve to educate and impact behavioral changes and an individual’s understanding and management of a disease. The literature related to CDSCs and CDSPs, also cites the need for chronic disease specific courses as opposed to generic chronic disease courses, as self-management techniques and strategies differ across genders, cultures and disease types. This study will seek to understand an HIV/AIDS specific chronic disease course and will seek to understand the impacts it has on the management of the HIV/AIDS disease. The effectiveness of the self-help mutual aid model was highlighted in the review of the literature. The use of the self-help mutual aid model has been identified as an effective method of group therapy as it furthers the underlying concept of understanding through shared experiences, allowing individuals to share not only their experiences with a specific disease but also coping techniques and strategies in managing it. The self-help mutual aid model allows individuals to
learn and grow together and to further develop their self-efficacy as they create a support network, educate themselves and each other, work to reduce stigma, and foster greater access to treatment and services. This study also looked at the use and the effectiveness of the self-help mutual aid model in group therapy, as it was a major component of the CDSP being analyzed. The positive use of peer educators to deliver disease specific information as well as self-care and management techniques has also been an effective intervention that the literature review noted, as it allows individuals to relate to each other through shared experiences and also in that it allows information to be delivered in a horizontal and non-hierarchical manner, making it less prescriptive and directive and relatable as it is delivered in a neutral and non-authoritative manner. Finally, the theories that guide this research in understanding the impacts that a CDSP has on changing behavior and impacting individual empowerment are found in strength-based approaches to working with individuals exemplified by self-efficacy theory. The behavioral models of Social Learning Theory and understanding this theory in application and context through Albert Bandura’s Social Cognitive Theory assist in further guiding this study in understanding the impacts of a CDSP.
CHAPTER THREE
METHODS

Introduction

Advances in medication and treatment adherence for individuals living with HIV/AIDS have created a shift in understanding and treating the illness from the perspective of seeing it as a terminal illness to that of a chronic illness that can be treated and managed. The shift in this perspective requires a self-management approach where patients assume an active and informed role in the healthcare decision making process, make changes to lifestyle behaviors, and improve treatment adherence to influence better health outcomes. The purpose of this study was to measure the effectiveness of chronic disease self-management courses (CDSCs) and chronic disease self-management programs (CDSPs) have in improving the self-efficacy of HIV/AIDS clients to managing their chronic illness and if the promotion of self-efficacy is correlated to improved health outcomes (CD4 and viral load). Specifically, this study measured the self-efficacy rates and health rates of female clients who participated in a HAOSC’s CDSP called "Newly Empowered Women" at one of the HAOSC’s two (2) Southern California locations that participated in this study in 2007 and 2008.

This chapter discusses the overall design of the research project to identify if the self-management skills that were taught in the CDSP promoted
client self-efficacy and to assess if these behavioral changes were retained over time. The impact of behavioral changes through the promotion of self-efficacy in impacting client immunological measures (CD4 and viral load counts) is also reviewed. The research design in this chapter is broken down according to the following: the study design, the sampling method, the data collection and instruments, procedures, and data analysis.

**Study Design**

Participants for this study were recruited from an HIV/AIDS Organization in Southern California’s (HAOSC’s), "Newly Empowered Women" program, a chronic disease self-management program (CDSP) that the HAOSC piloted with its female clients in 2007 and 2008. Participants for this study however were only recruited from the Newly Empowered Women’s program that was administered at one of the HAOSC’s locations. A total of 35 women participated in the study at the HAOSC’s locations reviewed in this study (a total of 55 participated collectively at the two (2) Southern California locations) in 2007 and 2008 and participants in this study ranged in age from 18 to 63.

This study sought to measure the self-efficacy rates of clients and their health outcomes (CD4 and viral load) three (3) to four (4) years after these clients have participated in a CDSP. The goal of this study was to look at the long-term impacts that a HIV/AIDS CDSP has on self-efficacy rates as well as on health outcomes. The self-efficacy assessment measured client self-management and
specifically looked at the retention of these self-management skills over time. Self-efficacy was measured through questions related to self-management which assessed general health through a self-rated health scoring question, symptoms associated to their health by measuring health distress, physical activities by measuring exercise behaviors, self-efficacy in managing their chronic disease by addressing their confidence in doing certain activities, daily activities by measuring social activities, medical care by addressing communication with physicians and health care utilization by addressing physician visits, hospital emergency room utilization and the number of nights a client was in a hospital. The health outcomes in this study were measured through immunological measures, specifically CD4 and viral load counts. Finally, the study collected basic demographic information including age, ethnicity, and highest level of education achieved, to see if these cofounding variables contributed to variation in the outcomes in any way.

Sampling

In designing this study, the researcher looked to the explanatory research model to conduct a secondary data analysis on the original data that the HAOSC collected on its female clients that were enrolled in the chronic disease self-management program (CDSP) at one of the HAOSC’s locations in 2007 & 2008. The participants that were recruited into the original study met the Center for Disease Control’s (CDC) case classification for either HIV or AIDS. In 2008, in an article titled, Revised Surveillance Case Definitions for HIV Infection Among
Adults, Adolescents, and Children Aged <18 Months and for HIV Infection and AIDS among Children Aged 18 months to <13 Years, the CDC through the work of Schneider and colleagues, developed a re-classification of case definitions for HIV infection among adults, adolescents, and children to respond to diagnostic and therapeutic advances and to improve standardization and comparability of surveillance data regarding persons at all stages of HIV disease. This re-classification defines HIV through four (4) progressive stages, with stage one showing no AIDS defining condition and a CD4 count of >500 cells; stage two (2) as no AIDS defining condition and CD4 counts of 200-499 cells; stage three (3) as AIDS with a CD4 count of <200 cells and documentation of an AIDS defining condition; and stage four (4) as an "unknown" due to the unavailability of a CD4 count (CDC, 2008). The females in the HAOSC’s original study consisted of females that were HIV positive (CD4 >500) with no AIDS defining conditions and females who were identified as having progressed to AIDS (CD4 count <200 and documentation of an AIDS defining condition). This study did not look to distinguish differences between individuals classified as having HIV or AIDS and instead focused on the overall changes between members of both classification groups (HIV and AIDS) as it relates to overall health outcomes.

Given the study’s retrospective analysis of measuring self-efficacy change over time and its impact on health outcomes for individuals who are HIV/AIDS positive, a non-probability purposive sampling method was used to obtain past and current self-efficacy and immunological scores (CD4 and viral load counts) from
HIV/AIDS positive females who participated in the HAOSC’s, "Newly Empowered Women" CDSPs at one of its two (2) Southern California locations. In measuring the impacts, the CDSPs has had on influencing the attainment of self-efficacy over time, a retrospective longitudinal study was incorporated to measure client self-efficacy after the completion of the CDSP, at the 6 month original follow-up period and current self-efficacy at the time of this study, as the original standardized self-efficacy evaluation tool initially used by the HAOSC, was re-administered to participants to further inform the original study and this study. CD4 and viral load counts after the completion of the CDSP, at the six (6) month follow-up period, and the client's most recent CD4 and viral load counts (within the past twelve months) were used to measure the CDSP’s impact on health outcomes.

Data Collection and Instruments

Through the Pfizer Foundation's "ConnectHIV" program, a total of 20 AIDS Service Organizations (ASOs) were funded to provide "HIV prevention and delay of disease progression through a continuum of prevention and care services for high-risk HIV-negative and/or at-risk HIV-positive persons and their sex and/or needle-sharing partners" (Rogers et al., 2010, p.449). Through the “ConnectHIV National Evaluation Study” grantees were required to participate in a national evaluation and were also required to design and implement their own local evaluations that were approved by an Institutional Review Board (IRB), which included a cost-effective component. These program outcomes were specifically
developed according to the four (4) areas grantees were funded under in this study. The four (4) different goal categories included: prevent infections among high-risk HIV-negative persons, prevent transmission from HIV-positive persons to their at-risk sex and/or needle sharing partners, link persons living with HIV into high-quality care and treatment services, and promote adherence and delay disease progression among persons living with HIV (Rogers, Ahmed, Hamdallah, & Little, 2010). The HAOSC’s initial chronic disease self-management program (CDSP) was funded under the goal category of “link persons with HIV into high-quality care and treatment services.”

The dependent variables for this study were CD4 and viral load counts. CD4 and viral load counts were used to show health improvement as these are the primary biological determinant factors in measuring the progression, severity and treatment response of the illness. These dependent variables were presumed to be impacted by independent variables which in this study were self-efficacy rates which were used to measure understanding and knowledge of the disease as well as treatment adherence. The measurement of self-efficacy rates were obtained using a standardized evaluation tool. The local evaluation that the HAOSC implemented adopted the survey instrument developed by Lorig and Laurent (2007) at the Stanford Patient Education Research Center, to measure the impact a CDSP has on the promotion of self-efficacy. This survey instrument was chosen as it incorporated questions and scales for measuring each element attributed to the promotion of self-efficacy that were reliable and valid, and also as it was
compatible with the curriculum FAP used by Loring and colleagues (2006) titled, *Living A Health Life With Chronic Conditions*. The survey instrument was used to evaluate self-efficacy at various follow-up periods, which for the HAOSC’s initial study included measures at baseline, immediately after completing the CDSP and then again six (6) months later.

The results for each section of the survey that measured various areas related to self-efficacy were calculated using the *Chronic Disease Self-Management Questionnaire Code Book* (Stanford University, 2007), which implemented a scale and scoring system that was different for each question. Questions included a scoring range from 0 (zero) to 5 (five), 1 (one) to 5 (five) and 0 (zero) to 10 (ten). Each of these responses either rendered a response value that corresponded to a specific value category or scores for each scale were derived by adding the collective responses in a question and then taking the mean score of those responses which then corresponded to a specific value category. Each questions’ scale, consisted of specific instructions on how to score it. These scores were then calculated and summarized through each section and the scores of each section were added to create a final score for each respondent. These scores were captured in the HAOSC’s original study immediately after clients had completed the six (6) week Chronic Disease Management Program (CDSP), and then again 6 months later at the follow-up period. This study incorporated and utilized the same evaluation tool and methods that the HAOSC implemented in the original study to CDSP clients at the three (3) and four (4) year follow-up period.
(depending on cohort) to measure the long-term impacts of a CDSP and also collected current client immunological health outcomes to measure whether a positive relationship between the two (2) exists.

Procedures

The sampling of these files was done through a non-probability purposive population sampling method that identified female clients that participated in the HAOSC’s CDSP groups. To assist in the confidentiality and protection of data, the HAOSC agreed to work with the researcher to numerically code (without the use of client identifiers) the original study data for the researcher. Specifically, the researcher received the results of each client’s follow-up CDSP score and their most recent CD4 and viral load measures from 2011-2012 via this method. The HAOSC, then reached out to the clients that had participated in the initial study at one of the two (2) Southern California locations, and with their consent and participation, re-administered the original survey developed by Lorig and Laurent (2007) and captured the client’s current health outcomes (CD4 and viral load within the past 6 months) to replicate and capture the exact same measurable outcomes (behavioral and biological changes) three (3) and four (4) years after the initial measures were recorded. This new client data was also coded according to the original client code that was used in the original data and this new data was given to the researcher to allow for a comparative retrospective analysis in measuring change as it relates to self-efficacy and health outcomes. Given the limited amount
of research in this area and the reality that the HIV/AIDS population is still a highly stigmatized and vulnerable group in our society, stipulates that this data be collected in this manner, adhering to strict client confidentiality and the use of non-identifiers in the transferring of this data.

This sample included female clients from the HAOSC’s one of two (2) locations of clients who participated in the CDSP program in 2007 and 2008. This retrospective longitudinal analysis also compared the results of the two (2) cohorts at the four (4) year (2007) and at three (3) year (2008) follow-up, to measure for any differences or similarities amongst these two (2) cohorts. Finally, knowing the importance of sample size in the generalizability of results, the research sought to capture a response rate of at least 50% of the total population sample used in this study (n=35).

To enrich the results of this study the researcher developed and implemented a structured qualitative measure consisting of four (4) open-ended questions that were asked to client’s who were a part of the initial CDSP studies. This qualitative interview sought to ask questions that measured subjective responses that were not encompassed in Lorig and Laurent (2007) survey tool and it also sought to explain, between and in group variation through the collection of this subjective data. Specifically, this qualitative measure assessed additional areas or resources that could be measured as impacting the results. Clients for these interviews were identified and contacted by the HAOSC’s staff and their participation in this interview was completely voluntarily. Clients were interviewed
via face-to-face by the researcher using a structured interview sheet consisting of four (4) questions. Each interview lasted on average between ten (10) to fifteen minutes. These sessions were also thoroughly noted with the client’s consent to ensure that all of the client’s thick descriptions were captured. The interview sought to gain information about services received and the client experience as it related to what they believed was the most important skill or lesson they gained from the CDSP, what other components of the program they felt help them manage their illness, and if they felt that they had achieved self-efficacy and learned better self-management techniques as a result of the CDSP. The final question of this interview also asked the client for their input on what programmatic changes they would like to see the HAOSC implement to the CDSP to meet their individual needs or the needs of the clients as a whole. This interview question allowed for constructive programmatic feedback, to give the agency additional insight on needed or requested services as they seek out new funding and collaborative opportunities, so that these services can be realized. Finally, the researcher also allowed for open dialogue at the end of each interview session and asked clients to note any other areas that may have either positively or negatively impacted them after completing the program and since the duration of their last follow-up session, to account for and to identify individual attributes or barriers that may have not been captured in the standardized questions.
Protection of Human Subjects

In conducting a secondary data analysis on the CDSP data that an HIV/AIDS Organization in Southern California (HAOSC) collected from its clients, the only identifier the HAOSC used in releasing the post and follow-up survey results to the researcher was through an ID code for each participant in the study. Using only numerical codes to identify the clients as opposed to other personal identifiers protected the privacy and confidentiality of those whose information was used in this study.

In conducting the qualitative interview on clients, the researcher only identified the clients by the ID codes provided by the HAOSC and used no other personal identifiers for the client to document the interviews. The researcher obtained consent from the clients to take notes of the interviews in the collection of qualitative data in an effort to capture thick description and detail of the interview. These notes were destroyed after the gathering of this data. The sharing of this health data was guided by professional standards and the law. Information from this study were presented in agency and community meetings, classroom discussions and were published as part of a graduate research study. The information included at meetings or in the thesis did not include the names of any of the clients, ensuring that none of the information can be traced back to them.
Data Analysis

To measure the short-term and long-term impacts the CDSP had on behavioral changes related to self-management and the promotion of self-efficacy, analysis was done from the data collected between two (2) points in time, which included from completion of the CDSP to six (6) months and from completion of the CDSP to current (3 to 4 years depending on cohort). To measure if there was a difference from one group to the other, a paired sample t-test analysis was used to analyze and compare mean scores between these groups at these two (2) points in time. The difference in these mean scores served to show if there were any differences within these two (2) comparison groups as it relates to the retention of self-management skills and the promotion of self-efficacy. To analyze and identify the impact the independent variables measured had on health outcomes, the two (2) dependent variables (CD4 and viral load) were also measured at the same two (2) points in time (completion to 6 months and completion to current) to see if there were any significant changes and improvements in outcomes related to health.

A qualitative research method was also incorporated by the researcher through a short interview with at least 25% of the clients that participated in the original CDSP study at one of the two (2) HAOSC’s Southern California locations (n>9) to further analyze and assess individual client perspectives on the program. The interview also sought to identify additional influences and impacts possibly not captured by the survey in improving overall health outcomes, and to measure other
details, elements, or variables that influenced self-management and the attainment and sustainment of self-efficacy. A mixed-methods approach also allowed for comparisons between the groups thorough the use of a standardized quantitative data collection method and helped to, “explain between and within group variations by gathering more subjective qualitative data, through interviews, on the clients that participated in the CDSP” (Grinnell & Unrau, 2008, p.352). A mixed method research design that also incorporated a qualitative approach allowed the researcher to capture the experience of the program through the client’s voice to gain rich description and a thorough understanding of the self-management skills and concepts (independent variables) that were promoted and fostered and to further understand the relationship it had in impacting and improving the health outcomes (dependent variables) that the study also sought to measure.

Summary

This retrospective longitudinal study measured client retention rates of self-efficacy concepts learned through the HAOSC’s CDSP program in relation to a client’s current immunological measures (CD4 and viral load counts) to assess the overall short-term and long-term impacts CDSPs have on health outcomes. Finally, the shift in treating and working with this illness from a chronic care perspective will influence how services are rendered to this population and it may ultimately impact how AIDS programs are funded in the future.
CHAPTER FOUR
RESULTS

Introduction

This section presents the data that was obtained through the use of a survey tool and through participant interviews. To describe the sample, a description of the demographics of the participants is first given. The original survey that Foothill AIDS Project administered as part of their “Connect HIV” study included a total of eight (8) survey questions that were captured from the “Chronic Disease Self-Management Workshop”. This survey tool was used to gather data over time to assess improvements in overall self-management and self-efficacy. Although all eight (8) of the original Chronic Disease Self-Management Workshop survey questions were also collected in this study, only five (5) of the questions were used as variables in the analysis of the results, as the measurement of these variables (captured through a set of questions for each variable) were identified to specifically be applicable to the assessment of the attainment and retention of self-management skills and the promotion of self-efficacy over time. The variables assessed through these questions measured responses at two (2) distinct points in time which included from completion of the CDSP to the 6-month follow-up period, and from the completion of the CDSP to the current time of this study at which point the survey tool was re-administered.
(3 to 4 years after completion of the program depending on cohort). The key variables identified for the project are described and the inferential statistics are reviewed. Participant health outcomes were also collected, specifically CD4 and viral load counts, and analyzed as variables, to measure the impact and change the CDSP also had on health outcomes over time.

To enrich and further understand the participant’s experience in the CDSP, and to identify the program’s best practices and areas for improvement, a set of four (4) structured interview questions were created, from which, specific themes will be identified and presented which include: program benefits, peer/social support, and agency changes. Also, the participant’s voice was captured through quotes to illustrate their experience in support of each major theme. The conclusion of this chapter includes the summary of both the quantitative and qualitative results.

Presentation of Findings

Demographics

The study was comprised of fifteen participants. The ages of the participants ranged in age from 35 to 63 years old. The mean age of the participants was 49.1 years old, and the majority of the clients (33.3%) were between the ages of 50 to 54 years old. The grouping of participant ages (Figure 1), shows that 13.3% were in the age group of 35-39 years old, 6.6% were in the 40-44 age group, 26.6% were in the 45-49 age group, 33.3% were in the 50-54 age group, 13.3% were in the 55-59 age group, and 6.6% were in the 60-64 age
group. The minimum age was 35 and the maximum age was 63 years old. The majority of participants surveyed identified as Black/African American (40%), followed by Latino/Hispanic (26.7%) and Caucasian/White (26.7%), and Native American 6.6% (Figure 2).

Figure 1. Demographic Information of Participant Age
Additional demographic information was obtained from the participants including highest level of education completed. When asked about their level of education, 13.3% reported less than high school, 46.7% reported some high school, 20% indicated that they had completed high school a GED or vocational training program, 13.3% indicated that they had some college, and 6.7% reported that they had a bachelor’s degree (Figure 3).
Figure 3. Demographic Information of Participant Education

Survey Tool, Measurement of Attainment and Retention of Self-Management, and the Promotion of Self-Efficacy

Self-Rated Health

Participants were asked to rate their perception of their health to see if was impacted or influenced through participation in the CDSP. Previous studies related to CDSP and the promotion of self-efficacy for individuals who HIV/AIDS have found that self-rated health is a good predictor of future health (Ironson et al., 2005). Participants in this study were asked to rate their health through an
ordinal level of measurement which included: 1=Excellent, 2=Very good, 3=Good, 4=Fair, and 5= Poor. A lower number indicated an individual’s higher self-perceived health status while a higher rating would indicate a lower self-perceived health rating. The first point in time measured was from completion of the CDSP to the 6-month follow-up period. The analysis found a participant mean score of 2.6 with a standard deviation of 0.7 at the completion of the CDSP, and a participant mean score of 2.1, with a standard deviation of 0.71 at the 6-month follow-up period highlighting a small improvement in participant self-rated health for this time period. The second point in time measured the self-rated health variable from completion of the CDSP to the current time of this study. This analysis for this point in time again found a participant mean score of 2.6, with a standard deviation of 0.7 at the completion of the CDSP and a participant mean score of 2.3, with a standard deviation of 0.7 at the current time of this study, again showing a small improvement in participant self-rated health over time. Table 1 shows the descriptive statistics on participant self-rated health for these points in time.

Table 1. Self-Rated Health

<table>
<thead>
<tr>
<th>Completion of CDSP to 6-month follow-up</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Rated Health</td>
<td>2.6</td>
<td>0.7</td>
</tr>
<tr>
<td>6-month follow-up</td>
<td>2.1</td>
<td>0.7</td>
</tr>
</tbody>
</table>
Completion of CDSP to Current

<table>
<thead>
<tr>
<th>Variable-Self Rated Health</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completion</td>
<td>2.6</td>
<td>0.7</td>
</tr>
<tr>
<td>Current</td>
<td>2.3</td>
<td>0.7</td>
</tr>
</tbody>
</table>

Health Distress

To measure participant depression in dealing with health issues related to the disease, participants were asked to rate their health distress to see if it was influenced or impacted by their participation in the CDSP. Studies that have measured pre and post levels of health distress and depression in individuals with HIV/AIDS who have participated with a CDSP (Kemppainen et al., 2006) or case management program (Husbands et al., 2007) have shown the ability to reduce their depression and distress. Through a series of four (4) questions, participants were asked to rate their health through an ordinal level of measurement which included: 0=None of the time, 1=A little of the time, 2=Some of the time, 3=A good bit of the time, 4=Most of the time, and 5=All of the time. A lower score for each question as well as a lower overall participant mean for this series of questions would indicate a lower level of depression and negative emotion in dealing with the illness. Individual participant means were captured by scoring the four (4) responses for each participant from this question. A collective mean was then taken from all of the participant means. The first point in time measured was from completion of the CDSP to the 6-month follow-up
period. The analysis found a participant mean score of 2.2, with a standard deviation of 1.0 after completion of the CDSP, and a participant mean score of 1.6, with a standard deviation of 0.9 at the 6-month follow-up period, showing a lower level of health distress among the participants in the CDSP. The second point in time measured the health distress variable from completion of the CDSP to the current time of this study. The analysis found a participant mean score of 2.4, and a standard deviation of 1.1 after the completion of the CDSP, and a participant mean score of 2.4, with a standard deviation of 1.4 at the current time of this study, which showed that although there were no improvements in this area, participants were able to maintain a healthy level of emotion over the long term as the 2.4 mean score noted that they were distressed, “Some of the time” by their illness and did not identify with being overwhelmed with negative emotion relate to their illness. Table 2 shows the descriptive statistics on participant health distress for these points in time.

Table 2. Health Distress

<table>
<thead>
<tr>
<th>Variable-History</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completion</td>
<td>2.2</td>
<td>1.0</td>
</tr>
<tr>
<td>6-month follow-up</td>
<td>1.6</td>
<td>0.9</td>
</tr>
<tr>
<td>Completion</td>
<td>2.4</td>
<td>1.1</td>
</tr>
<tr>
<td>Current</td>
<td>2.4</td>
<td>1.4</td>
</tr>
</tbody>
</table>
Social/Role Activities Limitations

To measure the impact the HIV/AIDS illness has on an individual’s social role activities, and to see if there was impact as a result of their participation in the CDSP, participants were asked to rate and identify if the illness impacts their social activities and if it does to what extent. Studies that have looked at the impacts of a chronic illness on social roles and activities have shown that those who are involved in a CDSP or in a support group show improvements in increased social activities and in other social supports as they are able to connect with others who share the illness and similar experiences, and are able to identify additional coping strategies, solutions, and resources from other members in the group. Through a series of four (4) questions, participants were asked to rate if and how their health interfered with their social activities through an ordinal level of measurement which included: 0=None of the time, 1=Slightly, 2=Moderately, 3=Quite a bit, and 4=Almost totally. A lower score for each question as well as a lower overall participant mean for this series of questions would indicate a lower level of social activity interference as a result of managing the illness. Individual participant means were captured by scoring the four (4) responses for each participant from this question. A collective mean was then taken from all of the participant means. The first point in time measured was from completion of the CDSP to the 6-month follow-up period. The analysis found a participant mean score of 1.4 with a standard deviation of 0.9 after completion of the CDSP, and a participant mean score of 0.9 with a standard
deviation of 0.7 at the 6-month follow-up score, showing a slight improvement in participants being able to reduce interference on role activities. The second point in time measured was from completion of the CDSP to the current time of this study. The analysis found a participant mean score of 1.4 with a standard deviation of 0.9 after completion of the CDSP, and a participant mean score 1.4 with a standard deviation of 1.2 at the time of this study, again showing a small improvement in the participants ability to sustain long term gains in limiting interferences the illness had on their social roles and activities. Table 3 shows the descriptive statistics on participant social role and activities limitations for these points in time.

Table 3. Social Role/Activities Limitations

Completion of the CDSP to 6 months

<table>
<thead>
<tr>
<th>Variable-SR/Activities Limitations</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completion</td>
<td>2.2</td>
<td>1.0</td>
</tr>
<tr>
<td>6-month follow-up</td>
<td>1.6</td>
<td>0.9</td>
</tr>
</tbody>
</table>

Completion of the CDSP to Current

<table>
<thead>
<tr>
<th>Variable-SR/Activities Limitations</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completion</td>
<td>2.4</td>
<td>1.1</td>
</tr>
<tr>
<td>Current</td>
<td>2.4</td>
<td>1.4</td>
</tr>
</tbody>
</table>
Communication with Physician

The effective maintenance of any chronic illness involves effective communication with the health provider to ensure that the client is aware of the treatment plan as well as their treatment options and to ensure that their questions and concerns are answered in regards to that treatment plan. As this is an area that the CDSP worked to empower participants in, participants were asked through a series of three (3) questions, to rate how they prepared for their appointment with their physician (writing of notes, questions, etc.) and if they brought up questions directly related to their health as well as other personal problems that may have been related to their illness. Participants were asked to rate this experience and their preparation to meet with their physician through an ordinal level of measurement which included: 0=Never, 1=Almost never, 2=Sometimes, 3=Fairly often, 4=Very often, and 5=Always. A higher score for each question as well as a higher overall participant mean for this series of questions would indicate a higher level of participant preparation for their appointments with their physician as well as confidence to ask their physician questions related to their illness and the confidence to articulate and manage these questions. Individual participant means were captured by analyzing the three (3) responses for each participant from this question. A collective mean was then taken from all of the participant means. The first point in time measured was from completion of the CDSP to the 6-month follow-up period. The analysis found a participant mean score of 1.9 with a standard deviation of
0.7 after completion of the CDSP, and a participant mean score of 3.2 with a standard deviation of 1.1 at the 6-month follow-up period, showing an improvement in participants being able to prepare and effectively communicate with their physician. The second point in time measured was from completion of the CDSP to the current time of this study. The analysis found a participant mean score of 2.7 with a standard deviation of 1.1 after completion of the CDSP, and a participant mean score 3.2 with a standard deviation of 1.2 at the time of this study, again showing and improvement in the participants ability to maintain the self-management skill of preparing for their appointment and communicating with their physician about their illness. Improvement in this area and its impact on fostering better client self-management and promoting self-efficacy was highlighted and supported in the studies by Lorig and colleagues (2001) and Barlow and colleagues (2005) which also showed improvements in this area for clients that participated in a CDSP. Table 4 shows the descriptive statistics on participant social role and activities limitations for these points in time.

Table 4. Communication with Physician

<table>
<thead>
<tr>
<th>Variable-Communication w/ Physician</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completion</td>
<td>1.9</td>
<td>0.7</td>
</tr>
<tr>
<td>6-month follow-up</td>
<td>3.2</td>
<td>1.1</td>
</tr>
</tbody>
</table>
Completion of the CDSP to Current

<table>
<thead>
<tr>
<th>Variable-Communication w/ Physician</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completion</td>
<td>2.7</td>
<td>1.1</td>
</tr>
<tr>
<td>Current</td>
<td>3.2</td>
<td>1.2</td>
</tr>
</tbody>
</table>

**Self-Efficacy**

One of the primary focuses of this study was to assess how the other components of the CDSP including the psycho-educational, emotional/social support, and support services impacted and promoted the concept of self-efficacy, the belief and confidence that one’s abilities will meet situational or needed demands. The impact of the CDSP in promoting and developing self-efficacy as well as identifying its impact over the short-term and maintenance over the long-term was analyzed. Through a series of six (6) questions, participants were asked to rate on a scale that used an ordinal level of measurement, their confidence in managing different domains related to their illness. These domains included symptom control, role function, emotional functioning, and communication with physicians. Scores at the lower end of the scale would determine a “not at all confident” response, while scores at the higher end of the scale would determine a “totally confident response.” A higher score for each question as well as a higher overall participant mean for this series of questions, would indicate a higher level of perceived self-efficacy by the participant in managing their illness. Individual participant means were captured.
by scoring the six (6) responses for each participant from this question. A collective mean was then taken from all of the participant means. The point in time measured was from completion of the CDSP to the 6-month follow-up period. The analysis found a participant mean score of 5.1 with a standard deviation of 1.5 after completion of the CDSP, and a participant mean score of 6.9 with a standard deviation of 1.5 at the 6-month follow-up period, showing an improvement in short term participant perceived self-efficacy. The second point in time measured was from completion of the CDSP to the current time of this study. The analysis found a participant mean score of 5.4 with a standard deviation of 1.7 after completion of the CDSP, and a participant mean score 6.7 with a standard deviation of 2.2 at the time of this study, again showing and improvement in the participants ability to maintain their perception of self-efficacy over the long term in self-managing their illness. Table 5 shows the descriptive statistics on participant self-efficacy for these points in time.

Table 5. Confidence About Doing Things

Completion of the CDSP to 6 months

<table>
<thead>
<tr>
<th>Variable-Self-Efficacy</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completion</td>
<td>5.1</td>
<td>1.5</td>
</tr>
<tr>
<td>6-month follow-up</td>
<td>6.9</td>
<td>1.5</td>
</tr>
</tbody>
</table>
Completion of the CDSP to Current

<table>
<thead>
<tr>
<th>Variable-Self-Efficacy</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completion</td>
<td>5.4</td>
<td>1.7</td>
</tr>
<tr>
<td>Current</td>
<td>6.7</td>
<td>2.2</td>
</tr>
</tbody>
</table>

Measurement of Health Outcomes

**CD4**

As this study sought to measure the impact that a CDSP has in not only promoting behavioral changes but also in impacting health outcomes, biological markers were also analyzed to measure the impact the CDSP had on health outcomes. The first biological measurement captured and analyzed to determine the CDSPs impact on participant health outcomes were CD4 counts, also commonly referred to as white blood cell counts. Changes in client CD4 counts were analyzed to determine if a participant’s involvement in the CDSP produced better results in this area. Better results in this area would mean increased CD4 counts as this would indicate biologically that the participant’s body and immune system was making progress in fighting off the infection. Subsequently, a lower CD4 count would indicate progression of the disease, further compromising an individual’s immune system and making them susceptible to other infections. In a similar study that focused on individuals diagnosed with AIDS by Ironson and colleagues (2005), researchers also looked at the impacts of self-efficacy on health and also measured changes related to client CD4 counts, as this is one of
the disease progression markers related to health that are often identified with
HIV/AIDS clients to track the diseases’ progress. The first point in time
measured was from completion of the CDSP to the 6-month follow-up period.
The analysis found a participant CD4 mean score 597.0 cells with a standard
deviation of 353.9 cells after completion of the CDSP, and a participant mean
score of 668.6 cells with a standard deviation of 441.8 cells at the 6-month
follow-up period. The second point in time measured was from completion of the
CDSP to the current time of this study. The analysis found a participant CD4
mean score of 597.0 cells with a standard deviation of 353.9 cells after
completion of the CDSP, and a participant mean score 873.0 with a standard
deviation of 623.6 cells at the time of this study. Although there were increases
in client CD4 counts over the points in time measured, extreme participant CD4
count outliers in this area as identified by the standard deviation, found this
outcome to be statistically insignificant. Table 6 shows the descriptive statistics
on participant CD4 counts for these points in time.

Table 6. CD4
Completion of the CDSP to 6 months

<table>
<thead>
<tr>
<th>Variable-CD4</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completion</td>
<td>597.0</td>
<td>353.9</td>
</tr>
<tr>
<td>6-month follow-up</td>
<td>668.6</td>
<td>441.8</td>
</tr>
</tbody>
</table>
Completion of the CDSP to Current

<table>
<thead>
<tr>
<th>Variable-CD4</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completion</td>
<td>597.0</td>
<td>353.9</td>
</tr>
<tr>
<td>Current</td>
<td>873.0</td>
<td>623.6</td>
</tr>
</tbody>
</table>

**Viral Load**

The second biological measurement captured and analyzed to determine the CDSPs impact on participant health outcomes were viral load counts. As viral load counts identify a participant’s response to antiretroviral therapy, and decreases in this area demonstrate better response to treatment. Changes in client viral load counts were analyzed to determine if a participant’s involvement in the CDSP produced better results in this area. Better results in this area would mean decreased viral load counts as this would indicate biologically that the participant’s body was responding to treatment, and that less of the virus was present in the body. Subsequently, a higher viral load count would indicate progression of the disease, identifying an individual’s unfavorable response to antiretroviral treatment to successfully fight the virus. Optimal viral load suppression is defined as a viral load persistently below the level of detection which is < 20 to 75 copies/ml depending on the test that is used (U.S. Department of Health and Human Services, 2014). The first point in time measured was from completion of the CDSP to the 6-month follow-up period. The analysis found a participant viral load mean score 9,172,698.5 copies/ml.
with a standard deviation of 30,421,324.8 copies/ml after completion of the CDSP, and a participant viral load mean score of 22,256.6 copies/ml with a standard deviation of 71,764.8 copies/ml at the 6-month follow-up period. The second point in time measured was from completion of the CDSP to the current time of this study. The analysis found a participant viral load mean score of 11,211,065.3 copies/ml with a standard deviation of 33,632,017.0 copies/ml after completion of the CDSP, and a participant viral load mean score of 11,214,143.2 copies/ml with a standard deviation of 33,545,253.9 copies/ml for this time period. There were decreases in client viral load counts over the short-term (from completion to 6-month follow-up) but increases in participant viral load counts over the long-term, due again to extreme participant viral load count outliers in this area as identified by the standard deviations in each of the points in time measured. Analysis on the impact of the CDSP on this variable found it to be statistically insignificant. Table 7 shows the descriptive statistics on participant viral load counts for these points in time.

Table 7. Viral Load

Completion of the CDSP to 6 months

<table>
<thead>
<tr>
<th>Variable-Viral Load</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completion</td>
<td>9,172,698.5 copies/ml</td>
<td>30,421,324.8 copies/ml</td>
</tr>
<tr>
<td>6-month follow-up</td>
<td>22,256.6 copies/ml</td>
<td>71,764.8 copies/ml</td>
</tr>
</tbody>
</table>
Completion of the CDSP to Current

<table>
<thead>
<tr>
<th>Variable-Viral Load</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completion</td>
<td>11,211,065.3 copies/ml</td>
<td>33,632,017.0 copies/ml</td>
</tr>
<tr>
<td>Current</td>
<td>11,214,143.2 copies/ml</td>
<td>33,545,253.9 copies/ml</td>
</tr>
</tbody>
</table>

Qualitative Interview Data

After completion of the survey, participants that were interested in sharing their experience about being in the CDSP (as identified by the HAOSC staff) were contacted by the researcher to make arrangements to schedule an interview. A total of nine (9) participants or approximately 25% (n=15) of the participants who completed the survey also participated in the interview. The purpose of the participant interviews was to capture qualitative data that encompassed details and outcomes not measured by the survey tool and to identify strengths of the program and possible areas for program improvement. Interviews were conducted via a face-to-face methodology to allow the researcher to build rapport and trust with the participants in explaining the purpose of the study and the interview to the participants in person. By taking on this personal approach the researcher sought to create a safe and comfortable environment to allow the participants to openly express themselves. Through this process thick descriptions and details related to the program were captured and identified. The interviews ranged from 20 to 45 minutes and averaged approximately 30 minutes. Participants were asked to share their experiences and insight as it related to their participation in the CDSP through four (4) open
ended questions that focused on: what self-management skills taught in the CDSP they felt were most important in managing the disease, other components of the program that were beneficial, improvements or suggestions to the CDSP, and whether they felt that they had achieved self-efficacy as a result of this program. Based on individual participant responses to these open-ended questions, common themes and topics were identified. The qualitative insight and meaning identified through the interviews in assessing the participant experience as expressed and captured in participant responses, allowed for their voices to be heard in the identification of best practices and in identifying changes or improvements that can be made to enhance and shape the program to better meet participant needs. The themes identified through the interview process and the experience of participants involved in the CDSP are noted and described.

Benefits of the Program

In assessing if the objectives of the CDSP rendered the anticipated program outcomes, which was to improve self-management skills to promote participant self-efficacy, the interview process sought to identify subjective viewpoints on how participants felt they had been assisted by the program in managing their illness. In discussing this area, a common theme emerged as participants described specific benefits or self-management skills they felt had helped them as a result of the program. In addressing the specific benefits related to the CDSP, 88% of the participants interviewed felt that the education
offered regarding specific topics relating to the disease greatly helped them with understanding and better managing their illness. Specific areas and benefits of the program identified and reported by the clients (each client reported multiple benefits) included medication adherence at 66%, understanding the biological impacts of the virus and other Sexually Transmitted Diseases (STDs) at 33%, antiretroviral therapy regimens at 33%, resource identification at 66%, social activities and supports at 66%, nutrition and diet at 66%, and the monitoring of disease specific progression markers (CD4 and viral load) at 77%. These benefits were identified as being essential in the development of needed skills to manage their illness. The impact of education in understanding the illness and in this instance the importance of medication adherence was highlighted by a participant who noted, “I was off my meds before coming to the program and the disease progressed and my condition deteriorated. I’m thankful for this program for it has taught me the importance of taking my meds” (Participant 4, personal interview, May, 2012).

In addition to the specific benefits identified by the participants, the translation of these learned skills identified specific self-management strategies in areas that participants felt they had developed as a cumulative result of the lessons taught and the discussions that were fostered in the CDSP. Specific self-management areas identified by the participants in helping them manage their illness included, self-management of anxiety and stress related to the illness through learned coping strategies at 66%, self-management of nutrition and diet
at 77%, and the self-management of medication adherence at 66%. In discussing the mental health impacts the program had in teaching positive self-management coping strategies to deal with stress or in identifying social supports to assist, one participated stated, “Through this program, the lessons taught, and through my interaction with others I learned how to love life and still keep things positive, even though the illness and its effects can be hard to deal with at times” (Participant 6, personal interview May, 2012).

Peer Support

In the identification of best practices and in learning about each client’s experience in the CDSP, a reoccurring theme expressed by all of the participants interviewed was the concept of peer or mutual support. Although examples of how this support was experienced differed between participants, as some valued the friendship and personal connections they made while others valued the advice and lived experience that was shared by others, the importance of peer support was acknowledged by each participant interviewed. For some of the participants interviewed, the peer support offered in the CDSP was expressed as a reason or motivator to continue returning to the group at 44%, and for many of the participants interviewed at 88%, the support groups were one of the most important components of the program. Some of the areas discussed around this theme centered on support group topics, education, resource sharing and identification, and the hope and support experienced through the lived experiences of others. In highlighting the impact and influence of acceptance
and understanding by others in the program, a client in discussing the importance of being involved in the support group noted, "I felt accepted and supported by the others who shared the same condition as I did. They understood you as you can't talk to everyone about something like this" (Participant 1, personal interview, April, 2012). Other comments around the support group also highlighted the notion of being accepted by others, "I've learned to accept and deal with myself now. Before I didn't know what was going to happen to me. The program and the experiences shared by others gave me hope" (Participant 2, personal interview, April, 2012). Other participant comments related to the impacts of peer support, highlighted their enjoyment and involvement in social outings with other members and noted how this process was empowering. This was illustrated by one participant who stated, "I feel like myself again and with the support of others have learned to get my self-esteem and confidence back to go out into the world and enjoy life" (Participant 9, personal interview, May, 2012).

Finally, 55% of the participants interviewed identified that the sharing of best practices by other participants who had lived experience had a profound impact on their learning and gave them hope, "Having the communication and the support of others who have lived with the illness and who share the same experiences. Drawing from their knowledge, their journey, and from the experiences of others in the group gives me hope" (Participant 8, personal interview May, 2012). It was the many facets of peer support that were
presented in the CDSP that allowed participants to grow, learn, and feel supported by providing an environment of acceptance and understanding.

Agency and Program Changes

Another primary reason for administering the interview was to identify what changes the participants felt were needed to the CDSP to better meet their needs and also what changes they felt were needed at the HIV/AIDS Organization in Southern California (HAOSC) as this was not an area that was captured by the survey. The HAOSC was also interested in identifying this information from an operations standpoint, as they wanted to ensure that they were meeting the needs of their clients through the CDSP and services and wanted to identify areas or services that needed improvement. In the interview participants were asked to identify what changes (if any) they felt would benefit the CDSP, and also what changes (if any) they felt were needed at the HAOSC.

In identifying improvements for the CDSP, the only area that interviewed participants identified was the need to have more consistency in the therapist that facilitated the group sessions at 44%. Participants who identified this as an area for improvement described the frequent changes of the therapist in the CDSP group sessions as disrupting, in that they felt that a trusting relationship between the therapist and the participants was essential in allowing members to open up and share their thoughts and feelings, and that this trust had to be rebuilt each time there was a change in the therapist. As one client noted, “When we had changes in therapists, I felt as if I and maybe other members were
not being as open and truthful” (Participant 2, personal interview, April, 2012). In
the interview sessions, a majority of participants interviewed indicated that they
felt that there were no changes that needed to be made at 66% to the CDSP.
Participants who responded by indicating that there were no changes that
needed to be made primarily expressed gratitude for the services and supports
provided through the program. As one participant noted, “The HAOSC doesn’t
need to improve or change anything. They have done so much for me. They
saved my life” (Participant 9, personal interview, May, 2012). Another participant
commenting on the services provided at the agency and the self-efficacy attained
as a result of having participated in the CDSP stated, “None. Everything that
was done was excellent and the HAOSC is very helpful. I feel good about myself
and I now have the confidence to do things” (Participant 4, personal interview,
May, 2012).

In identifying improvements for the agency, interviewed participants at
66%, felt that there should be more social activities and outings built into program
services to allow clients to connect, get to know each other better, and to be
additional supports to each other. As one client noted, “It would be nice to have
more recreational activities to get to know each other better as many of us have
issues with accessibility and funds.” (Participant 3, personal interview, April,
2012). Another area for agency improvement identified by the participants
interviewed at 55%, center around case management services and the need for
more attention from their assigned case managers. As one participated noted, “I
would like to be able to communicate with my case manager better. I feel that
case managers are overwhelmed with too many clients” (Participant 1, personal
interview, April, 2012). Interviewed participants also identified a need for better
outreach and promotion of services at 66%, as they felt that more individuals that
had an HIV/AIDS diagnosis could benefit from the program if it was publicized or
promoted more in the community. As one client noted, “There needs to be more
community outreach to inform people about HIV/AIDS and about the services
offered at the HAOSC” (Participant 8, personal interview, May, 2012). The last
area that interviewed participants identified as an area for improvement in the
agency at 33%, was the need for the agency to incorporate more individuals with
lived experience, into the staffing and services. Participants felt that having
these individuals as supports in the programming of services to assist clients in
navigating the system to access benefits and resources, or in being involved with
outreach in the community was essential in helping individuals feel comfortable,
and in helping them to be successful in accessing services. As one participant
noted, “I would like to see a more comprehensive peer advocate component or
position developed at the HAOSC. I believe this would be empowering for the
members to see (Participant 2, personal interview, April, 2012). Another
participant expressed the importance of having peer advocates as an effective
way to conduct outreach in sharing their status and lived experience by stating,
“Incorporate clients in prevention and outreach methods. At first, I too was
scared about doing this, but now I feel empowered by disclosing my status and by educating others" (Participant 3, personal interview, April, 2012).

**Paired T-Test**

Paired sample t-tests were performed on the data. The t-tests included measuring the means of the identified variables at two (2) points in time, which included completing to 6-months and completing to current. The following are the significant findings from the data analysis.

A paired sample t-test was performed on each of the variables identified. The purpose of this analysis was to measure differences in means between the two (2) points in time to assess the short-term and long-term impacts of the CDSP as it relates to learned behavioral changes that taught self-management skills and promoted self-efficacy and the impacts on health outcomes as a result of these changes. In measuring variables for the first point in time, from completion of the project to the 6-month follow-up period, the test showed that four (4) of the seven (7) variables measures were found to be significant. Participant self-rated health, social/role activities, communication with physician, and self-efficacy were significant. In measuring participant self-perceived health, this variable was shown to be significant at the 6-month follow-up period, t (11) =3.31, p=.007, showing that participants had a better perception of their health from completion of the program to the 6-month follow-up period. The analysis of social/role activities limitations to assess how the illness impacted this area, was
shown to be significant from completion of the program to the 6-month follow-up period, \( t(11) = 3.54, p = 0.005 \), showing that there were less limitations on participant social role activities from completion of the CDSP to 6-month follow-up period. The analysis of participant communication with their physician was shown to be significant from the completion of the program to the 6-month follow-up period, \( t(11) = -5.57, p < 0.0005 \), showing that participants felt that they had and were able to communicate more effectively with their physician regarding their illness. Finally, the variables of self-management that were measured culminated into understanding if self-efficacy had been promoted as a result of the self-management skills that were taught in the CDSP. Analysis of participant self-efficacy was shown to be significant from completion of the program to the 6-month follow-up period, \( t(11) = 3.57, p < 0.0005 \), showing that participants perceived a higher sense of self-efficacy in managing their illness from completion of the CDSP to the 6-month follow-up period.

In analyzing the long-term impacts the CDSP had on the retention of self-management skills, and the promotion of self-efficacy in impacting health outcomes, these variables were measured from the completion of the CDSP to the current time of this study. In analyzing these variables only one (1) of the seven (7) variables measured were found to be significant in the long-term. Communication with physicians was found to be significant from completion of the program to the current time of this study, \( t(12) = -2.74, p = 0.018 \), showing that participants improved their communication and relationship with their physician.
and were able to sustain this improvement over time. Table 8 shows the t-test analysis for the variables that were shown to be statistically significant for these points in time.

Table 8. Paired T-Tests

Completion of the CDSP to 6 months (short-term)

<table>
<thead>
<tr>
<th>Variable</th>
<th>t</th>
<th>df</th>
<th>Sig (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Rated Health</td>
<td>3.31</td>
<td>11</td>
<td>.007</td>
</tr>
<tr>
<td>Social/Role Activities Limitations</td>
<td>3.54</td>
<td>11</td>
<td>.005</td>
</tr>
<tr>
<td>Communication With Physician</td>
<td>-5.57</td>
<td>11</td>
<td>.000</td>
</tr>
<tr>
<td>Self-Efficacy</td>
<td>-3.57</td>
<td>11</td>
<td>.004</td>
</tr>
</tbody>
</table>

Completion of the CDSP to Current (long-term)

<table>
<thead>
<tr>
<th>Variable</th>
<th>t</th>
<th>df</th>
<th>Sig (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication With Physician</td>
<td>-2.74</td>
<td>11</td>
<td>.018</td>
</tr>
</tbody>
</table>

Summary

This section presented the data obtained through the use of the survey tool, participant immunological measures (CD4 and Viral Load), and through participant interviews. The survey tool was used to measure the short-term and long-term attainment and retention of self-management skills and to assess if participants perceived these changes as having helped them achieve self-efficacy. The measurement of participant immunological measures over time
was used to determine the impact of the CDSP on the health outcomes. Through the use of participant interviews, more detailed and descriptive qualitative data was captured which revealed specific themes in several categories. Improvements to the CDSP identified more consistency in the use of the therapists that facilitated group sessions. Participants also identified agency improvements that included receiving more personalized attention in case management services, more outreach and education in the community, and the use of peers in conducting outreach and in assisting clients to navigate the system. Some of the participants interviewed noted however that there were no changes needed to the CDSP or to the HAOSC services. Through the use of participant quotes, a more thorough and meaningful understanding of the participant experience was illustrated, and specific suggestions and improvements in programming or in agency operations were also identified. Finally, an analysis of the variables measured identified significant short-term findings in the areas of self-rated health, social/role activities limitations, communication with physicians and self-efficacy. Long-term findings identified communication with physicians as statistically significant. There are no other significant findings from this data.
CHAPTER FIVE

DISCUSSION

Introduction

The following chapter provides an overview of the major themes identified from this study and their importance as it relates to CDSPs for individuals with HIV/AIDS in the development of self-management skills and the promotion of self-efficacy. A brief discussion is also provided on the limitations of this study and how methods related to the design of this study and the collection of data may have impacted and influenced the results. Finally, this chapter also discusses and reviews recommendations for social work practice, policy, programming and suggestions for future research to identify additional themes and outcomes for special and diverse populations.

Discussion

Social Learning Theory

The conceptualization of this study was grounded in a behavioral theorist framework, understanding that individuals learn from observing and modeling others. This study further applied and sought to understand Bandura’s social learning theory, through the use of a CDSP, that modeled and taught self-management skills and applied other resources, to impact these participant’s
social environments in an effort to change and influence their behaviors to improve health outcomes. Bandura’s social cognitive learning theory, was further explored and applied in this study understanding that humans learn by modeling the behaviors of others and by testing the outcomes of those behaviors in their own lives (Turner, 2011, p.429). This concept was further illustrated in this study through analyzing how the self-management techniques taught in the CDSP promoted participant self-efficacy, how this was retained over time, and how this in turn impacted participants in both their behavioral and health outcomes (CD4 and viral load counts).

Based on similar studies by Ironson and colleagues (2005), and based on the HAOSC’s own initial data results from their participation in the Pfizer Foundation’s “Connect HIV”, which showed improved behavior and health outcomes as a result of participants being in the CDSP, it was anticipated for this study that increased participant outcomes in the self-management of the disease and an increase in client perceived self-efficacy would lead to better health outcomes for individuals with HIV/AIDS. Although this study did observe improved short-term outcomes in self-management skills and general self-efficacy in four (4) of the seven (7) variables measured from completion of the program to the 6-month follow-up period, and one (1) of the seven (7) variables measured from completion of the program to the current time of this study that were identified as statistically significant, the analysis determined that there was not a relationship between learned self-management skills in the promotion of
self-efficacy on improved health outcomes that were found to be statistically significant in this study. The null hypothesis that learned self-management skills in CDSPs that promote self-efficacy do not have an impact on behavioral and health outcomes could not be rejected.

Although this project was unable to reject the null hypothesis, it did identify significant learning from the areas that were found to have produced positive quantitative results through the analysis of the survey and also the areas of learning that were identified qualitatively through the participant interviews that allowed the participant's voice to be heard in the description of the CDSP experience and in identifying best practices and areas for improvement. The learning themes identified in this study are discussed below.

**Significant Themes**

There were a number of variables that were analyzed and reviewed in this study and as a result significant themes that were identified in the quantitative and qualitative data. In looking at the quantitative data that was captured through the use of a survey tool, it illustrated the short-term impacts that a CDSP has in teaching specific self-management skills related to the HIV/AIDS disease and how this serves in promoting self-efficacy. The positive impact and the importance of a social support system was highlighted in the survey through increases in client social activities and reduced limitations on these activities and was further captured and supported by qualitative means through participant interviews, which highlighted the importance of providing a socially supportive
environment promoted through activities and support groups offered by the CDSP. Finally, changes and suggestions to the CDSP and agency to enhance programming and to better meet the needs of the participants, as identified through the participant interviews are discussed.

Self-Management Skills and the Promotion of Self-Efficacy

One of the main outcomes that informed this study was the analysis of self-management skills taught in the CDSP to determine if they promoted the concept of self-efficacy, which as Bandura (1997), noted is, “the belief in ones’ capabilities to organize and execute the courses of action required to produce given attainments” (p.3). In analyzing the variables of the survey that measured the attainment of self-management, this study found that participants felt that they had learned better self-management skills in the managing their illness over the short-term. This was highlighted in the 6-month follow-up participant survey variables that were measured which saw client increases in self-rated health, lowered health distress, increase in daily activities and fewer limitations on these activities, and better communication with their physicians. These short-term results, highlighting the increase in self-management skills as a result of participant involvement in a CDSP was also supported by the research by Wright and colleagues (2003), which conducted follow-up at four (4) months and found increases in self-management skills, and by the research by Barlow and colleagues (2005) which also saw an increase in the attainment of client self-management skills for those that participated in a CDSP at the 6 (six) month
follow-up period. The study also found that there was an increase in participant self-efficacy as a result of their involvement in the CDSP through the self-management skills taught in the areas of diet, exercise, and physician communication, and through the psychoeducation offered in helping participants understand the biology of their disease, different antiretroviral medications, the importance of medication adherence, and understanding other complexities of their disease. Previous research by Lorig and colleagues (2001), Barlow and colleagues (2003), and Ironson and colleagues (2005) in assessing the impacts a CDSP has on the management of a chronic illness supported the results of this study. This research also highlighted self-efficacy as an important outcome in measuring the effectiveness of a CDSP, as it encompasses all of the elements learned in a CDSP in fostering an individual’s ability to be able to manage the daily tasks in managing the physical elements of the disease, but also the coping mechanisms to deal with the psychological impacts. The implementation of a disease specific CDSP and disease specific self-management skills in programming, for individuals with HIV/AIDS, like the participants in this study, was also supported in the research by Ironson and colleagues (2005), which also found increases in self-management skills in the promotion of self-efficacy in a CDSP for individuals with HIV/AIDS.

In addition to measuring the short-term impacts of the CDSP, this study also implemented a longer term follow-up period than the studies by Wright and colleagues (2003) and Barlow and colleagues (2005), to measure if these self-
management skills were retained over the long-term by following up with the participants of the CDSP three (3) and four (4) years after its completion. In the analysis of long-term survey data, it was identified that these self-management skills were not all effectively sustained over time. The only variable that was found to be significant at the long-term follow-up period measured was communication with physicians. No other variables were found to be significant.

It was encouraging to see that participants were assisted by the program in being able to prepare for their physician appointments and also that they were more cognizant of their health and scheduling of these appointments. This concept was highlighted by a participant in the client interview that noted that, “This program encouraged me to take care of my health and to go see my doctor regularly” (Participant 5, personal interview, April, 2012). Unfortunately, the fact that not all of the self-management variables that were measured were sustained over the long-term highlights the need for longer term sustainment of CDSPs or for successful elements or components of the CDSP to be identified and offered by agencies or organizations as stand-alone services or collectively as comprehensive wrap around services for clients that are still in need of these supports. This sentiment was also captured in qualitative interviews as 44% of the participants interviewed expressed a need for certain services to be offered longer. This sentiment was captured by one of the participants interviewed when asked about identifying any suggestions or improvements to the CDSP or agency and they noted,
I know that it eventually had to come to an end and that we all had to go our own ways, but I wish it could have continued somehow even in a more reduced form. I wish there was a way we could continue learning and growing together (Participant 3, personal interview, April, 2019).

At the time of this study, the HAOSC was no longer implementing the CDSP in whole, but they were facilitating quarterly health forums to discuss various topics on HIV/AIDS over the course of a full day of training which was made available to all of the clients as well as to their family members. They also continued facilitating support groups throughout the week for females as well as other specialized support groups for subcultures (gay males, substance use disorder, etc.) within this population, which was encouraging.

**Social/Emotional Supports:**

Another area that was found to be of importance in the results of this study as identified in both the quantitative and qualitative analysis of data, was in understanding the impact that social emotional supports have not only on physical self-management techniques related to a disease but also how it impacts its psychological and emotional management. The impact of this was analyzed quantitatively through the results that were captured in the survey tool that measuring participant health distress and social/role activities limitations. The analysis of these two (2) variables were shown to be statistically significant or reaching significance at the short-term follow-up period of 6-months. In measuring the short-term impacts that the CDSP had on participant health
distress, participants noted a lower level of health distress, feeling that they could better manage their disease, and reported that they were more involved in social activities they liked to partake in and had less limitations on these activities due to their illness. The short-term impacts a CDSP has in reducing health distress were also supported in a number of research studies (Barlow et al., 2005; Ironson et al., 2005; Kemppainen et al., 2006; Wright et al., 2003). These studies saw reductions in the levels of health distress (also reported as a reduction in anxiety) in participants who were in a CDSP due to social and recreational activities facilitated by the program, through friendships developed, and through self-management skills that allowed them to enjoy these activities. Although there was slight improvement in the mean scores of the same variables for both the short-term and long-term follow-up periods of this study, the impact in reducing health distress as a result of being involved in the CDSP was not found to be statistically significant. The slight improvement in mean scores in this study for participant health distress may show that the education, support, and social encouragement that participants received through the CDSP may have allowed some of them to have a reduced level of stress for the short-term period measured. In looking at limitations on social role activities due to a chronic illness, participants enrolled in the CDSP initially noted reduced limitations on their social roles and activities as a result of their disease. This area, was found to have improved over the short-term follow-up period measured at 6-months, and was found to be statistically significant. It was however not
found to be statistically significant in the long-term or at the current time of this study, possibly highlighting the need for more supports in social activities to be built into the programming or services for clients at the HAOSC.

Another area of social support that was highlighted almost exclusively through the qualitative analysis of this study and captured through the details in participant interviews, highlighted the concept of mutual aid among participants as supported by the self-help mutual aid model. Though self-help is defined as having many dynamics which promote the mutual support of helping each other, the notion of mutual aid is best conceptualized by Steinberg 2004, who notes, “To the extent that group members emerge from some process, have gained greater insight into themselves or a greater capacity for empathy, that result is mutual aid” (p. 16). The notion of the mutual aid concept was implemented and fostered in the CDSP through the sharing of knowledge by others that had lived experiences. This knowledge of lived experience was implemented in the delivery of services through the training modules that were also co-facilitated by a peer mentor and through the groups which allowed participants to simply process their feelings or to share information or resources to assist other members of the group. In the interviews, participants reported that they believed the support groups offered were one of the most important components of the CDSP as it was reported as an important theme in 88% of the participants interviewed. Participants shared their experiences of finding others to connect with who shared similar experiences, the insight and resources offered by others,
and the network of support among those in the group. The concept of the self-help mutual aid among members who share similar experiences and its impact on supporting and empowering other members of a group or CDSP have been supported in research by Finn (1999), Gifford & Sengupta (1999), Wright and colleagues (2003), and Barlow and colleagues (2003), which have all identified this shared experience as empowering. The self-help mutual aid model is empowering as it utilizes a strength-based approach in allowing members to share their experience in an effort to help another and to receive support themselves through the reciprocal process. Barlow and colleagues (2005), accurately and descriptively capture the expression, sentiment, feeling of connectedness, and the support that the participants interviewed shared as far as how they felt the support groups impacted them by noting, “Sharing engendered feelings of peer belonging and acceptance, thus, participants, realized that they were not alone” (p.870). The CDSP and support groups created a sense of acceptance, belonging, and connectedness for participants that shared a common disease. This concept of “we-ness” that was identified in participant interviews and fostered in the support groups is further supported by Steinberg (2004) that sees the development of “we-ness” as one of the primary tasks in making the mutual aid process effective by helping group members feel secure about themselves, about accepting one another, and is empowering in that it helps them identify ways in which they might help one another (p.25). This is empowering on an individual level and also helps connect group members buy
making them informally accountable in supporting each other. This informal notion of accountability was further supported in the research by Barlow and colleagues (2005), where several participants felt that having to provide feedback to the rest of the group on a topic of discussion or on their individual success, was a motivation for action (p.868). It is an accountability and supportive relationship that is fostered through this reciprocal learning and support process. Interviewed participants also expressed that the support group was also a safe environment for participants to process their feelings and to share their lived experiences with other members of the group, which was fundamental in the empowerment, education, and in the creation of a support network for participants of this study. The effectiveness of creating a safe environment for the discussion of sensitive topics was also an area that interviewed participants identified as allowing for greater expression, learning and processing of information as they felt safe in sharing information among other participants' they felt connected to. This effective of creating a safe environment is supported and highlighted by Steinberg (2004) in noting, “When a group provides a safe haven for its members to explore differences and to try new ways of thinking, being, or doing, that too reflects mutual aid” (p.15). This notion of creating a safe environment for each other as members, further fosters the mutual aid process in empowering members to be supportive of others feelings, ideas, and suggestions.
Chronic Disease Self-Management Program and Agency Changes

Through the participant interviews, additional insight was shared in identifying changes to the CDSP and to the agency to better meet the needs of the participants. One of the changes directly related to the CDSP support groups identified needed improvements in the use of a consistent therapist, as some of the participants interviewed expressed frustration with CDSP’s inconsistent use of the therapist at times which they felt disrupted the trust and connectedness that the group had worked to develop. They felt that when a new therapist came to the group, this relationship had to be recreated and that the group essentially had to start over. Additionally, some participants expressed that when students or outside staff from the agency came in to observe the group that this was also disrupting as they felt that, “Participants could not be themselves in openly expressing their thoughts, sharing their experiences, or in addressing personal feelings in front of people they did not know” (Participant 2, personal interview, April, 2012). Impacts that disrupt a group’s connectedness through allowing outside observers is something that therapists should be cognizant of and sensitive to in facilitating a group session either in disallowing it or in asking for feedback from the group prior to it occurring as to not disrupt the rapport and trust the group members have worked to build among themselves and with the therapist.

Another area of improvement that was identified through the participant interviews as it related to changes with the agency included the more inclusive
use of peer staff in agency operations. Examples identified by a few of the participants interviewed identified them being utilized in roles as peer educators and navigators of the system for clients that were new to the agency or were newly diagnosed. Another suggestion included using them in the community in outreach efforts as educators and in sharing agency resources as they had lived experience, knew the system and the services, and could appeal to others in need of services by helping to reduce the anxiety or stigma associated to accessing services related to HIV/AIDS. One of the participants who was interviewed and suggested the inclusion of peer staff as part of the HAOSC’s permanent operations shared that she had once been a part of the HAOSC’s education efforts as a guest speaker in a classroom at a local university and shared that she felt empowered by the process. In describing her experience, she noted” At first I was scared in doing this, but felt empowered by disclosing my status and by educating others” (Participant 3, personal interview, April, 2012).

Additional insight was gained from interviewed participants who felt that they needed more personalized attention from their case managers to effectively navigate benefits and needed services related to managing the disease and felt that this lack of needed personalized attention was due to the HAOSC being understaffed and as a result current staff were overwhelmed with clients. The need to hire additional staff members to adequately meet the high need of service interaction especially for clients who are new to the agency or have been
newly diagnosed was also noted. Interviewed participants felt that case management services would also be more effective through the creation of a more personalized relationship with their case managers to better meet their needs. As one interviewed participant noted, “Get to know your clients more so that you can relate and understand the feelings and emotions they are going through” (Participant 9, personal interview, May, 2012). Effective client to staffing assignment ratios could also allow for more specialized staff attention that could lead to better outcomes for the clients and agency. The effective management of staff workloads could also lead to reduced levels of case management staff burnout (and subsequent turnover) and the elimination of staff apathy to serving clients, due to feeling overworked, overwhelmed, and underappreciated.

The final area of improvement identified through the quantitative data and through the qualitative data captured in the participant interviews, addressed more time to be added to the CDSP in some capacity either as a recurring program offered to other clients in the agency, or for stand-alone elements encompassed in the CDSP including education sessions, specific therapy groups for special sub-populations, social activities and group outings, be extended as permanent services and resources either in whole or in part depending on the individual’s needs. The need to have these supports sustained in some form was further supported in the quantitative analysis of the data which showed that although there was some improvement in participant self-management and perceived self-efficacy, they were not able to sustain these improvements to
levels that were found to be statistically significant as they had been over the short-term measurement at the 6-month follow-up period. The embracing of a programming concept that is inclusive of best practices outside the construct of the CDSP would allow needed services to be extended to other clients of the agency, would promote and foster the concepts of social learning theory by allowing other members to learn and grow from the knowledge and lived experience of others through the modeling of behaviors to assist other clients of the agency to change through the application self-management techniques, foster the promotion of self-efficacy and allow them to exert control over their lives by taking control in managing their disease. This would not only promote the delivery of an empowering client driven perspective and model in the actualization and delivery of services and resources, but it would also produce better overall outcomes for the agency, the individual, and for the community at large.

Limitations

There were several limitations noted in this study. The first limitation addresses the quantitative analysis and subsequent outcomes of the study due to the studies population size (n=15). As this study included a small sample size, the results found to be significant in this study could not be generalized to the HIV/AIDS population. Additionally, due to the small sample size, the analysis of the variables that were found to be statistically significant could be either
positively or negatively altered by a larger sample size with greater variance in client responses (Grinnell & Unrau, 2008). It was also anticipated that the learning of self-management techniques taught in the CDSP would foster self-efficacy and would lead to improved health outcomes, but this was not found to be significant in this study. The fact that health outcomes were not found to be statistically significantly impacted by participant increases in self-management and self-efficacy scores measured, and given that these same measures were found to be significant in impacting health outcomes in other similar studies with individuals who have HIV/AIDS, could further be attributed to this study's small sample size, as there were extreme outliers in these areas that did not have positive results as it related to the measurement of their health outcomes (CD4 and viral load). A combination of the study's small sample size and participants with extreme and adverse outlier health outcome scores adversely skewed the analysis and measurement of the health outcomes that were anticipated to be statistically significant in this study. To offset the low sample size rendered in this study, future studies can implement an electronic form of collecting the data either by sending it electronically to participants via an e-mail and attaching the survey as a fillable document or having it posted online. An electronic survey method would also serve to address issues related to accessibility for participants who were unable to come down to the participating HAOSC study location to have the follow-up survey re-administered.
Another limitation with this study was in the demographic information collected from the participants. Although education level, gender, and age were collected, the inclusion of other socioeconomic variables including employment status, income, and marital status, could have given this study further insight into the variance in client scores and could have identified additional variables that contributed to the results of the study.

The lack of a centralized electronic collection system, as in an electronic health record or an electronic database also impacted and limited the collection of data for this project. Agency staff assisted the researcher in the collection of the quantitative data (survey data and immunological scores). The staff however had difficulty at times locating some of the data captured for this study as some of it was located in participant hard files and some of the information was located online on a state or county reporting system. Having a centralized database where this information could have been easily located could have assisted this study in identifying more participants and data, creating the opportunity to make the statistically significant results of this study generalizable. Having this data in a centralized and easily accessible electronic format, could also help the agency to do further analysis on the results related to this project and this information would be easily accessible and organized allowing it to guide and inform future studies. More importantly however, having this type of system could improve access to care by allowing staff and clients to be able to easily access client service related or health information and could assist in providing more effective
service coordination and care with other agencies or organizations as client information could be shared quickly via an electronic format.

Finally, the analysis of the data for this study only included a t-test comparison of variable mean scores at two (2) points in time, which included from completion of the CDSP to the 6-month follow-up period and from completion of the CDSP to the current time of this study (3 to 4 years depending on the cohort). These two (2) points in time were used to assess change in means scores and to identify the short-term and long-term impacts of the CDSP. Although the analysis of variables in this study did identify significance in the relationship of results for certain variables, it was not able to specifically identify if the significance in the application of each variable was attributed to the variable in applied isolation or as a collective combination of working with one or all of the other variables. A regression analysis of each variable to determine which variables were individually or collectively significant in predicting the promotion of self-efficacy and its impact on health outcomes would draw more detailed insight into this study. Further research utilizing a regression analysis for each variable is needed.

Recommendations for Social Work Practice, Policy, and Research  
**Chronic Disease Self-Management Programs for HIV/AIDS**

This study was not able to show that the short-term or long-term variables that were identified as significant had a direct impact on health outcomes, but
some of the outcomes and results that were identified were meaningful in identifying a successful model of treatment that can be implemented with HIV/AIDS clients. The results and the process that were observed through this strength-based approach of working with individuals, allowed participants to explore and understand their disease, to develop connections with others who had similar lived experiences and to learn self-management techniques to have the confidence to manage the disease. The impact that the educational and psychosocial elements had on clients was observed quantitatively through survey results and the experience of the program, the impact of the support groups, and the benefits of the CDSP, were vividly captured and described in the participant interviews. The results related to self-management and self-efficacy that were identified as being significant in this study, as well as the experience of the participants in the CDSP are noteworthy for the field of social work as it allows us to understand the importance of the promotion of self-efficacy in empowering individuals to have control over the management of their illness, and their lives. The concepts promoted by the CDSP in allowing participants to achieve self-efficacy through learning from others and the empowerment they also feel in sharing their own knowledge and experience further supports the concepts fostered by mutual aid, and as Steinberg (2004) notes, “In terms of professional work with groups, a review of the literature reveals very clearly that mutual aid has always been at the heart of social work practice (p.14). A strength-based approach applied through the use of a mutual aid application continues to be
effectively applied and used in social work practice and the implications and results of this study continue to highlight it as an effective intervention and strategy to empower the clients we serve.

**Cultural Competency**

Understanding that differences exist, even among individuals who share a similar illness, necessitates the need to understand how cultures and perspectives influence and shape how services are delivered, interpreted and received. Accommodations or modifications to services are sometimes needed to meet the needs of the participants a service or program aims to serve. In this study, the focus on the recruitment of clients into the CDSP focused on the females diagnosed with HIV/AIDS served by the HAOSC. The age, demographic and cultural make-up of each individual was different, and their cultural experiences impacted the way they each perceived and managed their disease. The self-management techniques that were facilitated in the CDSP included generic education and self-management skills for individuals with HIV/AIDS, but also included information and skills that were specific to women in the management of this disease. This gender specific affiliation allowed women to explore the impacts of the disease on the female body as well as the social and cultural implications that women face who are diagnosed with the disease. These gender specific commonalities were also openly explored in the support groups without bias or objection from individuals of the opposite sex, who would be incapable of fulling understanding the experience and impacts of the disease.
as a female. With this being said, the lessons learned from this study can be used to drive other CDSP programs in social services that are gender, language, or cultural specific, allowing individuals to further explore how their illness is further impacted and influenced by the lens and cultures they most identify with. A gender related CDSP that looked at the needs of males with HIV/AIDS would be helpful in identifying certain self-management skill sets that are male specific in managing the disease and would identify specific gender related physiological changes, like the gender specific skills and interventions highlighted in this study for females. These CDSP or support groups could extend to include groups that were specifically formed around language, as in a group specifically for Spanish speakers understanding that there are linguistic differences in how the information is presented and absorbed, especially if it is an individual’s native language. Forming groups on sexual orientation for individuals that are LGBTQ, or a group that has an ethnic or cultural focus as in services for individuals that are African American or who are Asian Pacific Islander, would further draw insight into similarities as well as specific differences and needs for each group. As different cultures perceive the HIV/AIDS disease differently, and for that reason experience or may have stigmas attached to it, it would be important to develop culturally specific and appropriate ways of conducting outreach and delivering services with an understanding of these different cultural needs.

The importance of implementing a workforce that is culturally competent to effectively deliver services as to reduce health disparities among ethnic and
minority groups, was highlighted by the Health Research and Educational Trust in a training guide for hospitals and care systems that notes, “Hospitals and care systems must prepare their clinicians and staff to interact with patients of diverse backgrounds to increase patient engagement and education and to help eliminate racial and ethnic disparities in care” (Health Research and Educational Trust, 2013, p.6). Taking into consideration the cultural, linguistic and diverse values of other individuals and cultures will allow us as social workers to build rapport in developing a relationship of trust and understanding and will help us deliver services in a way that acknowledges, recognizes and addresses the unique individual needs of those we serve.

Peer Educators

Another programming change which was highlighted in the participant interviews which could help support the delivery of services would be the incorporation of peer staff to assist in education and outreach efforts. Many of the comments rendered through the participant interviews in regards to identified participant benefits of the CDSP highlighted the impact the lived experiences of others had in offering self-management skills, advice, and hope. This was especially highlighted by some of younger CDSP participants who had been recently diagnosed. Utilizing the concept of lived experience could change programming through the inclusion of peer staff as staff members in the delivery of services. Outreach efforts in the community that are inclusive of peer staff that have lived experience could allow them to better connect and identify with
individuals who need services, may have a stigma to accessing services, and as peer staff with lived experience, could better identify with them to capture them into care. This concept of having peers conduct outreach, peer education and to assist new clients in accessing and navigating services has been supported in past research as was highlighted in the literature review and this concept also supported in the research for this study, as it highlights the peer educators unique understanding of the culture and its needs, as they are also sometimes subscribing members of that culture and can relate through lived experience. Implementing peer educators into social service programming can help in the identification and encouragement of clients into a system of care, easier navigation of the system, better access to treatment and services and better overall outcomes for the agency or organization.

**Technology**

In this study, another important concept that was highlighted was the use of technology in tracking, monitoring, and in the analysis of services. The use of an electronic database in managing the original results captured by this study would have not only made it easier to find and track the data but it would have also saved hours of time spent retrieving this information. Having this information centralized could also assist in organizing this information so that it is available to this organization and to any organization for any future research or studies that expand on these results. Additionally, having updated client information in an electronic format that is easy to access would allow services to
be more effective by allow service staff to actively track and monitor the delivery of services, ensure that services delivered were accurate and could further serve in providing service coordination or referrals to other agencies or organizations.

The benefits of incorporating technology into research efforts, especially as it relates to the completion of a survey, was also something that was learned from the data collection efforts of this study and an application that should be utilized by researchers, as technology was not used in this study to target participants for the survey and the omission of this method may have been reflected in the low sample size of this study. Increases to the sample size through participant survey responses could have been improved through the creation of an electronic survey that could have been e-mailed or completed online to allow for greater participant response and to address issues with accessibility that some participants may have had. As social workers working with populations with diverse background and varying degrees of accessibility to resources, is it incumbent on us to utilize technological resources that at our disposable whenever possible, so that more inclusive representations of outcomes are represented in survey responses, especially for marginalized, stigmatized, and underserved populations, as it sometimes these responses from clients and other stakeholders that are utilized to help to create or modify existing services.
Policy

The four (4) short-term variables and the one (1) long-term variable which were found to be statistically significant was encouraging as it was supported by results and similar research (Barlow et al., 2005; Ironson et al., 2005; Kemppainen et al., 2006; & Wright et al., 2003), where significant outcomes in the area of self-management and the promotion of self-efficacy lead to overall improved outcomes in psychological well-being, physiological health or a combination of both. With this being said, it can be safely hypothesized that CDSPs in general produce more favorable outcomes in client physical and psychological health than clients who do not participate in CDSPs, although more research in this area is needed.

Current HIV/AIDS programs are funded through federal programs such as the Ryan White Act of 1999, which provides federal funding to individual states to subsidize their HIV/AIDS programs and services. States can also subsidize funding for HIV/AIDS services through health service allocations that are made annually and specifically for HIV/AIDS programs. In the state of California, additional funding allocations for HIV/AIDS services are allocated by the California Department of Public Health (CDPH) and they specifically have an Office on AIDS (CDPH/OA) division that oversee HIV/AIDS state programs as well as HIV/AIDS programs funded at the county level. Many public HIV/AIDS programs in the country and in California are funded through federal monies and through federal programs like the Centers for Disease Control and Prevention,
Health Resources and Services Administration, Substance Abuse and Mental Health Services Administration (SAMHSA), National Institutes of Health, and Housing and Urban Development) and through pharmaceutical rebate funds through the state’s AIDS Drug Assistance Program (ADAP) (San Francisco AIDS Foundation, n.d.). The Health Resources and Services Administration (HRSA), through their HIV/AIDS Bureau (HAB) currently oversee Ryan White funding, which are funds rendered via grants that are allocated to states, cities, counties, and local community-based organizations to provide care and treatment services to people living with HIV/AIDS to improve health outcomes and to reduce HIV transmission among hard-to-reach populations (U.S. Health Resources and Services Administration, 2019).

Although there is some funding allocated to the HRSA’s special projects division that allows for the funding of new research based projects that look at new interventions and treatment models through “demonstration projects”, these projects are time limited and are not sustained (like the CDSP researched in this study that was only funding one time over two [2] years) and there is no language or policy that mandates the longer-term sustainment or implementation of CDSPs into funding allocations at the state or federal level. Effective evidence-based programs like CDSPs only currently exist as research projects, as they are not sustained as institutional and permanent services in current HIV/AIDS funding. Current HIV/AIDS funding supports outreach and education services, prevention and early intervention services, case management services and general medical
services. Changes in policy could mandate that a certain percentage of funds be allocated to CDSPs or to the development of special training programs for consumers that incorporate comprehensive teaching modules related to HIV/AIDS self-management and care.

Finally, to offset the gaps in HIV/AIDS services and to fund additional needed services, California voters could seek the passage of a proposition to establish a law which implements a tax on the sale of a consumer item or on individuals in a specific earned income tax bracket. This proposition would be similar to the Children and Families Act of 1998, also known as Proposition 10, passed by California voters in 1998 which imposes a $0.50 sales tax on tobacco related products for the funding of children’s programs ages zero (0) to five (5) or the Mental Health Services Act (MHSA) passed by California voters as Proposition 63 in 2004, which imposes a 1% sales tax on millionaires to fund mental health services in California. A similar proposition to impose an income or item tax would help raise needed funds to continue providing prevention and comprehensive HIV/AIDS programs for individuals residing in California.

Recommendations for Research

Like similar research studies that have sought to measure the impact of programming or specific interventions in impacting behavior or to health outcomes, this study also sought to further explore impacts of a program in changing behavior to drive better health outcomes for individuals with HIV/AIDS. A t-test t was used in this study to compare mean scores between two (2) groups
and time points to measure change in these scores and thus the long-term and short-term impacts of the CDSP. In this study, there were some changes in the behavior variables measured that were found to be statistically significant as a result of the CDSP. Additionally, although not statistically significant, the study also observed slight improvements in participant health scores. Due to the limitations of the t-test however, the research was unable to identify which of the variables (if any) or which combination of the variables influenced or were predictive of the impacts to participant health outcomes (CD4 or viral load). A multiple regression analysis on each of the variables measured in this study would help to predict which of the variables influenced health outcomes. As this research study recruited participants that were already involved in treatment services and measured points in time from completion of the CDSP to the two (2) follow-up periods, future studies should include capturing measures at the start of a participants’ services with the agency and then after completion of a CDSP. Future research could also focus on the impacts that individual service components within the agency that are encompassed in a CDSP have in impacting service and participant outcomes. Additional research should be conducted utilizing this methodology, because as of to date there are few studies that have measured the long-term impacts of a CDSP for individuals with HIV/AIDS. A follow-up study implementing a different analytical methodology to measure the impacts of this type of social service intervention would draw further insight and lend to additional applied knowledge to the field of social work.
Conclusions

This study examined the impacts of a Chronic Disease Self-Management Program (CDSP) for individuals with HIV/AIDS. The purpose of the study was to assess whether the self-management skills taught in the CDSP were retained by participants over time and if these skills fostered the attainment of self-efficacy. The study also sought to understand if these behavioral changes and the attainment of self-efficacy impacted or influenced health outcomes through the measurement of participant biological disease markers which included CD4 and viral load counts. Through a mixed methods approach, the researcher collected survey data from participants that were involved in Foothill AIDS Project’s “Newly Empowered Women” CDSP and compared it with new follow-up survey scores to see if they had retained the self-management skills taught in the CDSP, achieved self-efficacy, and improved their health outcomes. To assess for the short-term impacts changes in scores were measured from completion of the CDSP to the 6-month follow-up period and from completion of the CDSP to the current time of this study. To understand what components of the CDSP participants felt assisted them most and to identify areas for changes and suggestions, the study implemented a participant interview to capture more thorough and descriptive details outside of the survey.

The analysis of the variables showed that participants of the CDSP improved their self-management skills over the short-term term period which measured from completion of the CDSP to the 6-month follow-up period as
identified by improvements in self-rated health, reduced (though not significantly) health distress, decreases on limitations to social activities or functions as a result of their illness, increased communication with their physicians, and an increase in self-efficacy. Over the long-term period however, which measured from completion of the CDSP to the current time of this study (3 to 4 years depending on participant cohort) the only area that was shown to have significance in maintaining or improving was participant communication with their physician. In measuring biological disease markers, although improvements were seen for some participants, these changes were not found to be statistically significant nor were they found to be impacted by changes in self-management skills or attainment of self-efficacy. Through the participant interviews, specific components which made the CDSP successful were identified as participants highlighted the education provided in assisting them to biologically understand the impacts of the disease, the importance of medication adherence and nutrition, and the identification of additional supportive resources. The overwhelming theme and component highlighted in the interviews however, was the impact of the support group. Participants expressed the feeling of being able to relate to others who shared similar experiences. Participants also spoke of the learning that was realized through this sharing process from the lived experience of others. Participants felt that the sharing of these feelings and the mutual support expressed by members to one another allowed strong bonds to form, thus increasing their support network. Several of the clients interviewed
identified this component of the program as a motivator to return and as one of
the most important components of the CDSP they believed helped and motivated
them most in managing their disease.

This study’s finding in improving participant self-management skills and
promoting self-efficacy through a CDSP for individuals with HIV/AIDS is
noteworthy. Through a strength-based approach, clients were better able to
manage their illness and felt that they had achieved self-efficacy. The inability of
participants to retain these improvements over the long-term however identifies a
gap in services and the need for CDSPs to be sustained for longer periods of
time or for successful elements of a CDSP to be fully incorporated into an agency
or programs’ continuum of services, to better support clients and improve
outcomes. As health outcomes were not found to have been impacted by these
positive behavioral changes in this study, more research is needed in this area
utilizing a larger sample size and a multivariate regression analysis to measure if
there are specific variables of self-efficacy that are predictive specifically to
improvements in either CD4 or viral load counts.
APPENDIX A

PARTICIPANT SURVEY
Newly Empowered Women
Follow Up Questionnaire
2012

Name: ____________________
Background

Age

Highest level of Education (please check one): _____some high school     _____HSD/GED     _____Some College
     _____Bachelor’s     _____Master’s     _____Doctorate
     _____Other     Specify Other:__________________________

Please indicate below which chronic condition(s) you have (check all that apply):

☐ Diabetes     ☐ Asthma     ☐ Emphysema or COPD
☐ Other lung disease     Type of lung disease:__________________________
☐ Heart Disease     Type of heart disease:__________________________
☐ Arthritis or other rheumatic disease     Specify type:__________________________
☐ Cancer     Type of Cancer:__________________________
☐ Other chronic condition
     Specify:__________________________
General Health

Self-Rated Health

In general, would you say your health is: ...........................................(Circle one)

Excellent.......................... 1
Very good .......................... 2
Good .................................. 3
Fair ................................... 4
Poor .................................. 5

Excellent health - a state of physical, mental and social well-being to achieve daily tasks normally and without pain.

Very Good - a state in which you are able to achieve most daily tasks normally and without pain.

Good Health - a state of being able to achieve some daily tasks with little bodily discomfort or mental distress.

Fair Health - the state of being able to achieve minimal tasks with having bodily discomfort or mental distress.

Poor Health - a state of being unable to achieve any tasks or to function normally and without pain.

Symptoms

Health Distress

These questions are about how you feel and how things have been with you during the past month. For each question, please circle the one number that comes closest to the way you have been feeling.

How much time during the past 2 weeks...

<table>
<thead>
<tr>
<th>Question</th>
<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the time</th>
<th>A good bit of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Were you discouraged by your health problems?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Were you fearful about your future health?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. Was your health a worry in your life?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. Were you frustrated by your health problems?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
## Confidence About Doing Things

### Self-Efficacy for Managing Chronic Disease 6-item Scale

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1. How confident do you feel that you can keep the fatigue caused by your disease from interfering with the things you want to do?
   - not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 totally confident

2. How confident do you feel that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?
   - not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 totally confident

3. How confident do you feel that you can keep the emotional distress caused by your disease from interfering with the things you want to do?
   - not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 totally confident

4. How confident do you feel that you can keep any other symptoms or health problems you have from interfering with the things you want to do?
   - not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 totally confident

5. How confident do you feel that you can the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?
   - not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 totally confident

6. How confident do you feel that you can do things other than just taking medication to reduce how much your illness affects your everyday life?
   - not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 totally confident
### Daily Activities

**Social/Role Activities Limitations**

During the past 2 weeks, how much... *(Circle one)*

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Almost totally</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Has your health interfered with your normal social activities with family, friends, neighbors or groups?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>2. Has your health interfered with your hobbies or recreational activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3. Has your health interfered with your household chores?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>4. Has your health interfered with your errands and shopping?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

### Medical Care

**Communication with Physicians**

When you visit your doctor, how often do you do the following *(please circle one number for each question)*:

<table>
<thead>
<tr>
<th></th>
<th>Almost</th>
<th>Some-</th>
<th>Fairly</th>
<th>Very</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never</td>
<td>never</td>
<td>times</td>
<td>often</td>
</tr>
<tr>
<td>1. Prepare a list of questions for your doctor</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Ask questions about the things you want to know and things you don't understand about your treatment</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Discuss any personal problems that may be related to your illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

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INTERVIEW GUIDE

1. What is the most important skill set or lesson that you learned through the Newly Empowered Women’s Program?

2. What specific components of the program do you believe helped you manage your illness?

3. What other improvements or suggestions do you believe should be made to the services at the HIV/AIDS Organization in Southern California (HAOSC) or what changes would you like to see to the Newly Empowered Women’s Program CDSP?

4. Do you feel that you learned better self-management and achieved self-efficacy as a result of this program? Why or why not?

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APPENDIX C

INFORMED CONSENT
CONSENT TO TAKE PART IN A RESEARCH STUDY
AND
AUTHORIZATION TO DISCLOSE HEALTH INFORMATION

Principal Researcher: Adán C. Gómez
Address: HIV/AIDS Organization in Southern California
(909) 884-xxxx or via e-mail at:
gomea318@coyote.csusb.edu

INTRODUCTION TO AND PURPOSE OF THE RESEARCH STUDY
You are being asked to take part in a follow up evaluation study of an HIV/AIDS Organization in Southern California’s (HAOSC) Chronic Disease Self-Management Program (CDSP) entitled “Newly Empowered Women,” that you participated in either 2007 or 2008.

The goal of this study is to assess the impacts of a Chronic Disease Self-Management Program (CDSP) as it pertains to both biological markers (CD4 and viral load) and other measures of psychosocial wellbeing. The findings of this study will also be used to fund future evidence-based approaches for HIV/AIDS access to care and treatment.

Your participation is entirely voluntary.

INFORMATION ABOUT THE STUDY
You are being asked to take part in a series of interviews over the next six months. The follow up survey will be conducted with you by an HAOSC staff member and the interview will be conducted by a graduate student from California State San Bernardino’s (CSUSB’s) School of Social Work. Several other program clients who participated in the “Newly Empowered Women” program will also be involved in the study.
WHAT WILL HAPPEN DURING THE STUDY
An HAOSC staff member will administer a survey asking you about your HIV/AIDS knowledge as well as related attitudes and behaviors at it pertains to self-management. In this survey you will also be asked to disclose your most recent diagnosis (within the last six months) as it relates to you CD4 and viral load counts.
The CSUSB Social Work graduate student will also conduct a one on one interview with you over the next six months. The second interview will include a list of four open ended questions that will include questions related to your experience with the CDSP, what elements of the program you felt were most helpful and what programmatic changes you would like to see the HAOSC make to meet the needs of their clients. Each interview will not take more than 15 minutes of your time.

You will be asked to provide a telephone number where you can usually be reached. Taking part in this study will involve a small commitment of your time. Your responsibilities as a study participant include the following:
- Being alert during the interview.
- Telling the truth about your medical history, health behaviors and other questions that will be asked of you.
- Telling the researcher about any problems you have had during, after, and since the completion of the CDSP.

RISKS OF THE STUDY
There are no physical risks involved in your participation. However, you may feel some discomfort when asked about your HIV status or your personal drug use and sexual practices. You may also experience some degree of distress if the results of the CDSP have not produced favorable or improved health outcomes. If you are uncomfortable answering any of the questions in either the survey or interview, a HAOSC counselor will be available to you to talk to during or after each of the interviews.

PO TENTIAL BENEFITS OF BEING IN THE STUDY
There are no personal benefits to your participation in the study. However, your participation will have an effect on the services that others receive in the future. The answers you provide will be used to evaluate the effectiveness of previous programs in an effort to improve services to others who are diagnosed with HIV/AIDS. For that reason, your participation has important public health benefits.
YOUR INCENTIVE FOR BEING IN THE STUDY
You will receive an incentive for your participation in the study worth at least $10. You will receive an incentive worth at least $5 at the end of each interview that you complete for the study. You will be paid at the end of each study visit.

PROTECTING THE PRIVACY OF YOUR HEALTH DATA
The only identifier in releasing your survey results will be an ID code so that individuals outside the HAOSC will not be able to trace back information to you. Your health data needs to be shared for the research. Therefore, complete privacy of your health data cannot be promised. However, sharing your health data will be guided by professional standards and the law. Information from this study may be presented at meetings and will be published as part of a graduate thesis project. The information included at meetings or in the thesis will not include your name or information that can be traced back to you.

GETTING ANSWERS TO YOUR QUESTIONS ABOUT THE STUDY
You can ask questions about this consent form or the study (before you decide to start the study or at any time during the study). Questions may include:

- Any payment for being in the study.
- Your rights and your responsibilities as a study subject.
- Other questions.

For any questions directly related to this study please contact the graduate researcher’s faculty supervisor Dr. Carolyn McAllister at (909) 537-5559 or via e-mail at cmcallis@csusb.edu. You can also contact the director of programs for the HAOSC location participating in this study, Mrs. Marie Francois if you have any other questions or concerns. Mrs. Francois can be reached at (909) 884-XXXX.

VOLUNTARY PARTICIPATION
Entering a research study is voluntary.

- You may always say no. You do not have to take part in the study.
- If you start the study, you may stop at any time. You do not need to give a reason.
- If you do not want to be in a study or you stop the study at a later time, you will not be penalized or lose any benefits.
- If you stop, you should let the researcher know and follow the instructions they may give you.

Your part in the research may stop at any time for any reason, such as:
- The sponsor or the researcher decides to stop the study.
• The sponsor or the researcher decides to stop your part in the study for your safety.
• You decide to stop.

You may be asked to stop the study even if you do not want to stop.

RESULTS
Results of this study will be available September 2012. A bounded copy of the results of this study will be available at California State San Bernardino’s Pfau Library, 4th floor. A copy of the thesis will also be given to the HAOSC.

STATEMENT OF CONSENT
I have read this form and its contents were explained to me. I agree to be in this research study for the purposes listed above. All of my questions were answered to my satisfaction. I will receive a signed and dated copy of this form for my records. I am not giving up any of my legal rights by signing this form.

______________________________          __________________________
Signature of Research Participant                  Date

______________________________
Printed Name of Research Participant

I consent to being audio taped during the interview? ___ Yes ___ No

STATEMENT OF PERSON EXPLAINING CONSENT
I have carefully explained to the participant the nature and purpose of the above study. There has been an opportunity for the participant to ask questions about this research study. I have been available to answer any question that the participant has about the study.

______________________________          __________________________
Signature of Person Explaining Consent                  Date

______________________________
Printed Name of Person Explaining Consent
APPENDIX D
DEBRIEFING STATEMENT
Study on Chronic Disease Management Program (CDMP)

Debriefing Statement

This study you have just completed was designed to investigate the long-term health impacts of Chronic Disease Management Programs (CDMP). In this study two decision biases were assessed: Changes in the psychosocial wellbeing of clients after completing the CDMP program and also how these changes are reflected by biological disease markers (CD4 and viral load). These two decision biases were seen as instrumental in measuring the effectiveness and retention of information offered in the CDMP over time. The goal of this study is to measure the short-term and long-term benefits of a Chronic Disease Management Program for individuals with HIV/AIDS.

Thank you for your participation. If you have any questions about the study, please feel free to contact Mrs. Marie Francois at (909) 884-XXXX or Professor Carolyn McAllister at (909) 537-555. If you would like to obtain a copy of the group results of this study, please contact the HAOSC after September 2012.
APPENDIX E

INSTITUTIONAL REVIEW BOARD APPROVAL
CONSENT TO TAKE PART IN A RESEARCH STUDY

AND

AUTHORIZATION TO DISCLOSE HEALTH INFORMATION

Principal Researcher: Adán C. Gómez

Address: [redacted]

(909) 884-____ or via e-mail at:
gomea318@cowote.csusb.edu

INTRODUCTION TO AND PURPOSE OF THE RESEARCH STUDY

You are being asked to take part in a follow up evaluation study of the Chronic Disease Management Program (CDMP) entitled “Newly Empowered Women,” that you participated in 2007 or 2008.

The goal of this study is to assess the impacts of a Chronic Disease Management Plan (CDMP) as it pertains to both biological markers (CD4 and viral load) and other measures of psychosocial wellbeing. The findings of this study will also be used to fund future evidence based approaches for HIV/AIDS access to care and treatment.

Your participation is entirely voluntary.

INFORMATION ABOUT THE STUDY

You are being asked to allow for the collection of your biological markers (CD4 and viral load) by a graduate student of California State San Bernardino’s (CSUSB’s) Social of Social Work. This information will be accessed through the documents you have on file with [redacted]. Specifically, your biological markers will be taken at the time of you ending the “Newly Empowered Women’s” program and your most recent biological markers in 2011 will also be recorded. The collection of this data will be numerically numbered and no personal identifiers as it pertains to proper names will be collected. You will also be asked to participate in a follow up survey that will also be conducted with you by graduate student of California State
REFERENCES


Retrieved April 24, 2018 from

https://www.cdc.gov/mmwr/preview/mmwrhtml/00001257.htm


https://www.cdc.gov/mmwr/preview/mmwrhtml/00000137.htm


https://www.cdc.gov/mmwr/preview/mmwrhtml/00000137.htm


Retrieved June, 13, 2011 from


Retrieved April 24, 2011 from

https://www.cdc.gov/mmwr/preview/mmwrhtml/00000137.htm


