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Carizma Amila Chapman

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LOMA LINDA UNIVERSITY
School of Behavioral Health
in conjunction with the
Faculty of Graduate Studies

To a Better Understanding of Professional Practice: Provider Decision-Making When
Delivering HIV Services

by

Carizma Amila Chapman

A dissertation submitted in partial satisfaction of
the requirements for the degree
Doctor of Philosophy in Family Studies

December 2015

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Each person whose signature appears below certifies that this dissertation in his/her opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Philosophy.

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God

Max Richer's song, On the Nature of Daylight, is the accompaniment to the following prayer and thank you.

I dedicate this work to you as I have my life. It is my prayer that my efforts have been in accordance with your will. Though I have not understood this process, I have appreciated your love and faithfulness. I understand that this work is in itself not an end or start, but yet another step among many in my life journey. Thank you for blessing me with a servant's heart and evolving my heart and character to serve you. I am remembering, and I will strive to not forget. My life is a form of devotion, and my work an art, all an unfolding to celebrate you.

May your will forever be done.

Carizma Amila

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Abbreviations

HIV	Human Immunodeficiency Virus
AIDS	Acquired Immune Deficiency Syndrome
CDC	Center for Disease Control
STD	Sexually Transmitted Diseases
MSM	Men who Have Sex with MEN
NIDA	National Institute on Drug Abuse
LFI	Level of Family Involvement
FLE	Family Life Educator

ABSTRACT OF THE DISSERTATION

To a Better Understanding of Professional Practice: Provider Decision-Making when
Delivering HIV Services

by

Carizma Amila Chapman

Doctor of Philosophy, Graduate Program in Family Studies

Loma Linda University, December 2015

Dr. Curtis Fox, Chairperson

Dr. Brian Distelberg, Chairperson

Understanding Professional Practice: Provider Decision-Making when Delivering
HIV/AIDS Services

Over the last several decades an abundance of research has been conducted on HIV/AIDS. These studies have focused on the infection, impact of the disease on the health and quality of life of people living with the infection, and on treatment effectiveness. However, limited studies are available that explore the experiences of providers delivering HIV/AIDS services. Research demonstrates that providers have an important impact on treatment, shaping not only patient retention, but also treatment adherence. The critical role HIV/AIDS providers have in shaping treatment makes understanding provider experiences a pertinent area of inquiry to understand HIV/AIDS care. In this study, an analytic autoethnography was performed to acquire an understanding of provider experience working in an HIV/AIDS treatment milieu. A reflexive research treatment practice was used to write about experiences as a provider, and processed in context of the limited available literature. In doing so, a number of institutional, professional-contextual, client, and provider level factors were identified as shaping professional practice. The findings of this study provide insight into the

intuitional, relational, and contextual factors shaping HIV/AIDS care. The findings validate the importance of researching HIV/AIDS provider experiences, and punctuates the necessity of continued research in this area.

CHAPTER ONE

INTRODUCTION

“And you? When will you begin that long journey into yourself?”

(Rumi & Green, 2005, pg.50)

Overview

This chapter will include an overview of the rationale for an analytic autoethnographic research study of a provider’s development of a culturally sensitive treatment practice of Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS) networks. In addition, background information on this study will be reviewed to provide the context of the research. More specifically, the purpose and focus of the study will be presented. This will include a review of the personal and professional demographic and background information of the author, specific HIV/AIDS infection demographic and statistical information among vulnerable groups, description of the theoretical frameworks informing the ideas presented throughout this work, and presentation of the objectives and rationale for this study.

The influx and complex nature of family wellness and healthcare systems requires providers to be intentional and active in updating their competency and skill (Mann, Gordon, & MacLeod, 2009). Reflection can be a purposeful means of expanding knowledge and evolving as a professional. By reflecting upon intellectual and affective experiences on an ongoing basis providers function in a dual capacity, as both the actor and critic of their experiences (Mann et al., 2009; Osterman & Kottkamp, 1993). Critical self-evaluation, a process that allows for need identification, integration of personal and

professional attitudes, beliefs, and behaviors, and the linking of new information with previously acquired knowledge, is a means by which providers develop competency and become effective professionals (Bandura, 1986; Gordon et al., 2009; Mann et al., 2009). Competency and skill are acquired as professionals develop a heightened awareness of their behaviors and the ideas that drive them. From such awareness professionals can make more informed changes (Osterman et al., 1993). Consequently, the culmination of professional reflection can be the development of new understanding and a novel means of engaging with the world (Boud, 2001; Boud, Keogh, & Walker, 1985).

It is through reflection, on an ongoing basis, that a reflective practice is developed. Professionals who actively and consistently reflect upon themselves develop a practice of self-monitoring and regulation, one that heightens their consciousness (Bandura, 1986; Gordon et al., 2009). This practice allows professionals to reframe and reconstruct understandings of what they know, what they have done, and what they intend to do in the future (Osterman et al., 1993). The process of developing a reflective practice often begins with a research question or problem, which is then used to facilitate exploration.

In this study, I construct a self-reflective practice to develop proficiency as an HIV/AIDS network provider. I purposefully used the autoethnography research methodology to analyze published literature and my documented experiences delivering HIV/AIDS services to comprehend the variables informing HIV/AIDS treatment. In particular, I explored factors shaping the course of services, and care related dynamics shaping provider decision-making.

Though a number of experiences shaped my choice to complete this study, the initial shock and confusion I experienced when I learned about the prevalence of HIV/AIDS was the catalyst that prompted my interest to develop proficiency as an HIV/AIDS provider. My awareness of the HIV/AIDS epidemic seemed to arise suddenly and fill my mind with what seemed like an endless thread of questions. How can this be? What is being done? Why are more population specific interventions not available? More research being conducted? I have to do something! What can I do? These questions were among the range of thoughts that flooded my mind in 2012, as I learned about the crisis that is HIV/AIDS globally. Untouched by the infection myself, and untrained on the epidemic, I was unaware of its pervasiveness, of the multifaceted disparities that shape and perpetuate its transmission, or of the havoc it wrecks daily on the health and relationships of persons infected with it.

In hindsight, I understand my ignorance was possible, at least in part, because I did not have a personal relationship with HIV/AIDS or a connection to an HIV/AIDS community prior to my doctoral studies. However, upon learning about the infection, and in particular, coming to understand the disproportionate impact that it has had on the African American community, I felt an inner pull to be a part of those efforts focused on eradicating its existence and harmful effects. I realized to successfully attend to the infection and its related treatment disparities, some of which are perpetuated by providers, I would have to further master myself.

My interest in self-mastery is very much in line with the fields of Family Therapy and Family Studies, which are increasingly emphasizing the importance of both personal and professional development vis-à-vis provider competency in self-knowledge and

command, access of self (i.e. values and memories), and conscious and intentional use of selves in treatment contexts (Aponte, 1982; Aponte & Winter, 2000; Aponte & Carlsen, 2009; Watson, 1993). It is through pattern/theme identification, issue confrontation, personal witnessing, and use of selves in treatment contexts that providers are able to become more aware and responsive. By observing ourselves, our development is informed and our skills improved (Aponte et al., 2009). Such heightened personal awareness, integration, and action can inform how we participate in and conduct treatment, shaping everything from the treatment relationship to our technique and process (Aponte et al., 2009). Because self-mastery has significant implications for not only providers but also the treatment contexts in which we are a part, such exploration is needed.

Problem Statement

Carizma's Relationship with the Problem: An Unanticipated Professional Dilemma and Training Opportunity

I was privileged to acquire an internship working at an HIV/AIDS treatment facility. At the time, I had already developed the professional goal to serve those most adversely impacted by HIV/AIDS: African Americans, Hispanic Americans, gay men, and men who have sex with men. The internship provided the much needed opportunity to begin to develop experience in the area. Though my initial transition into the clinic was smooth, a number of contextual and relational changes in the HIV/AIDS system immediately following my entrance, impacted my integration into the milieu. These changes had a direct effect on my relationships and care within the HIV/AIDS treatment

system. Subsequently, I found myself over the course of several months trying to develop a system of care while trying to stabilize treatment with an HIV/AIDS network that had been significantly disturbed by a number of program and provider changes. More specifically, I worked to: (a) develop a treatment approach with my new co-facilitator; (b) mend strained relationships with an HIV/AIDS network frustrated with recent programmatic changes; and (c) communicate and negotiate the needs of the network to clinic administrators. I focused on these issues to improve the relationships and overall delivery of therapeutic and educational services. Struggling to understand the nature of the turmoil present in the system as well as the angst, at times, directed toward me, I began to question my family studies practice. More specifically, I questioned my role as a provider, my training, and the manner in which I used myself in treatment. I continually found myself challenged by my questions, but unable to find professional literature to inform my work. For example, while a plethora of research is available on HIV/AIDS patient treatment decision-making and the patient-provider relationship (Apollo, Golub, Wainberg, & Indyk, 2006; Earl et al., 2013, Mallison et al., 2007; McCoy, 2005, 2007; Staff et al., 1996), a limited literature attends to provider experience when rendering care. More specifically, little information is available that explains how treatment choices are made, or how provider identities and professional training inform care. Consequently, confronted with research limitations, but motivated by a strong desire to understand factors that contribute to sensitive and relevant care, I felt compelled to investigate my professional engagement and treatment related behaviors with HIV/AIDS positive networks.

To better understand and work through the professional and relational struggle I experienced at the time, I began journaling as a means of exploring the unique dynamics I encountered in the HIV/AIDS treatment system. My journals became a way of watching myself in process, challenging myself, and developing strategies to address the relational and contextual dynamics I was confronted with, and thus called to address. It also became a means of holding myself accountable as a developing professional both to myself and to my clients.

The United States' Relationship with HIV/AIDS

The human immunodeficiency virus is currently an incurable infection that damages or compromises the cells of the immune system, preventing the body from being able to combat infection and diseases (Center for Disease Control (CDC), 2013). Over time, HIV positive persons become susceptible to developing acquired immunodeficiency syndrome (AIDS), which is caused when the immune system of an HIV infected person becomes severely compromised or the person becomes ill with an infection or illness. This happens because untreated HIV progressively prevents the body from being able to protect itself against infection (National Institute on Drug Abuse, 2012). HIV positive persons typically develop AIDS eight to ten years after their initial infection; however, the onset of AIDS can be delayed with early diagnosis and treatment (CDC, 2013). Yet, the mode of the infection's progression is highly variable based on a number of factors. In some instances, people learn they have been HIV infected at the time of their AIDS diagnosis; while some persons' progress quickly from HIV to AIDS, other infected persons do not show signs of infection and are long-term survivors (Cui et al., 2015;

Huber, 1996; Leserman, 2008; McLaren & Fellay, 2015). Technological developments in the last two decades have significantly improved the life outlook of HIV/AIDS infected persons with life expectancy increasing from a few years in the early 1990s to a normal life expectancy currently (CDC, 2013).

In 2012, an estimated 35 million people were living with HIV/AIDS worldwide. Since the start of the epidemic in the 1930s, it is estimated 75 million people have been infected with the disease (Joint United Nations Program on HIV/AIDS, 2013). While millions of people become infected with HIV/AIDS annually, infection rates for the disease have been declining since 2001. In fact, since 2001, infection rates have declined by 33% worldwide. However, rates of decline have varied significantly by country, with 26 countries experiencing infection decrease levels at 50% or higher (UNAIDS, 2013). Locally, it is estimated there are 1.2 million people living with HIV/AIDS in the United States, with an estimated 50,000 new infections occurring annually. The rate of new infection has remained relatively stable at that level for over two decades (CDC, 2015)

People who are at a particularly high risk of contracting HIV/AIDS are injection drug users or people who have a partner who inject drugs, persons who have multiple or concurrent sexual partners or who have partners who have multiple or concurrent sexual partners, infants born to mothers with HIV/AIDS who did not receive treatment during pregnancy, and persons with multiple sexually transmitted diseases (CDC, 2012; Levy, 2007; UNAIDS, 2010; National HIV/AIDS/AIDS Strategy; 2020, 2015) It is important to note however, disparities in infection rates do exist in the US, with certain groups being disproportionately affected by HIV/AIDS (CDC, 2012; Cargill & Stone, 2005; National HIV/AIDS/AIDS Strategy; 2020, 2015).

Gay, bisexual, and other men who have sex with men (MSM) continue to be the most significantly impacted by the HIV/AIDS epidemic. Among this group young (15-29) minority men are especially at risk, with African American and Latino young men being the most at risk (CDC, 2011, 2012). It is estimated that 67% of the new HIV/AIDS infections that occurred in 2010, among Latino men, happened in men under the age of 35. In 2010, while MSM accounted for only 4 percent of the US population they represented 78% of new HIV/AIDS infections among men, and 63% of all new infections (CDC, 2011, 2012). Similarly, African Americans are the ethnic group most severely impacted by the HIV/AIDS epidemic. African Americans, while only making up 14% of the US population, account for more than one million of the people estimated to be living with HIV/AIDS in the US. Young black gay, bisexual, and other men who have sex with men (MSM) account for majority of new HIV/AIDS infection annually. African American heterosexual women are infected with HIV/AIDS at higher rates than women of any other racial or ethnic group. For example, the rate of infection for young African American females (13 to 29) is 11 times higher than that of white females and four times that of Hispanic females (CDC, 2011, 2012). Black men account for 70% of new infections among blacks and 31% of all new infections in the US. African Americans are not only the group with the highest infection rates annually (44%), but also account for majority of the people currently living with the infection (44%) (CDC, 2011, 2012). Similarly, though Latinos only make up 16% of the US population they accounted for 22% of new HIV/AIDS infections in 2011. Latino men were the most significantly impacted among Latinos accounting for 87% of infections. Also, 79% of the infections

among Latino men occurred among men who have sex with men. Latinos were infected with HIV/AIDS three times more frequently than whites (CDC, 2011, 2012).

HIV/AIDS is spread through the transmission of blood or other bodily fluids of an infected person to a non-infected person (CDC, 2015; Flagg et al., 2015; Huber, 1996; Levy, 2007). Very small amounts of the infection have been found in the saliva, sweat, and tears of infected persons; however, it is generally believed that the probability of transmission of infection vis-à-vis one of these sources is relatively low (Huber, 1996; Levy, 2007; CDC, 2015). However, the blood, semen, pre-seminal fluid, vaginal fluid, breast milk, and rectal fluids of an HIV/AIDS positive person can transmit the infection (CDC, 2014, 2015; Levy, 2007). This becomes possible when an HIV/AIDS positive person's fluids come in contact with the mucous membrane, damaged tissue, or blood stream of a non-infected person (CDC, 2014). Infection happens in a number of ways: sharing of drug injection equipment, anal or vaginal sex, during pregnancy delivery, and breastfeeding from mothers to infants (CDC, 2014, 2015; Levy, 2007; Whitehead, 2000). In the United States, HIV/AIDS is most frequently contracted through male homosexual contact and intravenous drug use, but HIV/AIDS is contracted predominately through sexual contact worldwide (CDC, 2015; Weller et al., 2011).

A complex situation comprised of multiple personal and cultural interacting factors are thought to exacerbate HIV/AIDS disparities (Adimora & Schoenback, 2005; CDC, 2012; Cargill et al., 2005; Harawa & Adimora, 2008; Loue, 2006; Masci, 1996; Wright et al., 2009). This is especially the case for ethnic and racial minorities. It is believed that HIV/AIDS more adversely impact these groups as a consequence of historical, social, economic, and environment issues (Adimora et al., 2005; Adimora et

al., 2014, CDC, 2012; Cargill et al., 2005; Loue, 2006; Masci, 1996; Harawa et al., 2008). More specifically, poverty, discrimination, stigma, homophobia, HIV/AIDS and STD community prevalence rates, substance and alcohol abuse, incarceration rates among men, language barriers, and immigration status, are among the issues identified as shaping infection rates in these communities (Admiora et al., 2005; CDC, 2012; Cargill et al., 2005; Frye, 2014; Loue, 2006; Masci, 1996; Mayer, 2014). For example, with a greater prevalence of HIV/AIDS in the African American and Latino communities, higher prevalence of sexually transmitted diseases, as well as preferences to have sex with persons who share ethnic and racial identity, African Americans and Latinos are at a greater risk of being exposed to HIV/AIDS than persons in other minority groups (CDC, 2012; Cargill et al., 2005). Also, structural issues such as discrimination, poverty, racism, incarceration, and limited access to health care increase the risk of infection as they directly impact social networks, partner availability, and testing behaviors (Admiora et al., 2005; CDC, 2012; Cargill et al., 2005; Neaigus, 2014; Vaughan et al., 2014; Zeglin, 2015).

To acquire a deeper understanding of the impact these cultural, structural, and relational factors are having on the transmission of HIV/AIDS, research is being conducted on HIV/AIDS networks. Increasingly, it is believed understanding social networks can provide critical insights into the health and wellness of those prone to be most adversely impacted by HIV/AIDS (Adimora et al., 2005; Amirkhanian, 2014; Aral, 1999; Friedman, Cooper, & Osborne, 2009; Schensul, Levy, & Disch, 1999; Shippy & Karpiak, 2005). Such research has focused on the connections and behaviors among groups to understand HIV/AIDS infection rates. This includes the actual system of

support available to positive persons and actual network changes over time, all of which shape infection transmission and quality of life (Adimora et al., 2005; Laumann & Youm, 1999; Montgomery et al., 2002; Neblett, Davey-Rothwell, Chander, & Latkin, 2011). Networks are defined by the characteristics of its members and the stability, cohesiveness, and contact frequency of persons (Amirkhanian, Kelly, Kabakchieva, McAuliffe, & Vassileva, 2003; Schensul et al., 1999; Skippy et al., 2005; Amirkhanian, 2014). Network dynamics coupled with socio-contextual factors (male-female ratios, poverty, oppression, discrimination, incarceration of African American black men, and racial segregation) shape sexual behavior and sexual infection transmission among minorities (Adimora et al., 2005, 2006, 2014; Friedman et al., 2009). Understanding and treating HIV/AIDS from a relational and contextual perspective is imperative given the power social networks have in shaping treatment adherence and consequently the health of infected persons (Adimora et al., 2014; Amirkhanian et al., 2003, 2005).

Statement of the Problem

Though HIV/AIDS was diagnosed decades ago, and millions of people are currently being treated for the infection in the United States, limited professional literature on HIV/AIDS attends to the experiences, issues, and challenges encountered by providers when rendering care (CDC, 2011, 2011; Mbanya et al., 2001; Stein, Lewin, Fairall, & 2007). The lack of information persists though considerable research is available that documents on the significant influence providers have on shaping treatment engagement, adherence, and subsequent health outcomes (Beach, Keruly, & Moore, 2006; Carr, 2001; Earl et al., 2013; Mallison et al., 2007). Limited information means

providers like myself may enter into service provision roles with little if any information about the choices and dilemmas that will be encountered when rendering care. To better prepare providers to attend to the needs of HIV/AIDS networks, and to orient them to manage the range of variables informing their care, research is needed that educates on the experiences, challenges, and types of choices encountered by professionals.

Consequently, such research should illuminate the range of treatment related issues or dilemmas navigated by providers, the influence context has on shaping and organizing care, and the role provider knowledge, identities, and experiences play in treatment (D. Becvar & R. Becvar, 1998, 2013). The availability of such information would be of much utility to family therapists and family educators working with HIV/AIDS networks.

Purpose of the Study

This dissertation informs on the personal, relational, and contextual factors that shape provider engagement and practice with HIV/AIDS treatment systems. I explore available research and my documented experiences as a new provider, in an HIV/AIDS milieu, functioning as a therapist, educator, and program evaluator. More specifically, I examined the influence of contextual-relational factors on provider professional practice, practitioner engagement with HIV/AIDS clients, and the influence of provider identities on treatment decisions. In so doing, I uncovered a range of dilemmas and choices encountered and the strategies employed to navigate such issues. In doing so, I am expanding the available literature on the experiences of HIV/AIDS providers. In addition, in studying myself in action, I was able to develop a more competent, culturally sensitive, authentic, and relational way of being and working.

During this process, I was able to acquire answers to many of the questions that I developed while working with an HIV/AIDS treatment community. The guiding questions for this study were:

1. In what ways do personal and professional identities shape professional decisions?
2. What variables or dynamics do providers take into consideration when making treatment related decisions?
3. How do professional practice and identities evolve through engagement with HIV/AIDS networks and reflective practice?

Rationale for Study

The limited literature that informs on the experiences of providers delivering care to HIV/AIDS networks, illuminated the need for intentional research in the area. Exploration of the personal, relational, and contextual factors shaping provider care increase awareness of dynamics shaping the treatment process, including the patient-provider relationship (Matthias, et al., 2010; Roter & Hall, 1998; Spenser, Carr, & Doherty, 2012). It is important to note, capturing the experiences of providers is not an indirect way of promoting paternalism, but is instead an attempt to purposefully promote patient-centered care (Forchsen, Deshpande, Thorson, 2006; Roter et al., 1998; Storm & Davidson, 2010). It is through investigation of the personal and systemic factors shaping our care that providers can become increasingly vulnerable, conscious, and intentional in training and treatment (Aponte et al., 2009; Aponte, 1982; Aponte & Winter, 2000; Aponte & Carlsen, 2009; Watson, 1993). It is with such intentionality that we can

become increasingly conscious of our actions and the ideologies informing them, and thus make changes as appropriate.

My professional interest in this area reflects a natural evolution in my professional focus. I have progressed beyond focusing exclusively on families and socio-cultural context, to exploring how provider dynamics influence and shape people and space. My training as an educator and mental health clinician has sensitized me to the powerful role providers play in shaping the course of treatment, whether consciously or unconsciously, as informed by our identities, knowledge, and or blind spots (Burgess, Van Ryn, Crowley-Matoka, & Malat, 2006; Carlson & Erikson, 1999; Keeney, 1983). This sensitivity, coupled with an awareness of the marginalization encountered by African Americans, women, and positive persons in healthcare treatment systems, heightens my interest in exploring provider experience and decision-making. Sensitive to these issues, I was motivated to study provider treatment processes. Consequently, in this study, I worked to generate an understanding of the factors that shaped my treatment behavior when delivering HIV/AIDS services. My interest in providing an intimate account of HIV/AIDS provider treatment experiences, in context of the current literature, made the utilization of an autoethnographic study both relevant and appropriate.

Autoethnography is a research methodology that allows for the updating of social practice (Lillis, 2008). A method born from discourses outside of mainstream contexts, the approach redefines research (Spry, 2001). The autoethnographic process can be integrative and emancipatory in nature. In the research process, social and contextual dynamics, and our very identities and experiences are explored, deconstructed, challenged, discarded, and transcended. Typical research boundaries dissolve, as self,

other, and context, all merge and become the subject of study (Spry, 2001). Through the process, personal evolution can occur as new knowledge is accessed and identity integration occurs (Spry, 2001). Such integration is critical to service delivery, as the competency of providers is as critical to treatment as the wellness and treatment needs of clients (Aponte, 1982; Aponte et al., 2000). As treatment is not just an intellect affair, but a process in which both clients and providers are mutually informed and shaped by treatment related interactions, research is needed to understand the conditions and factors that inform HIV/AIDS network treatment provision (D. Becvar & R. Becvar, 1998, 2013).

This study raises awareness of dynamics that shape HIV/AIDS provider decision-making and treatment. The insights of this study could potentially inform provider ability to attend to challenges inherent in health care systems and in their professional practice (Epstein & Hundert, 2002; Gordon et al., 2009).

CHAPTER TWO

CONCEPTUAL FRAMEWORK

Over the last 50 years the social science field has made considerable leaps in its comprehension of familial relationships (Bengston et al., 2005). The professional literature has become much more informed on family development and family configurations and has developed an increased capacity to understand complex individual and family growth in different contexts (Allen, 2000; Bengston et al., 2005; Carter & McGoldrick, 1998). Yet while the field has progressed in its accumulation of information about family functioning, the field has been criticized for not advancing awareness of the how's and why's of family functioning (Allen, 2000; Bengston et al. 2005). Consequently, the field is believed to be lacking in useful theories that can guide the exploration and explanation of natural phenomena.

Theories are believed to be critical to the field of family science because they facilitate processes that permit prediction, alteration, and control, allowing information to be used to inform programs and interventions (Bengston et al., 2005). It has been purported that the field of family studies has failed to consistently engage in recursive processes of theory development and research. This failed connection is evident in the plethora of accessible published studies in which the frameworks that informed the studies are not apparent (Bengston et al., 2005). The absence of theoretical framework in family research challenges the interpretation and application of study findings at theoretical, policy, and practice levels.

In order to advance comprehension of family processes, the theoretical ideas informing research must be made explicit. By being transparent, family scholars will

expand insight into the complexity and diversity of family life. Transparency, however, requires more than just the naming and describing the theories that inform research. It also demands that the influence theories have on research is also made explicit. Such clarity is important, as theorizing is an active and evolving process that includes theory application and development (Bengston et al., 2005). These values are theoretically congruent in many ways with the conceptual tenants of analytic autoethnography, as both punctuate the importance of the research process and product as a means to develop theory (Bengston et al., 2005; Ellis, Adams, & Bochner, 2011; Anderson, 2006).

Theory and identity development are central areas of focus in this dissertation. In this study, I use several family theories to explore how personal, relational, and contextual factors converge to inform provider participation in HIV/AIDS networks. In this way theory and identity converged in this work, generating a greater awareness of theory and identity in action. Though prior to this study I was conscious that my identities as a woman, African American, graduate student, Christian, researcher, family educator, and therapist, shaped how I lived in the world, I was unsure of how my identities, training, and experiences informed my professional decisions. To expand my skills and sensitivity in serving HIV/AIDS networks, I explored in this dissertation, how such factors shape professional choices in HIV/AIDS milieus. It is typical of autoethnographic studies to explore personal experiences to understand and expand upon the awareness of cultural experiences. In fact, it is through the performing of research and capturing the experiences of others that the methodological process becomes a socially and politically conscious and just action (Ellis et al., 2011).

This autoethnographic study is guided by family life course perspective (Carter et al., 1998; Demom, Aquilino, & Fine, 2005), cybernetic epistemology (Bateson, 1979; Becvar & Becvar, 1998, 2013), and the levels of family involvement model (Doherty, 1995). Together these theories, coupled with the theoretical tenants of critical race theory (Delgado, 1995; Delgado & Stefancic, 2001) and consciousness-in-action (Rasado, 2007) which informed the methodological approach of this study, produced a framework attentive to the personal, social, and political realities typically of autoethnographic works (Ellis et al., 2011). The combination proved to be instrumental in understanding the influence of personal, relational, and contextual factors on provider decisions making.

Family Life Course Perspective

The family life course perspective is a lens that helps family scholars to conceptualize how family composition changes over time and how such shifts impacts individuals and families (Demom et al., 2005; McGoldrick, Carter, & Preto, 1998). At the individual level the model stresses the importance of understanding how factors such as age, health (i.e. physical and mental), abilities or disabilities, socio-cultural factors (i.e. race, gender, sexual orientation, finances, spirituality, language, and addiction), loss and trauma, and hopes inform development (McGoldrick, et al., 1998). Similarly, the framework punctuates the importance of understanding family development factors such as, life cycle stage, family structure, family emotional and relational patterns, socio-cultural factors, and values, practices, and rituals. The framework punctuates understanding family and individual development in context of life stressors (McGoldrick, et al., 1998). Such stressors include but are not limited to: poverty, racism,

violence, addiction, developmental milestones, unpredicted life events (i.e. death, unemployment), and historical and political life events (i.e. war, economic depression) (McGoldrick, et al., 1998). These ideas are further understood in conjunction with Elder (1994) core ideas of life course theory: timing of lives, linked or interdependent lives, human agency, historical time and place.

The family life theory holds that individual and social change is continuously happening. For example, while functioning as an HIV/AIDS network provider, it was imperative that I was conscious of not only my development (i.e., doctoral intern, woman, African American), but also of the status of clients/network (age, health trajectory), and the treatment facility (years of operation, growth phases). The theme of timing of lives speaks to the meaning that exists in the interaction of dimensions such as age, social roles, life transition points, and family experience. Particular experiences at certain developmental positions can have significant implications on life trajectory. Families naturally experience stress as they transition from one developmental position to another because growth requires redefining and shifting of relationships (Carter et al., 1998). For example, in addition to understanding the developmental positions of each of the aforementioned systems, it was also important that I was conscious of how the systems influenced one another. Understanding the impact change can have on the stability of systems and their parts is critical to understanding how systems function. New clinic policies or provider departures are examples of the types of dynamics that must be considered to appropriately understand and attend to the developmental needs of systems. Transition stress is shaped by whether or not events happen at appropriate developmental times. Appropriate timing of events is measured by expectations and values that are

constructed by culture and experience. The meaning placed on developmental transitions makes the study of transitions points critical to understanding how individuals and families change (Elder, 1998). Transitions can vary in complexity and difficulty. Whether or not a transition is predictable or a disrupted event (i.e. death or illness) it can shape the level of stress experienced, coping strategies used, and thus future growth. Early or sudden transitions can be particularly challenging for families depending on the type of transitions and meaning attributed to the transition. Depending on the meaning internalized, early transitions can have long-term positive or negative impact on individual and family development to the point of influencing subsequent transitions (Elder, 1998).

The concept, interdependent lives, describes the multidirectional and reciprocal nature of influence that occurs across multiple relational systems including: individual, nuclear family, extended family, community, cultural group, and society. This view captures the connection and influence that happens across and within subsystems (Carter & McGoldrick, 1998; Demon et al., 2005; Elder, 1998).

The concept, human agency, speaks to the capacity for individuals to make personal decisions that allow them to grow in desired ways. Individual growth is described as occurring within the context of familial and larger societal systems/parameters (Carter et al., 1998; Elder, 1998). However, individuals choose how they interact with the systems that they are a part. Such action might include but may not be limited to challenging, averting, or minimizing personal or relational issues. Whether or not changes are planned or not has significant implications on the degree to which people experience themselves as having a sense of agency (Elder, 1998). These ideas are

particularly salient as they punctuate how individuals are shaped by the systems they are a part. While individuals execute actions, their behavior is very much informed by contextual factors (Elder, 1998). Understanding these ideas helped me to comprehend provider development in context, as the actions of professionals can only be understood in relationship to the systems in which they interact. In positioning myself to complete this study, I understood that in order to prevent a conceptual or practice error that I could not study providers as isolated systems. Instead, I had to study providers as systems connected to other systems to understand how their conduct is shaped by systems, and consequently how systems are shaped by providers.

Historical time is an important theme in the life course perspective and addresses how individuals and families are shaped by their experiences (Bengston et al., 1993). Recognizing that development is dynamic and not static is imperative to grasping the intricate and evolving nature of life (Bengston et al., 1993). The theme of time looks at the interaction of personal and relational development, and social-historical events on personal development. Because individual and family development is shaped by identity (race, religion, age, gender, ability, etc.) it is important to understand how historical and contextual factors such as economic stability and cultural norms shape development (Bengston et al., 1993; Carter et al., 1998; Demo et al., 2005). Families from different cultural backgrounds vary on what constitutes a life cycle change and when those changes are appropriate (Bengston et al., 1993; Carter et al., 1998; Demo et al., 2005). Similarly, the presence of multiple generations in families presents a unique form of diversity, as various generations may potentially espouse different outlooks, values, and lifestyles. Consequently, openness is generally needed to permit appropriate boundary

negotiation and shifts to accommodate multiple and co-occurring major life transitions (Carter et al., 1998).

Understanding the developmental position of individual, family, and community systems is critical to relationship development and treatment provision. In this study, the family life cycle theoretical construct aided my ability to appropriately gauge system need. More specifically, I was able to assess the needs of clients, the treatment network, and the actual treatment system. However, I also wanted to explore how I both filtered information, and engaged with the HIV treatment network given my own developmental position and identities. I was able to do so by using the Cybernetic framework.

Cybernetic Epistemology

Many researchers, theorists, and clinicians interested in families adopted the language or paradigm of Cybernetics in the 1940s. The theory describes all phenomena as existing in the world as whole and parts; however, the whole does not equal the sum of its parts. In short, when studying systems, individual parts and wholes make up the context (Bateson, 1970, 1979; Bertalanffy, 1968). System complexity increases with size. Systems (i.e., individuals, families, and communities) are described as possessing an identity, or unique view and meaning. The focus of the theory is on understanding the interactions or exchanges of information between systems, with a particular focus on their interconnectedness and interdependence (Bateson, 1979; Becvar & Becvar, 1998, 2013; Bertalanffy, 1968; Weiner, 1948). For example, the theory holds that a person's behavior is not determined by internal factors alone (i.e. temperament, personality), but is also significantly shaped by social context. Consequently, to understand a person's

behavior a provider must understand the self-organizing, self-directing, and self-governance of the person through his or her established feedback tendencies in interactions with other systems. The provider must also explore the organization and functioning of the other systems in the interaction, and develop an understanding of relationship dynamics of all participating systems (Bateson, 1979; Bertalanffy, 1968; Weiner, 1948). Thus, similar to the life course perspective, cybernetics theory stresses the importance of understanding the relationships among systems and how they inform one another. However, cybernetics theory is more advanced in its exploration of the interconnectedness and mutual influence of systems. The advanced understanding provided by the theory was needed in this study to facilitate my conscious study of multiple systems and their relationships. One cybernetic construct that explores such relationship is recursion.

Recursion is a cybernetic concept that explores reciprocal causality in human events and relationships. Nothing happens in isolation, but is instead a mutual interaction that results in mutual influence. Meaning is born through interactions in which individual elements shape and define one another. In this way, reality is co-constructed, producing redundant interacting patterns (Becvar et al., 1998, 2013; Bertalanffy, 1968; Weiner, 1948).

Systems are able to influence one another through feedback (Bateson, 1979; Bertalanffy, 1968; Weiner, 1948). In interactions, information from previous encounters is integrated into system communication and consequently has an impact on behavior. The degree to which a system is influenced and or responds to feedback is indicative of the type of feedback. If change occurs and is accepted by a system that is indicative of

positive feedback (Weiner, 1948; Bateson, 1979; Bertalanffy, 1968; Keeney, 1983). In contrast, if change does not occur and homeostasis is maintained, it is indicative of negative feedback. Positive feedback is not necessarily always good just as negative feedback is not always bad. The response of a system to positive or negative feedback can only be evaluated based on contextual related factors. Instead, feedback operates in a corrective capacity, maintaining and regulating system change and stability, ensuring the survival of systems (Bateson, 1979; Becvar et al., 1998, 2013; Bertalanffy, 1968; Weiner, 1948). My comprehension and application of feedback within the treatment system proved to be instrumental to both navigating care, and interpreting my behavior. By understanding the dynamics that shaped my practice, I was better equipped to appropriately engage with the HIV/AIDS network.

Cybernetic theory is sensitive to the complexity of change. Both stability (morphostasis) and change (morphogenesis) are necessary for a system to function optimally. While growth is good, too much change or too little of either can lead to chaos and or entropy (D. Becvar & R. Becvar, 1998, 2013; Bertalanffy, 1968; Keeney, 1983). Consequently, exploring the nature of stability and change within an HIV/AIDS treatment system helped me to develop timely interventions that were sensitive and practical.

While facilitating change as a provider it is critical to understand the range of opportunities that can be used to actualize desired goals. Cybernetic theory espouses that it is possible to arrive at one final state from multiple initial states (equifinality), and to achieve any range of endings from an initial start condition (equipotentiality) (Bertalanffy, 1968). These ideas promote flexibility in practice and research and

position providers to be open to diversity in interactions, interpretation of information, and use of resources.

Cybernetic concepts of feedback, wholeness, and systems are more theoretically complex at the level of cybernetics of cybernetics, a second level of the theory. The cybernetics of cybernetics theory extends beyond the aforementioned communication and system interaction dynamics, and addresses larger context related factors, and the observer. At this level, the observer is viewed as a participant in the observed. In fact, what is observed by the observer informs as much about her as it does about what is witnessed. The focus is on the internal structures of systems and the interconnectedness of the observed and observer. At this level of theoretical abstraction, reality is punctuated based on the perceptions of the observer (D. Becvar & R. Becvar, 1998, 2013; Kenney, 1983; Maturana, 1978). Because the observer is both subject and object in experience limits to systems awareness exist, as one cannot step outside of oneself to observe (Maturana, 1978; Varela & Johnson, 1976). The powerful role the observer has in defining and describing the observer punctuates the importance of understanding the manner in which parts relate to one another (Keeney, 1983). While understanding reality is important, effort is not placed on discerning the validity of differing realities among observers. The cybernetic of cybernetic construct, reality as a multiverse, espouses that multiple realities can exist and be equally real and valid. As observers, we create our worlds through our perceptions (Maturana, 1978).

Consequently, it becomes important that effort is made to understand the assumptions with which we construct our reality (D. Becvar & R. Becvar, 2013; Keeney, 1983; Bateson, 1968). In this study, these ideas facilitated my conscious exploration of

providers in the context of the systems they were embedded. It helped me to continuously be oriented to looking at patterns and interconnectedness, and in so doing, allowed for greater comprehension of provider experience.

The cybernetic framework builds upon the ideas discussed in the family life course theory. The framework adds relevant information on the existence of multiple levels of phenomena and their interdependence. The framework is particularly useful in this study, as it sensitized me to the important role providers play in shaping what is seen, and what is attended to in systems. The theory oriented me to the interdependent nature of systems. These ideas helped me to look at encounters and experiences with HIV/AIDS networks in a very interactional or relational way. Consequently, I understood that it would have been a conceptual error to study providers in isolation, as isolation is an illusion. I approached this study with the understanding that what I noticed and how I interacted in the treatment systems was very much informed by my identities, my training, and life experiences. Yet, to understand myself, and those I encountered, I studied interpersonal interactions and the treatment context. I did so sensitive to the developmental stage of multiple systems, but also conscious of our recursive relationship, and worked to gauge the appropriate level of personal interaction given my combined training in family therapy and family studies. Consequently, I drew upon the Levels of Family Involvement Model in this study.

The Levels of Family Involvement Model

The Levels of Family Involvement Model (LFI) is a theoretical framework that provides conceptual clarity about the spectrum of education and therapeutic services that

can be rendered to families by family educators and therapist (Doherty, 1995). The framework provides clarity on how family interventions can vary in depth, emotional intensity, and content. This distinction is important because the framework enables health care professionals to: (a) abstain from working outside the scope of their practice, (b) develop targeted intervention that are context and situation specific, and (c) render services consistent with the level of care expected by treatment populations (Doherty, 1995).

The model has been adapted from physician models of care by parent and family educators. The adapted model specifically attends to the needs of parents and family members who are raising children. The approach seeks to provide caregivers (i.e. parents, couples, family members) with parenting assistance. The model depicts a spectrum of services that include didactic lectures and activities, support groups, and intense programming for high-risk families (Doherty, 1995). The LFI model describes five levels of care, and is arranged hierarchically from low levels of program intensity/involvement to high levels of intensity/involvement. The LFI are: (a) Level One: Minimal Emphasis on Family, (b) Level Two: Information and Advice, (c) Level Three: Feelings and Support, (d) Level Four: Brief Focused Interventions, and (e) Level Five: Family Therapy.

The levels with a brief description are as follows:

1. Level 1. Minimal Emphasis on Family- At this level, contact is not family focused. Families are addressed only when relevant for practical or legal reasons.
2. Level 2. Information and Advice- Providers work collaboratively with parents and family members to obtain information that promotes understanding of the child

wellbeing and functioning. Teaching is tailored to the specific interests of the family, but specific information is not sought out about family functioning.

3. Level 3. Feelings and Support-Information is shared and exchanged about parent-child relationships. Specific information is sought out to learn about specific experiences from families but does not try to intervene.
4. Level 4. Brief Focused Intervention- Exploration of child rearing concerns is conducted. An assessment of familial dynamics is performed and reviewed with the family.
5. Level 5. Family Therapy-Intense treatment with the family around parenting difficulties. The therapist might address a number of concerns raised by the family that are related to the presenting concerns with the child, though primarily indirectly (Doherty, 1995).

The LFE model provides a clear structure for facilitating interventions at appropriate levels of intensity.

The model is an instrumental resource for providers dually trained in family therapy and family life education (FLE) because it positions them to appropriately design and implement interventions. It model can also inform provider practice decisions in instances when a person's (i.e. client, another provider, stakeholder) action prematurely begins to transitions care from one level of intervention to another.

Being a dual trained provider in family life education and marriage and family therapy, it was critical that I practiced with consideration of levels of care. In doing so, I supported the development and implementation of services, and aided in the protection of service boundaries and care transitions.

The aforementioned theories created a cohesive relational, developmental, and contextual lens by which to view I was able to explore personal, social, and political realities shaping provider treatment decisions. Such a framework was needed in this study to adequately understand the range of factors shaping provider decision-making.

CHAPTER THREE

REVIEW OF THE LITERATURE

HIV/AIDS treatment often includes complex system of care (CDC, 2014; WHO, 2013). Combinations of pharmacological and psychological interventions are often needed to address the complex interplay of physiological, relational, mental, and emotional health related issues that exist, or are soon develop after diagnosis (AIDS. Gov, 2013; CDC, 2014; Cargill et al., 2004; Hull, Wu, Montaner, 2012; National HIV/AIDS/AIDS Strategy: 2020, 2015).

Once diagnosed, HIV/AIDS infected persons need to develop a health management system to manage their care (CDC, 2014; Hull et al., 2012; Masci, 1996, 2001; National HIV/AIDS/AIDS Strategy: 2020, 2015). The development of a comprehensive system of care often includes multiple steps that starts with an official HIV/AIDS diagnosis and treatment follow up plan. More specifically, these steps often include: HIV/AIDS infection diagnosis, identification of health concerns requiring immediate attention, treatment planning/staging, health screening, assessment of psychological reaction to infection, education about health issues, prevention treatment initiation, antiretroviral therapy initiation if appropriate, and follow up care planning. This process includes informing others who were exposed to the infection, providing emotional support, and instruction on how to prevent transmitting the infection to others (CDC, 2014; Masci, 1996, 2001; National HIV/AIDS/AIDS Strategy: 2020, 2015). After health management is initiated the wellness of positive persons is tracked. Particular attention is focused on evaluating specific signs and symptoms of sickness in illness progression (i.e. diarrhea, nausea/vomiting, pain, and joint complaints) (CDC, 2014;

Masci, 1996, 2001; WHO, 2013). Even after appropriate assessments and health management initiation, ongoing care is critical as the techniques used to treat HIV/AIDS are always evolving. Research and technological advances have created breakthroughs that improve the health and functioning of positive persons (Charlebois, Das, Porco, Havlir, 2011; Fauci, Folkers, & Dieffenbach, 2013; Gardner et al., 2011; Masci, 1996, 2001).

Health management for HIV/AIDS positive persons often means the proactive development of a healthier lifestyle. For many persons this may include a healthier diet, exercise, and mental health treatment (Brunner et al., 2001; Fields-Gardner, 2010; Gifford, Lorig, Laurent, & Gonzalez, 2000; Oggins, 2009; Stacks, McKendrick, Vazen, Sacks, & Cleland, 2011). It may also require the development and utilization of a health management team that may include lawyers, doctors, psychotherapists, pharmacists, and nutritionists (Gifford et al., 2000; Rhodes, Malow, & Jolly, 2010; Synder, Kaemphfer, & Rise, 1996; WHO, 2013; Weaver et al., 2009; Yehia, Kangovi, & Frank, 2013; Zaller et al., 2008). In addition to accessing one-on-one treatment from different providers, positive persons may find it meaningful to become involved in HIV/AIDS community organizations, workgroups, or community forums (Knox et al., 1998; Trapence et al., 2012; Wohlfeller, 2002).

While systems of care are needed to manage the health of positive persons, many struggle with engagement and treatment adherence (Katz et al., 2013; Kalichman, 2008; Whetten et al., 2008). Consequently, when delivering treatment, providers often encounter appointment cancellations/no shows, tardiness, poor follow through of medically advised health behavior (taking medications or acquiring needed testing), and

use of non-prescribed medications (Holzemer et al., 1999; Kamarulzaman, 2015; Knox et al., 1998; Saberi, 2015).

To understand the treatment engagement and compliance of HIV/AIDS positive clients their behavior must be understood in context of the challenges they are presenting with. Being diagnosed with HIV/AIDS is a life-altering event that has an immediate impact on the lives of infected people, and those persons connected to them (Cargill, Stone, & Robinson, 2004; Karin et al., 2015; Walter & Petry, 2015). An HIV/AIDS diagnosis is not necessarily a life-ending event; the diagnoses can create the opportunity for people to develop a healthier lifestyle as they learn how to live with and manage a chronic infection (Cargill et al., 2004; Millard, 2015). Nonetheless the diagnosis and subsequent need of treatment is often a significant source of stress (CDC, 2014, Ciambrone, 2003; Masci, 1996, 2001; WHO, 2013).

As mentioned above, HIV/AIDS treatment disparities are a well-documented issue, a concern found to disproportionately impact the treatment access and adherence of positive African American, Hispanic, and injection drug users. Disparities manifest in a number of ways, but one particular area of concern is differentials in treatment access. For example, once diagnosed, African Americans and Latinos have been found to delay HIV/AIDS treatment access; in addition, they receive much needed antiretroviral therapy at lower rates and later in infection than Caucasians (Anderson & Mitchell, 2000; Crystal, Sambamoorthi, Moynihan, & McSpiritt, 2001; King, Wong, Shapiro, & Cunningham, 2004; Shapiro et al., 1999; Turner et al., 2000; Stone, 2005). Treatment delays are a common issue among vulnerable groups, a concern which can have a negative impact on health (Andersen et al., 2000; Curtis & Patrick, 1993; Moore, Hidalgo, Sugland, &

Chaisson, 1991; Moore, Stanton, Gopalan, & Chaisson, 1994; Shapiro et al., 1999).

Negative outcomes occur as vulnerable groups choose to not access care or in some instances do not disclose pertinent information needed to guide treatment (Bernstein et al., 2008).

It is important to note that health systems can also contribute to treatment differentials. In fact, though health status based discrimination is illegal, some HIV/AIDS positive persons encounter it when they seek treatment (Department of Justice, 2012; Bird & Bogart, 2001; Bird, Bogart, & Delahanty, 2004; Schuster et al., 2005; Sohler et al., 2007). Health care discrimination can manifest both overtly and covertly in treatment (Bunting, 1996; Rintamaki, Scott, Kosenko, & Jensen, 2007; Schuster et al., 2005). Positive persons may encounter discrimination because of their infection status or as a consequence of other identity related factors (i.e. sexual orientation, race/ethnicity, or drug use), or a combination of these issues (Capitanio & Herek, 1999; CDC, 2004; Mays & Cochran, 2001; Thornburn, Bogart, & Delahanty, 2004). Often, identity and or lifestyle related factors, such as HIV/AIDS infection, homelessness, race, and drug use are perceived as contributing to encountered discrimination by medical and support staff (Sohler, 2007). Discrimination is highly likely among positive persons because as mentioned above, HIV/AIDS infection is disproportionately high among groups of people who possess stigmatized identities prior to infection. Such discrimination has been found to not only have a negative influence on patient treatment ratings, but also a direct impact on client health status disclosure, treatment access and adherence, and health choices (Australasian Society for HIV/AIDS Medicine (ASHM), 2012; Charbonneau, Maheux, & Baeland, 1999; Guthrie, Young, Williams, Boyd, & Kintner, 2002; Sayles,

Wong, Kinsler, Martins, & Cunningham, 2009; Schuster et al., 2005; Shacham, Basta, & Reece, 2008; Sohler et al., 2007; Ware et al., 2006). For example, discrimination both within and outside of health care systems has been found to have an adverse impact on physical and mental health (Brown et al., 2000; Pascoe & Richman, 2009; William et al., 2009). More specifically, persons who perceive themselves as having encountered discrimination have been found to experience a high level of physiological stress, psychological stress, and unhealthy lifestyle behaviors (Lyon & Munro, 2001; Pascoe et al., 2009; Thorburn et al., 2004; Williams et al., 2009). For many positive persons, discrimination is an issue that prevents them from accessing the most up to date HIV/AIDS treatment, a choice that can have an adverse impact on health and quality of life. This is a particularly concerning issue for a population that is already at an increased risk of not accessing appropriate care and not receiving consistent HIV/AIDS treatment (Kinsler, Wong, Sayles, Davis, & Cunningham, 2007; Sayles et al., 2009; Sohler, 2007; Thorburn et al., 2004).

While literature of treatment disparities is increasing, there continues to be limited outcome based research targeting those most adversely impacted by HIV/AIDS, African Americans, Hispanics, and men who have sex with men (Gonzalez et al., 2009; Operario, Smith, Arnold, & Kegeles, 2010; Peterson & Jones, 2009; Rowena et al., 2015; Tufts et al., 2015). Though there is conceptual understanding of this treatment and research issue, limited information is available to educate providers and health systems on how to successfully engage and retain those most impacted, and with the highest need (Gaston et al., 2015; Gruskin et al., 2007; Holtzman et al., 2015; Lorenc et al., 2015; St. Lawrence et al., 2015). Further, the limited research on the treatment of HIV/AIDS positive ethnic

minorities continues to paint a grim picture. For example, racial and ethnic minorities continue to be less likely to receive antiretroviral medications (Gebo et al., 2005; Gwadz et al., 2015; MacDonell et al., 2015; Reiman et al., 2015; Shapiro et al., 1999). In addition, treatment interventions acquired by HIV/AIDS positive ethnic minorities are not always systemic, addressing both health management and lifestyle related behaviors. This means that providers miss opportunities to provide comprehensive care (Abara et al., 2015; Morin et al., 2004; Rubincam et al., 2015; Singhal et al., 2015). However, research has found behavioral interventions to be beneficial in reducing risky behavior and decreasing infection transmission potential (Chesney, Chambers, & Taylor, 2003; Gwadz et al., 2015; Hidalgo et al., 2015; The Healthy Living Project Team, 2007).

There is a quickly growing body of HIV/AIDS prevention literature with these populations. The interventions, similar to those targeting the wider HIV/AIDS community, are offered in a variety of treatment mediums to increase the availability and accessibility of care. Services are delivered in individual or small group format, or a combination of both (Jemmott & Jemmott, 1992; Lauby et al., 2000; Loue, 2006; Operario et al., 2010; Villarruel, Jemmott, & Jemmott, 2006; Wilton, 2009). The interventions are becoming increasingly sensitive, attending to the complex web of psychological, social, cultural, and structural factors shaping infection rates within the aforementioned communities (Cargill et al., 2004; DiClemente et al., 2004; Jemmott, Jemmott, & O'Leary, 2007; Operario et al., 2010; Satcher, 2003). Consequently, these programs are better adept at addressing not only HIV/AIDS infection, but also the micro and macro level issues faced by African Americans, Latinos, and men who have sex with men. These multi concern focused interventions can vary in programmatic content,

attending to a wide range of issues in an effort to decrease the transmission of the infection and increase treatment access (Buseh, Kelber, Hewitt, Stevens, & Park, 2006). For example, *Women Involved in Life and Learning from Other Women* (WILLOW), a Center for Disease Control funded program, is a social skill development program for women living with HIV/AIDS. The program addresses gender pride, network development, stress reduction, safe sex communication skills, sexually transmitted infection awareness, and relationship education (Wingwood et al., 2004). Another program, the BRUTHAS Project, an intervention targeting African American men who have sex with men and women, is another culturally sensitive intervention. The program offers HIV/AIDS testing and counseling, education on sexual dynamics (including risky behavior), community outreach and counseling, and practical tips on negotiating safe sex behavior. Similar to WILLOW, the BRUTHAS project attends to cultural and gender related issues shaping relationship and sexual practices (Operario et al., 2010, Wingwood et al., 2004). Increasingly, interventions are being developed to treat HIV/AIDS networks (Amirkhanian et al., 2003; Amirkhanian et al., 2005). As aforementioned, treatment of social networks is critical as they directly shape member behavior (Amirkhanian et al., 2003; Curtis et al., 1995; Ennet & Baumen, 1993; Nicholas & Fowler, 2007). More specifically, HIV/AIDS networks can influence whether or not members engage in safe sex or high-risk sexual behavior (Amirkhanian et al., 2003; Rosthenberg et al., 1998). Consequently, treatment of HIV/AIDS networks can have direct effects on treatment adherence and infection transmission rates (Klovdahl, Potterat, Woodhouse, Muth, & Darrow, 1994). While insight is increasing on the impact of social networks on health-

related behavior, more relational interventions and research on their effectiveness is needed to more comprehensively attend to the HIV/AIDS epidemic.

Preventive interventions are generating positive outcomes. In addition to decreased risky sexual behavior (i.e., the use of condoms), these programs often have several additional positive outcomes that include increased social support, improved self-esteem, declines in unsafe sexual behaviors, reductions in sexually transmitted infections, and lower rates of sexual behavior while under the influence of drugs (Crepaz et al., 2009; Jemmott et al., 2007; Johnson et al., 2008; Lauby et al., 2010; Operario et al., 2010, Villarruel et al., 2006; Wilton et al., 2009). Improved outcomes have been increasingly possible as understanding on the dynamics shaping HIV/AIDS transmission have increased, and as more systemic interventions that address the complex factors influencing infection rates have been developed.

The continuum of care approach to HIV/AIDS treatment helps positive person to gain access to critical services that could include but may not be limited to housing, transportation, economic and food assistance, mental health treatment, hospital care, dental, hospice, and primary care. It is often the case, because HIV/AIDS is a lifelong infection, that the relationships forged to manage health and quality of life are ongoing or long-term (CDC, 2014; Cheever, 2007; Maulsby, 2015; Mugavero, 2013; Sohler et al., 2007). Positive persons may have difficulty identifying resources and engaging in care. Consequently, providers can be instrumental in facilitating the engagement of positive persons in treatment (Mallinson et al., 2007; Mallison, Dekker, Dolan, & Ford, 2005). Among all the relationships formed to maintain the health of infected persons, the patient-provider relationship is a critical treatment component that has been found to have direct

implications on patient health and treatment adherence (Bakken et al., 2000; Flickinger et al., 2013; HRSA, 2014; Sheffield & Casale, 2004; Saha et al., 2014)

Health care professionals become a pertinent source of support for positive persons, as they navigate multiple systems and learn how to manage their health (Brion et al., 2014; Carr, 2001; Frew, 2015; Higa et al., 2012; HRSA; 2014; Sheffield et al., 2014; Tomori et al., 2014). Important interpersonal dynamics of the patient-provider relationship identified by positive persons include factors such as provider accessibility, respect, and quality of patient-provider interaction (Bakken et al., 2000; Beach, Duggan, & Moore, 2007, McCoy, 2005; Hser et al., 2014; Mulder et al., 2014). Provider HIV/AIDS infection/treatment competency, respect of HIV/AIDS patient lifestyle/cultural decisions, display of empathy, use of effective communication skills, trust of client need to understand concerns raised, commitment to help positive persons address complicated life dynamics (poverty, mental illness, addiction, criminal activity), delivery of holistic care, and provision of important lifestyle and health information, have all been found to be valued dynamics of treatment for positive persons (Gaston, 2013; HRSA, 2014; Mallison et al., 2007; McCoy, 2007; Preau et al., 2004). Such factors are important as research on the patient-provider relationship have shown that when positive persons are more successfully engaged (i.e., provider access, information sharing, shared decision making, provider respect, provider concern management) in treatment, they tend to both adhere to clinical recommendations and attend appointments as scheduled (Bakken et al., 2000; Beach et al., 2007; Brion et al., 2014; McCoy, 2005; Oetzel et al., 2015; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004; Whetten et al., 2006).

Successful engagement can be challenging, however, because of anxieties and biases held by patients and or their providers. For some patients, their discomfort is a result of negative past experiences (i.e., rude, cold providers), encounters that caused them to feel powerless while receiving care (Dale et al., 2014; Mallison et al., 2005, 2007; Oetzel et al., 2015; Schuster et al., 2015; Underhill et al., 2015; Worthington & Myers, 2003).

One particularly important patient-provider dynamic is that of trust. HIV/AIDS patient trust in his or her provider has been found to improve service utilization patterns, improve patient satisfaction with care, and improve medication adherence (Bakken et al., 2000; Cleary & McNeil, 1988; Doescher, Saver, Franks, & Fiscella, 2000; Fagbami et al., 2015; Hall et al., 2002; Millinson et al., 2007; Murray & McCrone, 2015; O'Malley, Sheppard, Schwartz, & Mandelblatt, 2004; Parchmann & Burge, 2004; Piette, Heisler, Krein, & Kerr, 2005; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004; Thom, Ribisl, Stewart, & Luke, 1999; Whetten et al., 2006). Trust is a relational dynamic that includes both the process by which people engage and the outcome of those interactions (Carr, 2001; Morse, 1991). Its development in the patient-provider relationship may evolve as a product of negotiation, mutual investment, collaboration, and personal connection (Carr, 2001; Friedman et al., 2015; Hood et al., 2015; Ironson et al., 2015; McNeil et al., 2015). The connection can result in clients feeling known. For example, research has found that patients who reported feeling known by their provider and as having received personalized treatment, were more likely to receive and adhere to antiretroviral therapy, and have positive health outcomes (Beach et al., 2006; Friedman et al., 2015; HRSA, 2014; Mallinson et al., 2007).

While positive patient-provider dynamics can improve health outcomes, negative interactions can hinder treatment and have a negative impact on patient health and attitudes. For example, inappropriate provider or institution actions result in positive patients being denied care (e.g., being turned away), unjustly put under surveillance (i.e., competencies, life style questions and being scrutinized), or provided poor treatment (insufficient treatment time, not provided adequate information/treatment) (McCoy, 2007). These negative experiences often shape subsequent encounters with medical communities (Chambers et al., 2015; Gaston et al., 2015; Mallison et al., 2007; Zukoski & Thorburn, 2009).

As providers can have a positive or negative impact on client treatment and health outcomes, it is critical that we examine our treatment approaches to assess if we are providing informed, sensitive, and holistic care. Fortunately, providers and health organizations are increasingly reflecting on personal practices and exploring to what degree they perpetuate disparities in treatment. Such personal critique is critical, as providers have an important role in in engaging clients in treatment (Gu et al., 2015; HRSA, 2014; Mallison et al., 2007). Research findings have made it clear that provider biases can manifest in treatment whether consciously or unconsciously, impacting how care is rendered (Blackstock et al., 2012; Calabrese, 2013; 2014; Burgess, Steven, & van Ryan, 2004; Van Ryan, 2002, 2003; Westergaard et al., 2012). For example, provider beliefs regarding patient identity factors (i.e. gender, ethnicity, sexual orientation, and or income) have been found to influence decision-making. Sensitive to the identity of patients when rendering treatment, providers may operate from unconsciously activated emotions and make decisions informed by stereotypes, and or feel uncomfortable

interacting with stigmatized patients (Blackstock et al., 2012; Burgess et al., 2004; Calabrese, 2013; 2014; Naughton & Vanable, 2013; Schuster et al., 2015). These issues may be more prevalent when coupled with a health disparity like HIV/AIDS. For example, providers treating vulnerable groups of people who are also HIV/AIDS positive have reported feeling uncomfortable addressing the range of health and life-styled (i.e. sexual orientation, intravenous drug use) related factors needed to be attended to in order to provide comprehensive care (Gerbert, et al., MCPhee, 1991; Mayer, Safren, & Gordon, 2004; West et al., 2015). Discomfort can manifest in both nonverbal and verbal behaviors in which providers display incongruent communication, such as disengaging physically from clients (turn away from client when talking), avoiding discussing topics of importance to patients, and holding fractured dialogues (hesitation, vagueness, and idea reformulations) (Epstein et al., 1998). Treatment discomfort has been found to translate into service delivery hesitancy (i.e., disinterest in rendering care) for some providers (Epstein et al., 1998; Gerbert et al., 1991). Sometimes providers are completely unaware of the anxiety, awkwardness, and discomfort evidenced in their treatment (Epstein, 1998). Nonetheless, it is important that providers address such discomfort. However, not all providers are hesitant or uncomfortable addressing the complex treatment needs of positive persons. For example, some studies have found providers to be open to rendering care to positive persons, expressing and or displaying treatment empathy, hope, and a commitment to rendering services (Gu et al., 2015; Martin & Bedimo, 2000; Westburg & Guindon, 2004). Similarly, providers have been found to be willing and able to hold comprehensive conversations with clients; dialogues that include empathy, laughter, and

open communication about HIV/AIDS risk behaviors (Epstein, et al., 1998; Lohrmann et al., 2000).

It is evident that while some providers are knowledgeable, prepared, and willing to render care to positive persons, others are not (Gerbert et al., 1991; Walusimbi & Okonsky, 2004; Webber, 2007). However, what is less understood are the range of factors that distinguish the two groups. Research has made it clear providers from different racial and ethnic backgrounds and different countries hold misconceptions or limited information about HIV/AIDS infection, prevention, and treatment. These providers often possess stigmatizing attitudes, which can manifest as low levels of support to positive persons (Gerbert et al., 1991; Walusimbi et al., 2004; Webber, 2007). Limited information or training in HIV/AIDS and provider beliefs about patients are factors that influence confidence, anxiety, and treatment differentials when delivering care (Amed, Hassali, & Aziz, 2009; Breitbart, Kaim, & Rosenfeld, 1999; Gerbert et al., 1991; Mall, Sorsdahl, Swartz, & Joska, 2012; van Ryan, 2002). More research is needed to further explain provider dynamics shaping treatment relationships. Such information would provide critical insight into personality, education, and cultural dynamics that need to be addressed during professional training to better enable the provision of sensitive and informed care.

While information is still lacking on provider dynamics in HIV/AIDS treatment, assumptions about treatment relationships have been evolving for over two decades. Hierarchical treatment values that position clients to be subject to the conditions of treatment institutions and to the expertise of their providers have been slowing deteriorating (Fanning, 1997; Friedman et al., 2015; HRSA, 2014; Ironson, 2015). What

has been evolving in its stead are more collaborative treatment paradigms that organize institutional structures and treatment practices around patient need. The new paradigms typically position clients and their families to be active participants in a partnership with their health care network, a team approach to health maintenance that draws upon and integrates client strength and knowledge with provider expertise (CDC, 2014; Fanning, 1997; HRSA, 2014; McNeil et al., 2015).

To form collaborative partnerships and integrate client knowledge and strengths into treatment providers have to be prepared to respect the unique experiences of their clients. Doing so requires an awareness of, and sensitivity to, important identity and unique lifestyle related factors that impact client day-to-day experiences and behaviors. Important considerations include but may not be limited to ethnicity, religion, sexual orientation, education, and socioeconomic status (Anderson et al., 2003; Fanning, 1996; Keiswetter & Brotemarkle, 2010; Lanier & Demarco, 2015; McNeil, 2001; Nemoto, 2015; Schilder et al., 2001; Tucker et al., 2015). Attending to such factors while addressing HIV/AIDS specific treatment related issues prepares providers to attend to important client lifestyle and identify factors (Fanning, 1996; HRSA, 2014; Schilder et al., 2001).

While researchers continue to uncover the socio-cultural-structural dynamics shaping HIV/AIDS infection and treatment disparities, providers are being encouraged to become educated on how to provide culturally competent care (Stone, 2004; Singhal et al., 2015). Culturally competency is not so much a set of skills to be mastered, but is instead an ongoing process of knowledge acquisition and application that permits providers to progressively engage with families, communities, and individuals in aware

and sensitive ways (Campinha-Bacote, 1994). To render culturally competent care, providers need to position themselves to critically review research that explores the life course development of different groups of people, and in particular underrepresented groups (i.e. minorities, women) (Arredondo et al., 2001). Such study allows for the development of a multicultural framework that allows providers to approach their practice with a greater level of competency and skill. However, it is important to note that the development of cultural competency extends beyond the memorization of cultural facts. More accurately, cultural competency requires a mastery of self (provider), a comprehension or awareness of culture and the impact of structural and oppressive forces on human development, and a commit to participate in the eradication of injustice through active participation and collaboration in communities (McGeorge & Carlson, 2010; Palmer, 2004; Vera et al., 2003). Operating from a cultural competency and cultural humility allows for effective and sensitive treatment. This occurs because the approach takes into consideration system related factors that shape lifestyle and health behavior, while simultaneously addressing treatment dynamics (i.e. good communication and participatory treatment processes) (Satcher, 1999).

Culturally competent HIV/AIDS care necessitates attention to the unique treatment needs and expectations of positive patients (Stone, 2004; Teal & Street, 2004). To render sensitive and competent care, providers must successfully attend to the spectrum of previously discussed identity and context related factors shaping client health. Stone (2004) identified four steps providers can operate from when utilizing a culturally competent framework. First, providers should ask questions to elicit information on patient core cultural issues and values. In doing so, providers need to

directly ask clients about their values and treatment needs, attending to both verbal and nonverbal communication. Second, providers need to collect information to understand the meaning of HIV/AIDS infection in client lives. Questions in this area can be oriented around clients' beliefs about the onset of the infection and understandings of how the infection shapes health, lifestyle, and relationships. Third, providers should inquire into client social context. Exploration of patient environment can provide providers with critical information about client resources, contextual permanency (i.e., immigration), literacy and language, and social support and stressors. Finally, providers need to work with patients to co-construct the dynamics of the patient-provider relationship, facilitating the creation of a unique culture that produces a treatment plan that is mutually agreed to be acceptable.

In order to meaningfully engage clients in the aforementioned areas, it is pertinent that providers understand how to communicate with their patients. Providers need to be prepared to take the time to listen and understand the needs of their clients, to engage meaningfully by asking questions to learn about patients and their health, allow time for clients to ask questions and to receive needed answers, involve patients in treatment related decisions, and respect client time (i.e., attention to a wait times and apologizing if necessary) (Shapiro, Hollingshead, & Morrison, 2002; Stone, 2004; Teal et al., 2009).

In addition, to creating a space for informative and meaningful dialogues to happen, culturally competent care takes into consideration context, cultural knowledge, language, and the persons engaging in the dialogue. Context is the space or environment in which patients live that inform their health attitudes and treatment assumptions (Devieux, Malow, Rosenberg, & Dyer, 2004; McNeil, 2003). It is made up of social (i.e.,

relationships, roles), economic (employment), and political (issues of power) dynamics that inform behavior. Cultural knowledge is developed and maintained in contexts over time as groups of people commune together around common values, beliefs, and behavioral practices born from shared religion, history, language, and physical attributes and or ties (Devieux et al., 2004; McNeil, 2003). This is important to note, as reproductive decision- making, self-protecting actions, and susceptibility to sexually transmitted infections are very much informed by cultural expectations which have been found to be very much influenced by cultural factors (Pequegnat & Stover, 1999). The ability to assess and integrate cultural dynamics into treatment communicates an understanding and sensitivity to clients, a gesture that can facilitate the development of a positive patient-provider relationship (McNeil, 2001). Language permits the communication of cultural values, allowing for the disclosure and sharing of personal realities and meaning, a process that can transmit pertinent information between people (Devieux et al., 2004).

Increasingly, cultural competency trainings extend beyond educating about the structural and contextual dynamics shaping the lived experiences of HIV/AIDS/AIDS infected persons, and take into consideration the values, practices, and biases of providers. To be culturally aware, providers need to explore their own personal history, identity, and culture, in relationship to their professional training, and assess how these factors together interact and inform their worldview. Such exploration is imperative because it sheds light on the influence cultural background plays in informing behavior and perception, which can subsequently allow for a heightened understanding of personal biases and assumptions (Arredonodo & Arciniega, 2001; McGeorge & Carlson, 2010;

McNeil, 2001). Increased awareness on the influence of culture on human behavior may allow providers to more constructively explore and reflect upon their natural reactions to individuals and groups different from themselves, which may result in increased levels of cultural sensitivity (Arredondo et al., 2001; McNeil, 2001). These insights can permit the further uncovering of latent reactions rooted in oppression, loss, and painful life experiences. Professionals who have completed such personal exploration, a process that can trigger vulnerability and promote self-acceptance, may be better positioned to grasp the impact of social and historical contexts on human development (Aponte et al., 1994, 2009; Arredondo et al., 2001). Such insights not only have implications for clinical care, but can have a significant impact on the development of the professional. Trainings that integrate the development of the professional into programming permits professionals to gain deeper insights into themselves, identify and utilize personal assets and vulnerabilities in treatment, and allow for purposeful professional development to the betterment of treatment delivery (Lutz & Irizarry, 2009; McConnaughy, 1987). Intentional and meaningful interventions become not only possible, but a reality as professionals master themselves.

Aponte et al. (2009) outlines the importance of self-mastery, a process that requires personal exploration and increasing levels of responsibility. The concept is outlined in their *Person of the Therapist* framework, a three step developmental process professionals can go through that includes: (a) development of a deep understanding of self (considering cultural, historical themes shaping development), (b) observation, reflection, and drawing upon naturally arising experiences that emerge from their own patterns in interactions with clients, and (c) navigation of those experiences and working

from them purposefully in ways that are congruent with the treatment encounter. The ideas of this framework informed this study. This study explored my self-mastery in a unique treatment milieu. More specifically, in this study I explored the personal, relational, and contextual dynamics that shaped my practice as a provider rendering services within an HIV/AIDS network. In so doing, I broaden the conversation and understanding of HIV/AIDS treatment.

It is evident that since its discovery, much research has been done on HIV/AIDS and its related treatment. Though literature is available on patient-provider relationships, little is known about the professional practices of providers rendering care to HIV/AIDS networks. To better understand the scope of issues shaping the patient-provider relationship, and consequently, treatment related outcomes, additional research is needed that sheds light on the experiences of providers. The availability of such information would permit the development of more systemic and effective HIV/AIDS treatment strategies.

CHAPTER FOUR

METHOD

This chapter will begin with a brief overview of the social science research climate. Major tenants of autoethnography will then be described, followed by a discussion on the relevance of the methodology in this study. Subsequently, the research method and design will be clearly defined and relevant participant selection and data collection process details will be provided.

The way social scientists conceptualize and conduct research has been evolving rapidly in the 21st century. Debates on research methodology have become catalysts for the redefining of important research theoretical proposition and inquiry processes. The prototypical conversation has compared and contrasted the ontological, epistemological, axiological, and rhetorical positions of quantitative and qualitative research methodology. The variance in values and beliefs across methodologies has moved many researchers to view methodologies as being at odds with one another (Mahoney & Goertz, 2006). Quantitative and qualitative research approaches are often evaluated and critiqued by researchers who possess theoretical propositions of reality and whom use those beliefs to inform their research process. The philosophical assumptions of researchers can be considered the foundation upon which the merits of research methods are evaluated (Onwuegbuzie & Leech, 2005; Seale, 1999).

More often than not quantitative and qualitative research methodologies have been conceptualized as being completely different forms of inquiry (Onwuegbuzie et al., 2005; Pope & Mays, 1995). Each method is perceived as possessing unique theoretical

tenants that shape research processes. Great variation exists both within and across the two macro research approaches (Kendon, Pain, & Kesby, 2007).

A methodological continuum exists within the social science literature that captures the theoretically variance in the conceptualization and investigation of reality: subjective/objective; inductive/deductive; generative/verificative and; constructive/enumerative (Moon, Dillion, & Sprenkle, 1990). Conceptual distinctions are constructed and thickened by researchers that postulate that the research methods hold distinct ontological and epistemological differences (Sale, Lohfeld, & Brazil, 2002; Seale, 1999). Many researchers base the decision to employ a particular research methodology on research paradigms; however, many investigators punctuate the importance of constructing practical research designs (Morgan, 1998).

Quantitative methodologies are often guided by philosophical positions of empiricism and positivism that hold that there is an objective reality, one truth that is separate from the researcher that can be uncovered in the research process (Bryman, 1984; Carr, 1994; Sale et al., 2002). Grounded in the scientific method, most quantitative methodological inquiries are operated from a logical-positivist position (Gehart, Ratlift, & Lyle, 2001). Investigation is directed by fixed hypothesis testing (Bryman, 1984). Quantitative methodological purists value objectivity, reliability, and causal confirming investigative processes (Bryman, 1984). Researchers and research participants are considered to act independent of one another (Firestone, 1987). The research process is one in which the researcher is able to study phenomena without shaping or influencing what is being studied. Research participants are selected via statistical sampling by researchers to acquire insight into a particular group and to later generalize findings

(Carr, 1994; Rubin, 2008). An objective, formal, distant, and deductive approach to research is often employed in which phenomena are measured numerically in order to capture cause and effect relationships and outcomes (Carr, 1994; Firestone, 1987; Rubin, 2008; Sale et al., 2002). Relationships between variables are discovered through descriptive, correlational, and quasi-experimental research processes that permit investigators to make predictions about future outcomes (Carr, 1994). Research bias is thought to be minimized through the implementation of experimental or correlated research designs (Firestone, 1987). The reproduction and generalizability of research findings in quantitative research are markers of cause and effect relationships, and validity (Carr, 1994; Mahoney et al., 2006; Sandelowski, 1986).

In contrast, the qualitative research approach views experience as evolving, and reality as being constructed through experience (Sale et al., 2002). The theoretical tenants do not espouse a single reality that is independent of the researcher, but instead holds that there are multiple perspectives of the world that are born and constructed between persons in the research process (Mays & Pope, 2000; Sale et al., 2002). The researcher is considered very much a part of the research process and is conceptualized as becoming immersed in the phenomena under investigation (Firestone, 1987). Qualitative researchers tend to clearly articulate the philosophical and epistemological positions they are operating from, making explicit the ideas they presume to have a direct impact on research processes (Gehart et al., 2001).

Qualitative methodologies are used by researchers to understand lived experience. The focus is not on establishing cause and effect, but is instead directed toward acquiring rich and thick descriptions of phenomena (Gehert et al, 2001). Rich observations are

thought to privilege researchers with new knowledge and insight into experiences. The acquisition of such insight is thought to require flexible and fluid research designs that occur in natural spaces (Bryman, 1998). Small sample sizes in qualitative research are typically well defined but small in comparison to quantitative research. A wide range of data collection processes are employed which can include individual and group interviews and live observations (Rubin, 2008). The small scale of qualitative research studies have been described as a barrier to generalizability, however, the goal of qualitative research is not generalizability but to develop a deeper understanding of specific phenomena (Carr 1994; Gehart et al., 2001). The focus is placed on acquiring saturation, a complete capturing of lived experience, which is achieved through a cyclic pattern of interviewing and analysis (Daly, 2009).

Review of the theoretical and methodological tenants of qualitative and quantitative methodologies illuminates the conceptual, systematic, and purposeful variance that exists in investigative processes. While qualitative research is prone to processes of theory initiation and theory building, quantitative research tends to focus on theory testing (Mahoney et al., 2006).

In this study, the qualitative research approach, autoethnography, was utilized. A qualitative approach was the most appropriate methodology for this study, as the purpose of the research was to increase the available literature on the range of dynamics that directly and or indirectly shape provider engagement with HIV/AIDS networks. Again, acquiring such knowledge is critical given the significant role providers play in HIV/AIDS treatment adherence, and given the limited information available in this area. Though a number of qualitative research methods exist, autoethnography was the best

approach for this study. For example, phenomenology is a powerful qualitative research approach that is used to describe accurately the lived experiences of a phenomenon (Crotty, 1998; Holden, 1997; Moustakas, 1994). More specifically, researchers working from a phenomenological approach are interested in what people experience or how they experience something. Thus focused, researchers are able to describe what an experience is like. Researchers working from this method do so in an objective way, operating without any established framework, in order to adequately represent facts (Heidegger, 1996, 2000). Also, phenomenologists do not place too much emphasis on research techniques because doing so would comprise the integrity of the studied phenomena (Holloway, 1997; Hycner, 1999).

The intention of this study was in many ways not aligned with the philosophy and method of phenomenology. While the purpose of this study was to understand the experience of providers, many preconceived ideas and theories informed this study. Drawing from published literature, theory, and my own perceptions and experiences, was an important part of the research process because it allowed for a conscious, focused, and intimate inquiry. An intentional and informed focus on this issue was needed given the documented disparities in HIV/AIDS treatment (Burgess, Steven, & van Ryan, 2004; Epstein et al., 1998; Mallison et al., 2007; McCoy, 2007; Van Ryan, 2002, 2003), and limited understanding on provider and system factors shaping treatment. This study explored such factors intentionally exploring provider experience, and related factors provider decision-making. Thus, an autoethnographic approach was more appropriately inline with the intention and focus of this study.

Similarly, grounded theory has been used as both a theoretical framework and research methodology (Crotty, 2003; Cho & Lee, 2014). It is often used as a research methodology for qualitative inquiry. The methodology is used to develop theories or explanations about studied phenomena. Observation of phenomena allows researchers to collect data and engage in constant comparative analysis, from which ideas or theoretical constructs are developed (Glaser & Strauss, 1967; Charmaz, 2006, Creswell, 2009, Dey, 1999). Grounded theory and analytic autoethnography similarly share a focus on developing theoretical explanations about social phenomena. In fact, grounded theory can be used as an approach to analyze autoethnographic data by researchers interested in generating theory (Pace, 2012). Yet, though theoretical explanations are valued by both approaches, analytic autoethnography is not focus as much on theoretical analysis of data, as it is on using data to make generalization about social phenomena (Struthers, 2012). My purpose in completing this study, was to engage in a processes by which my personal experience and available literature could be used to understand a larger story of HIV/AIDS care and provider decision-making. As aforementioned, the need for provider reflexivity among social scientists and HIV/AIDS providers is relevant given the need for information on the issue, and much needed provider accountability. Consequently, as the purpose of this dissertation was to engage in an action-oriented, practitioner-researcher study, analytic autoethnography was the most appropriate methodology. The methodology allowed for both professional practice development and theoretical analysis, both of which are critical to the development of the field of family studies (Allen, 2000).

Transparency in professional practice and research is critical to the development of a systemic and conscious field of family studies. Purposeful study, in which family

professionals look at themselves, their life experiences, values, and socialization, can be a powerful vehicle by which providers become better adept to attend to family health and diversity (Allen, 2000). By increasing our consciousness of our own power, privilege, subjugation through personal exploration, confrontation, and integration, we become increasingly sensitive to issues of diversity and marginalization, and in so doing, become better prepared to attend to the many faces and needs present within families (Allen, 2000). This occurs as we become sensitive to the assumptions and values that inform how we navigate and encounter our worlds, which further allow us to acknowledge and own the influence of ourselves on our professional work. Such insights cannot only improve the effectiveness and efficiency of our work, but can impact the degree to which we actively show up or embody ourselves while working (Allen, 2000). Because the identities, experiences, and assumption of family scholars are integral to our work with families, research that illuminates our investments, interests, and experiences is relevant and needed (Allen, 2000). Consequently, autoethnographic research is highly relevant to the field of family studies.

Autoethnography is an approach to understanding human experience (Denzin, 2014). I am particularly drawn to Spry (2001) definition of autoethnography, in which he describes the method as, “a self-narrative that critiques the situatedness of self and others in social contexts” (p.710). He presumes that it is by studying self (auto), with others, as situated in cultural contexts (ethnos), that researchers develop an understanding of the world, from the position of interacting participants (Spry, 2001). In engaging in self-reflection or personal critique, researchers-practitioners can inspire or provoke other professionals to likewise study themselves (personal history, experience, identity), in

interaction with others, as situated in particular sociocultural contexts (Spry, 2001). It is through acknowledging and considering a range of dynamics such as the other (making known the perspective of those persons in contact with and consequently shaping the eye of the researcher, providing a double vision); gender, race, and culture (the inherent values and biases shaped by identities), family history (the relational and contextual origins informing the work) the presence/experience of the author (a person making meaning or sense out of a particular inquiry), objective makers (important information or points about the persons of study), real persons with real lives, life changing experiences, and statements of truth, that a unique work is created, one that allows for an experience to be told, known, and understood (Denzin, 2014). While understanding and meaning can be acquired through such work, it is important to note that the process can be a bit of a challenge, as researchers link the intimate issues of individuals to greater community challenges, making known the social discourse of those very problems (Denzin, 2014; Miller, 1959). It is in this way that autoethnography is not focused on the self, but instead on the acquiring of an understanding of others (groups, culture, society) through oneself (Change, 2008)

Again, such research is exactly the type of investigation needed to shed light on the unique issues impacting HIV/AIDS treatment milieus, and the experiences of family scholars as we make contact and engage with diverse families and systems. It is through such inquiry that we as professionals can further learn how to strategically position ourselves as agents of support and change within communities. The self-reflection or personal critique of one professional can inspire or provoke other researchers-practitioners to likewise study themselves (personal history, experience, identity), in

interaction with others, as situated in particular sociocultural contexts (Allen et al., 2005; Spry, 2001). As aforementioned, by investigating our subjective experiences through reflexive research, family scholars can become aware of provider positions, both our own and others, and become better adept at identifying and critically attending to family diversity (Allen, 2000; Spry, 2001).

The autoethnographic research process is one in which researchers write about select experiences. What is chosen for inquiry is often critical experiences born from or related to culture and identity related factors. Researchers not only explore and analyze pivotal encounters, but also consider the ways in which other people have faced similar experiences. In this way, researchers are able to use their personal history, and awareness and sensitivity to the potentiality of shared experience, to illuminate cultural phenomena (Chang, 2008; Ellis, Adams, & Bochner, 2011). A form of critical pedagogy is enacted as researchers-practitioners link theory, practice, and identity. From the research process autoethnographic researchers are able to make critical information known, and distinguish their work from typical autobiographies (Ellis et al., 2011; McIlveen, 2008).

During the autoethnographic research process, the individual and or interpersonal experiences of researchers come to life on paper, as a consequence of their investigation of cultural encounters or patterned behavior. Researchers make their experiences palpable through clear, rich, and thick descriptions, often creatively representing their work, by storytelling, personal histories, photography, short stories, conversations, personal narratives, creative nonfiction memos, interviews, or art. Their works tend to be evocative, conscious, and socially just in nature (Adams & Jones, 2008; Ellis et al., 2011; Richardson, 2000; Pace, 2012).

It is important to note, variation does exist in autoethnographic research process and data presentation. Dynamics such as power, context, focus (self/other), and research analysis all inform and distinguish between different forms of autoethnography (Ellis et al., 2011). For example, indigenous autoethnographic research is an approach that disrupts power imbalances and marginalization. Disruption is the byproduct of indigenous ethnographer's resistance to being ignored and silenced (Ellis et al., 2011). Consequently, the autoethnographic approach privileges the typically silenced voices of indigenous/native researchers and creates spaces for their wisdom and experiences to be accurately represented and known. Indigenous/native ethnographers who use this research methodology are able to create personal narratives that capture their unique cultural stories, a process that challenges subjugation (Denzin et al., 2008; Ellis et al., 2011). Such works are often empowering and emancipatory in nature (Denzin et al., 2008; Ellis et al., 2011). Similarly, narrative ethnography is a creative form of inquiry in which research is presented through stories, writings that capture the experiences of both the ethnographer and those persons researched. The data range includes the researcher, those persons studied, and exploration of processes and patterns (Denzin et al., 2008; Ellis et al., 2011). Narrative ethnography is a means of encountering, understanding, and speaking about lived experiences (Denzin et al., 2008; Ellis et al., 2011). In contrast, reflexive dyadic interviews, is an autoethnographic research process that is particularly organized around the emotion and meaning that occurs within interactions during ethnographic interviews. The focus of the interview is on a selected participant's story, but the experiences, thoughts, decisions, and motivation of the researcher during the actual research process is also very important to this form of inquiry. The integration of

researcher experience into the research provides depth and context to the story being told (DenZin et al., 2008; Ellis et al., 2011). Reflexive autoethnography is an approach that is focused on the researcher, and the change he or she encounters while conducting research in the field. More specifically, the focus is on both the researcher and the process at all phases of the research (Davies, 1993; Ellis et al., 2004, 2011). A great degree of variety exists within this form of inquiry. Researchers may study their initial research experiences, write an ethnographic biography, or even share about pivotal experiences while living or working with cultural groups (Ellis et al., 2004, 2011). In being reflexive, ethnographers showcase their consciousness of the connection that exists between themselves and their research, and illuminate the role they play in shaping research processes and data (Davies, 1993). In so doing, researchers engage in critical subjectivity, making transparent the effects of sociocultural contextual factors and personal and professional dynamics on research outcomes (Davies, 1993).

The various forms of autoethnography typically fall into one of two types, evocative or analytic. Evocative autoethnography is an autobiographical form of research and writing that connects the personal to the cultural through layered conscious writing (Ellis & Bochner, 2000; Pace, 2012). The method involves storytelling, using narrative as a means to participate in analysis and interpretation of culture (Pace, 2012; Change, 2008). The works are usually written in first person, focused on a single case, and presented as a story with a character and plot (Ellis, 2004; Pace; 2012). In addition, the works are evocatively written revealing emotional and private information. The work typically features an unfolding relationship over time and is focused on both the lives of participants in conjunction with the experience of the researcher. The researcher is

positioned as an involved participant (Ellis, 2004; Pace; 2012). Critics of the evocative methodology describe the works as being too aesthetic and emotional, and being void of rigor, theory, and an analytical approach (Ellis, 2009; Hooks; 1994; Keller, 1995, Anderson, 2012). Ellis challenges these ideas noting autoethnographers take a unique approach to social science research, one in which research values evocative and aesthetic writing. She describes the aforementioned criticism as putting science and art at odds with one another and that such a dichotomous view is polarizing. Ellis notes that autoethnographers hold that research can be analytical, theoretical, rigorous, and emotional, when attending to the personal and social nature of phenomena.

Analytic autoethnography is the newer version of the method (Vryan, 2006; Anderson, 2012). As aforementioned, this study is an analytic autoethnography. The purpose of analytic autoethnography extends beyond documenting personal experience and evoking emotional responses from readers, to using data as a means to provide insight into social phenomena. Data is used to not only truthfully capture studied phenomena but to also create broader generalization. The generalization of research finding is one of the distinct differences of analytic and evocative autoethnography, and delineates the methods from one another (Anderson, 2006). Characteristics of analytic autoethnography as outlined by Anderson, one of the major developers of the approach, include:

1. The researcher is a complete member of the social world under study.
2. The researcher engages in analytic reflexivity, demonstrating an awareness of the reciprocal influence between themselves, their setting and their informants;
3. The researcher's self is visible within the narrative;

4. The researcher engages in dialogue with informants beyond the self; and,
5. Commitment to theoretical analysis individual life or socio-cultural environment” (Pace, 2012, pg. 5; Anderson, 2006).

A few researchers have raised concerns about tenants of the methodology and have challenged the approach. For example, Vryan (2006) challenges Anderson’s position that additional data beyond the experiences of the researcher is needed. Instead he holds, that the appropriateness of additional information from, and about other people, will vary across research studies depending on the goals of the researcher. He notes that whether or not an autoethnographic work is written academically, in first person, or evocatively is not the distinguishing factor between the approaches, but rather whether or not the work includes explicit analysis (Vryan, 2006). Another criticism of analytic autoethnography is that the work lacks aesthetics and that it is divisive (Ellis & Bockner, 2006; Denzin, 2006). The approach is described as having the potential effect of silencing the self of the researcher, and negatively shaping the understanding, meaning and receptivity of the overall methodology (Ellis & Bochner, 2006; Denzin, 2006; Pace, 2012). Further, the framing of analytic autoethnographic work in line with traditional sociological analysis is believed to violate both the value and integrity of evocative autoethnographic work (Denzin, 1997). Anderson (2012) addressed the later sentiments, describing such views as potentially overshadowing the utility of different visions of autoethnography. He holds such approaches may be of important utility to some practices of social inquiry

The ideas organizing this analytic autoethnographic work are those espoused by the critical theory paradigm (Delgado, 1995; Delgado & Stefancic, 2001). The paradigm

is a qualitative research theory that identifies inequality and competing social needs as cultural realities. It is consequently, the important role of researchers to create discourses that not only increase consciousness about power and privilege, but that also challenges and changes structural and relational inequalities that perpetuate imbalances. Particular themes addressed by researchers operating from the paradigm include: race, ethnicity, and gender (Daly, 2007; Delgado, 1995; Delgado et al., 2001). Also, the historical and contextual dimensions shaping sociopolitical conditions are also critical dynamics of focus in the paradigm. Critical theory researchers attend to such dynamics by engaging in reflexive research practices. Reflexive practice not only illuminates sociocultural/political realities, but also permits the combating of injustice and inequality in research (Daly, 2007; Delgado, 1995). As it was my intention to use personal reflexivity to explore identity and contextual factors shaping HIV/AIDS treatment and research, an autoethnographic critical theory approach was very appropriate for this study.

In this study, I identified issues or challenges encountered by providers working in HIV/AIDS treatment systems by analyzing available literature and my documented treatment experiences. My particular interest in developing an understanding of the professional practice of HIV/AIDS providers working in HIV/AIDS treatment milieus, was very much in line with the theoretical tenants of analytic autoethnography.

The guiding questions for this study are:

1. In what ways do personal and professional identities shape professional decisions
2. What variables or dynamics do providers take into consideration when making treatment related decisions?
3. How do professional practice and identities evolve through engagement with HIV/AIDS networks and reflective practice?

In addressing the aforementioned questions, this study is in line with autoethnographic research, as I focused on my individual experience in the context of the bigger story of HIV/AIDS network treatment. Consequently, in this study I am able to provide a unique perspective on the influence of provider identity and decision-making on HIV/AIDS network treatment (Chang, 2008).

The findings of this analytic autoethnographic study are presented as a publishable paper. More specifically, one paper was written in place of the traditional dissertation results section. It is believed that the dissemination of this study may have a formative impact on the training and treatment provision of Family Therapists and Family Educators working with HIV/AIDS networks, as limited information on provider treatment experience is available.

Participant

In this work, I am the participant and the primary source of data. I intentionally explored my experiences as a provider in order to generate awareness of provider experiences rendering HIV services. I focused on my personal experiences, in addition to the perspectives, and behaviors of the clients and providers I encountered, and or observed in an HIV treatment system. Thus, in this study, my interactions with HIV clients, providers, and administrators in an HIV treatment context, in addition to literature on HIV provider experiences, are the focus of this study.

Archival Data

Consistent with autoethnographic research, this study used published literature

and my personal journals as the data (Chang, 2008). More specifically, self-reflective data, personal journals, documenting my experiences as an educator, program evaluator, and clinician, written over a period of eight months, were used for this study. A total of 36 journals were written totaling 85 pages of text. Each journal was written shortly after a professional encounter or experience while functioning as a part-time intern in an HIV clinic. The journals are self-reflective documents in which I reported experiences and purposefully attempted to work through a range of treatment related dynamics (i.e., interactions, experiences, and events) that naturally manifested during my work. In the journals, I documented my experience interacting with HIV/AIDS clients (individually and as a group), supervisors, and other providers (including case managers, mental health clinicians, and educators). Any information that would reveal either the identities of clients or other professionals were excluded from the journals.

As part of this study, a search of published literature was completed to collect data on provider experiences rendering treatment to HIV/AIDS positive networks. Though a limited number of articles have been published that document provider treatment experiences, I identified twelve articles for investigation as part of this study. To acquire the articles, a university library research database and Google Scholar were used to access and review relevant literature. The databases searched included: Academic Search Premier; Eric; PsycArticles; and PsycInfo. The key terms that guided the search included: HIV/AIDS provider experience; HIV/AIDS provider perspectives; HIV/AIDS provider decision-making; HIV/AIDS provider interviews; HIV/AIDS provider characteristics; and HIV/AIDS provider attitudes. The inclusion criteria were limited to work that: (a) addressed provider experience rendering care; (b) were written in English,

(c) and held direct quotes of provider experiences. Each work was reviewed for relevant citations. If relevant articles were identified, those were subsequently accessed and reviewed.

Rasado (2007) Consciousness-in-action theory informed both my data collection and my analysis processes. More specifically, my professional praxis during data collection and analysis were framed and guided by Rasado's four-stage model: 1. Perceiving Oppression; 2. Recognizing, Naming, and Acknowledging; 3. Understanding: Critical Analysis; 4. And Responding: Moving to Intentional Action.

My work within an HIV/AIDS clinic granted me complete membership within an HIV/AIDS milieu. My membership in the group preceded the research conducted as a part of this study. Upon studying my professional practice, I acquired an additional identity that extended my position of member/participant, to include a researcher. These combined identities resulted in a dual participant-observer identity and role (Anderson, 2012).

In this position, I participated in the social world of an HIV/AIDS clinic, while purposefully documenting and analyzing my action (Strathern, 1987; Anderson, 2012). During the process, I had multiple areas of focus. I rendered care, while also documenting events and experiences. I held complete membership within an HIV/AIDS community, while maintaining reflexive attention to my position, in the context of the relationship and discourses encountered while practicing (Anderson, 2012). In this way, I maintained a dialogue with my data and others. This research practice allowed for a focus on the interrelationships that existed between myself (as the provider-researcher), and others (clients and published literature). Doing so permitted me to avoid self-

absorption, while contributing a literary work informing professional understanding on HIV/AIDS treatment (Anderson, 2012).

Analytic Strategy

The data analysis of this study included my careful attention to and exploration of my personal journals and the published articles. I began my analysis with no preconceived themes or codes. I explored the data and identified important identity, culture, power, and contextual dynamics shaping provider interactions with HIV/AIDS networks. I paid particular attention to how such dynamics interfaced in my interactions with clients, and explored how contextual factors also informed my interactions and my practice. I used Rasado's (2007) Consciousness-in-Action theory during data analysis by engaging in a reflexive practice while reviewing the data.

Consciousness-in-Action

Consciousness-in-Action is a theory that outlines processes that facilitate liberation, transformation, consciousness, and wellbeing (Rasado, 2007). The theory is an adaptation of the Four Worlds Medicine Wheel (2001) and Ken Wilber's Integral Theory (2000). The model conceptualizes the importance of facilitating activities that permit the exploration of the multiple interconnected challenges that are faced by individuals, families, and communities (Rosado, 2007). More specifically, the model looks at systems of power and privilege, systems of ideologies –values-attitudes-and customs that make up a culture of imposition, systems of group identity, systems of core patterns, and self-perpetuating-interactive-and non-linear relationships. The model alternatives between

collective and individual levels of analysis (Rosado, 2007). The theory describes an ongoing process of change that entails action-reflection- and action, which is praxis. This insight-oriented process involves:

1. **Perceiving Oppression: Direction Attention, Developing Awareness-** Idea that consciousness in action requires awareness of the fact that oppression exists. Perceptual awareness is developed as oppression is experienced personally. Direct experience of oppression sensitizes people to the reality of beliefs, values, and feelings that exist at the societal and communal levels. Increased awareness can foster an acute awareness of oppression. While practicing as an HIV/AIDS intern, I paid attention to issues of identity, marginalization, and health disparities. I sought to understand how such dynamics shaped the lived experiences of HIV/AIDS networks and myself. In my journals, I documented about my experience working with marginalized and disfranchised groups. In addition, I documented about my possession of marginalized identities, and how I believed they informed my encounters, perceptions, and practice related decisions.
2. **Naming, and Acknowledging-** Is the developing of an enhanced ability to identify patterns of oppression, beginning to understand patterns of oppression, and intentionally focus on them. For many persons of marginalized groups this step is basic to their survival. This stage can help people to move beyond denial. As an intern, I actively tried to learn about and identify with the range of interacting identity, relational, and contextual factors that shaped the health of HIV/AIDS clients and their treatment access related behaviors. I strove to understand how such dynamics interfaced with my own identities and experiences as a provider

working in an HIV/AIDS milieu. When it was appropriate, I strove to acknowledge and address those dynamics in my work. More specifically, I tried to give voice to and attend to encountered oppression (whether experienced directly or witnessed).

3. **Understanding: Critical Analysis-** This step requires reframing perceptions and assigning new meaning to what we have been raised to believe. Questioning and testing are processes that are engaged in to develop answers to situations and events and to evaluate the patterns and behaviors that are partaken in personally. This also includes evaluating historical causes of oppression and developing more accurate understanding of history than what has been documented. Increased understanding helps people to increasingly critically examine the past and present. The developed capacity to be critically aware is what comprises critical consciousness. Yet, change requires more than critical consciousness, it requires action. As an intern, I persistently used interactions and contextual experiences as an opportunity to explore the ideas and assumptions informing my practice. When appropriate, I played with ideas, and shifted my values or assumptions to encompass information acquired through interactions and experiences working within the HIV/AIDS milieu. My journals document my reflections on such experiences and my persistent effort to critically reflect upon and develop strategies to attend to the needs and challenges I encountered when working.
4. **Responding: Moving to Intentional Action-** Movement from critical consciousness to action often includes emotional and behavioral reactions. Emotions experienced can include anger, fear, guilt, despair, and pain,

helplessness, and powerlessness. The manifestation of these emotions can both serve as a means of allowing oppressed persons to express themselves but they can also foster reactive emotional and behavioral states that can hinder critical action. Once people move from reactivity into a response position it is possible for them to access inner resources to act consciously and deliberately (Rosado, 2007). As an intern, I intentionally and persistently worked to use learned insights (from trainings and clients) to engage with HIV/AIDS networks in meaningful and sensitive ways. My journals document the range of emotions, thoughts, and encounters that I faced, and or experienced, while collaborating with the HIV/AIDS networks.

By continuing my reflexive practice during data analysis I was able to further name, explore, and identify interacting identity, interactional, and contextual factors shaping my practice with HIV/AIDS networks, thus furthering my understanding of personal, relational, and contextual factors shaping HIV/AIDS treatment.

In addition, I engaged in ethnographic thematic content analysis to identify salient thoughts, experiences, and interactional patterns or processes. Content analysis is a research methodology traditionally used to develop inferences from research (Weber, 1990). Ethnographic content analysis (ECA), is a specific form of the method, used to retrieve, identify, analyze, and document meaningful and relevant data (Altheide, 1987, 1996). ECA is focused on uncovering and describing the meaning, patterns, and processes within data. The approach can be used to understand data and develop meaning, in addition to verifying and developing theory. It is a reflexive and interactive research process in which researchers are central to data analysis and concept

development. Any meaning derived from the data is very much informed by data collection processes and the actual content (Altheide, 1987).

Data analysis is a reflexive process in which the researcher engages in a recursive dance of concept development, data collection, coding, analysis, and interpretation. Inherent to ECA is a process of discovery and persistent comparison of emergent themes of explored texts, images, and contexts. The process allows for creativity, discovery, and comparison as the concepts and theory emerge from analysis (Altheid, 1987; Weber, 1990). The process is also one in which researchers must strive to be systematic and analytical in their approach without boarding on rigidity (Altheide, 1987).

The ECA approach differs from traditionally quantitative content analysis (QCA), which focuses on data frequency, and numerical relationships among multiple variables. The QCA process is guided by operationally defined concepts designed to acquire data that is measurable, and flows from category development, sampling, data collection, analysis, and interpretation. In contrast, ECA is a much more reflexive process (Altheid, 1987). ECA can include both quantitative and qualitative data, and does not reduce that collected research to pre-defined categories. Instead, as aforementioned, the process builds upon preexisting theoretical claims through verifying, supplementing, and discarding data by collecting new information to construct new analytic constructs that can inform new inquiries (Altheid, 1987). As part of this study, I completed the ECA six-step process as outlined by Altheide (1987) includes:

1. I formulated a research problem to investigate.
2. I engaged in an exploratory phase in which I became familiar with the available literature on provider experiences rendering care to HIV/AIDS positive

individuals and networks. As aforementioned, I used a library research database and Google Scholar to conduct a literature search using keywords. Articles that did not specifically report on the thoughts, experiences, or behaviors of providers, from their perspective were excluded from this study.

3. I located twelve documents that met my inclusion criteria and examined them for information relevant to provider treatment of HIV/AIDS clients (i.e. ideas, experiences, behaviors, values). I subsequently completed the following steps and used the data to help development units of analysis.

a. Organized the data

i. I labeled each document with an identifier (DS#1).

ii. I became familiar with each document. I did so by rereading each work several times. Also, as I reviewed each work I underlined ideas of interest, wrote memos documenting impressions and or questions.

b. Generating categories and themes

i. I identified patterns across and within data sources.

ii. I developed categories by linking similar but distinct ideas.

iii. I explored whether or not relationships existed between categories.

iv. From the categories I identified larger themes encompassing the ideas.

4. I created a data code sheet and used it to document themes developed from my initial exploratory phase.

5. I continued to explore themes through review of my journals and published literature and engaged in theme verification, termination, and expansion.
 - a. I did this by re-reviewing themes, excluding ideas that seemed redundant, and building upon themes linking categories.
6. I refined my data by amending my code sheet to reflect the emergent themes from my overall data.
7. I explored the theoretical implications of the data in context of the theoretical frameworks guiding this study. I also explored alternative understanding of my ideas by re-reviewing the literature of HIV/AIDS treatment.

I used the above analysis to construct a narrative to present the storied nature of provider decision-making. A narrative emerged from the themes identified during analysis of the published literature and self-reflective journals. The narrative is used to capture both the experiences of providers when collaborating with HIV/AIDS networks and to clearly make generalization about provider practice. Narrative or storytelling is a valued means of representing the personal and social meaning of autoethnographic research (Anderson, 2011; Davis, 2005; Furman, 2005; Liggins, Kearns, & Adams, 2013; Sykes, 2014; Taber, 2005). It is a practice used by leaders to accept personal responsibility of influence, a means to purposefully learn how to make choices and grow, and mechanism by which we can inspire others to act (Ganz, 2006) I have selected it as the mechanism by which to share about provider experiences because a systemic, informed and intimate account is desperately needed in the literature.

Strengths and Limitations

This study has a few strengths and limitations. First, one strength of this study is that it provides an authentic, informed, and intentional account of my experience as an HIV provider. In completing this work, my practice as a family educator and researcher are in line with the family studies field's value of provider reflexivity, mastery, and research. In studying my work as a provider, I was better able to understand the needs of clients and the operations of an HIV treatment system, which helped to deepen my understanding of my practice as an HIV/AIDS provider. In addition, in this work I punctuate the importance of approaching our practice and research reflexively in order to better be able to identify and attend to personal, relational, and institutional factors shaping treatment. It is my hope that my transparent and genuine reflection will encourage other providers to intentionally reflect upon their practice, and prompt research on HIV provider experience and treatment system. The presentation of my practice and research experience in the form of a publishable paper meant that I was limited in the breadth and depth of the information I was able to cover. More specifically, I was not able to detail much of the subtle and important treatment nuances that I encountered as a provider. However, I believe I was successfully able to capture the essence of my experience and the factors that I encountered in my work and relationship with the HIV/AIDS network. I share of my experience in both reflective and descriptive ways.

In addition, I understand that though this study contributes to the family studies literature on factors that shape HIV/AIDS care, that I did not directly include the voices of clients. In this study, I did not purposefully interview clients, a dynamic that inhibits my ability to thoroughly represent their experiences in this work. However, I believe that

given the limited literature on provider experiences that the focus and method of this study was appropriate. I believe this study is formative in promoting awareness of provider treatment related processes, and it is my hope that the information from this study will inform future studies of provider treatment processes.

CHAPTER FIVE

**UNDERSTANDING PROFESSIONAL PRACTICE: PROVIDER DECISION-
MAKING WHEN COLLABORATING WITH AN HIV NETWORK**

Abstract

HIV/AIDS providers are a critical component of HIV/AIDS treatment. However, limited research is available that informs on the practice experiences of providers. This study explored how HIV/AIDS provider decision-making was informed by HIV/AIDS treatment systems. I used autoethnography as a means to explore factors shaping my practice rendering HIV/AIDS services. Data were collected through written reflections and a literature search on studies documenting HIV/AIDS provider treatment experiences. Thematic analysis was performed. I used coding to generate major themes in the data. I identified a number of institutional, professional-contextual, client, and provider level factors that impacted my professional practice. I employed a number of strategies to adequately attend to the treatment factors. The findings of this study provide insight into the personal, institutional, relational, and contextual factors shaping provider HIV/AIDS care. My results suggest providers working in HIV/AIDS contexts have to navigate a range of treatment related issues. These issues have a direct impact on not only the what, how, and when services are provided, but also on the overall quality of interactions and treatment with HIV/AIDS networks. The findings validate the importance of researching HIV/AIDS provider experiences, and punctuates the necessity of continued research in this area. Implications for providers working within HIV/AIDS systems are provided.

Introduction

Since the reporting of the first few cases of human immunodeficiency virus (HIV/AIDS) over three decades ago, the need for research on the infection has only grown. In fact, information on the infection has remained not only relevant, but critical to public health, as it has continued to spread. With a host of individual, relational, and structural factors shaping infection rates, and without the discovery of an appropriate antidote to cure it, the disease has reached epidemic proportions in the world (CDC, 2015; UNAIDS, 2015). To date, seventy-eight million people have acquired the infection and about thirty-nine million people have died due to the infection worldwide (CDC, 2015). In the United States (US) there are over one million people above the age of thirteen living with HIV/AIDS with more than one hundred thousand people infected but unaware of their status (CDC, 2015). The high incidence of infection coupled with the complex and evolving nature of the disease has prompted research on the disease and its many related issues.

Ongoing research has proved to be pivotal in raising awareness about the infection, its related health disparities, and the quality of life of persons living with HIV/AIDS (Adimora et al., 2005; Adimora et al., 2014; Cargill et al., 2005; CDC, 2012; CDC, 2015; Flagg et al., 2015; Huber, 1996; Levy, 2007; Loue, 2006; Masci, 1996). Such research has been instrumental in facilitating the development of sophisticated, and population specific HIV/AIDS interventions (Adimora et al., 2005; Aral, 1999; Crepaz, 2014; Ellison et al., 2014; Friedman, et al., 2009; Underhill et al., 2010; WHO, 2014). Consequently, interventions are increasingly available that attend to the range of physiological, mental and emotional, and relational pre-existing issues that develop soon

after infection and diagnosis (AIDS. Gov, 2013; CDC, 2014; Cargill, et al., 2004; National HIV/AIDS/AIDS Strategy:2020, 2015) This has resulted in a system of care of HIV/AIDS treatment, a multiple step and often multiple provider approach to care, spanning from diagnosis to long-term health management (CDC, 2014; Horberg et al., 2014; National HIV/AIDS/AIDS Strategy: 2020, 2015).

The patient-provider relationship is one critical component of the health management system of positive persons (Bakken et al., 2000; Brion et al., 2014; Carr, 2001; Frew, 2015; Gourlay et al., 2014; Higa et al., 2012; HRSA; 2014; Sheffield et al., 2014; Tomori et al., 2014). The importance of the patient-provider relationship is evident in research outcomes, which indicate factors such as trust, accessibility, collaboration, respect, and quality of interaction can improve service utilization patterns, improve patient satisfaction with care, and improve treatment adherence (Bakken et al., 2000; Beach, Duggan, & Moore, 2007; Cleary & McNeil, 1988; Doescher, Saver, Franks, & Fiscella, 2000; Hall et al., 2002; McCoy, 2007; Millinson et al., 2007; O'Malley, Sheppard, Schwartz, & Mandelblatt, 2004; Parchmann & Burge, 2004; Piette, Heisler, Krein, & Kerr, 2005; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004; Thom, Ribisl, Stewart, & Luke, 1999; Whetten et al., 2006; Martin & Bedimo, 2000; Westburg & Guindon, 2004). Yet, just as positive provider dynamics can improve client treatment access and health related outcomes, negative experiences can have an adverse impact on client treatment attitudes and behavior, and can taint subsequent encounters with medical communities (Bogart et al., 2013; Mallison et al., 2007; McCoy, 2007).

Research has found provider biases about patients can negatively influence treatment decision-making (Burgess et al., 2004; Epstein et al., 1998; Gerbert et al., 1991;

Mayer, Safren, & Gordon, 2004). In addition, limited information or training in HIV/AIDS/AIDS, can also influence provider confidence, anxiety, and treatment decisions when delivering care (Amed, Hassali, & Aziz, 2009; Breitbart, Kaim, & Rosenfeld, 1999; Gerbert et al., 1991; Mall, Sorsdahl, Swartz, & Joska, 2012; van Ryan, 2002). Given such dynamics can inform treatment, it is important that providers are trained to be aware of and to address biases and competency related issues.

It is evident that while some providers are knowledgeable, prepared, and willing to render care to positive persons, others are not (Gerbert et al., 1991; Walusimbi & Okonsky, 2004; Webber, 2007). However, what is less understood are the factors that distinguish the two groups. Because providers can have a significant impact on client health behavior and outcomes, it is imperative that we examine our treatment approaches, critiquing them for informed, sensitive, and cultural appropriate practices. Doing so could potentially curb conscious and unconscious biases that have been found to shape provider treatment practices (Burgess, Steven, & van Ryan, 2004; Dovidio et al., 2012; Sabin & Greenwald, 2012; Van Ryan, 2002, 2003). The fact that little is known about the professional practices of providers rendering care to HIV/AIDS networks illuminates the need for research in this area. Such research would provide critical insight into identity, training, contextual, and cultural dynamics informing provider treatment behaviors. The information acquired from such inquires could be used pragmatically to improve professional trainings to better enable the provision of sensitive and informed HIV/AIDS care.

My interest in contributing to the understanding of provider decision-making emerged from the challenges and subsequent questions that I unexpectedly found myself

confronted with as a new HIV/AIDS provider. I can recall clearly both the moment and the series of questions that prompted me to challenge the status quo of my professional practice and embark on this study. What has happened? Why is this happening? Did I contribute to this? How can this be fixed?...Can this be fixed? Were among the series of thoughts that cycled through my mind in a matter of minutes, as I sat, perplexed, in a treatment center with an upset group of HIV/AIDS positive clients. In that moment, I was incredibly conscious of the fact that the anxiety, frustration, and anger that I was encountering was in stark contrast to the warm and jovial greeting that I had received from the clients just four weeks prior, when I started at the organization. Yet, at the same time, I was not fully aware of the spectrum of issues that had contributed to the increase in conflict and distrust within the treatment system. My personal commitment to rendering informed and culturally sensitive care, coupled with my genuine concern about the nature of the complaints being filed against both myself and the system that I was a part, prompted a heightened state of self-reflectiveness, an event that moved me to study myself in relationship to a specific HIV/AIDS network.

The decision to research the influence of my identities and professional training on my engagement and treatment with an HIV/AIDS network, came at a time when I was already concerned about whether or not I had acquired the experience and training needed to adequately attend to family health. It was a time when I found myself repeatedly asking, am I prepared to attend to the systems that perpetuate inequality or have I become a part of the system? To answer that question, and the many others that emerged from my work, but remained unanswered due to a literature shortage on provider treatment decision-making in HIV/AIDS care, I began to look at my work more

intentionally. Consequently, I engaged in an autoethnographic study to better understand the dynamics that inform provider practice in an HIV/AIDS milieu.

Conducting research on provider experience is an important step to understanding the range of factors informing HIV/AIDS treatment and health outcomes. It is not possible to fully understand the context of HIV/AIDS care, and its related treatment outcomes, without insight into the experiences of providers. Such information is particularly important at this time given the documented importance of the patient-provider relationship on treatment outcomes. General research on provider reflection has demonstrated that the strategy can improve treatment practice, increase professional support and collaboration, and facilitate the personal and professional development of staff (Lillemoen & Pedersen, 2015; Alexander, Best, Stupiansky, & Zimet, 2015; Wald et al., 2015). It can also inform on the influence provider assumptions and knowledge have on treatment, and of the impact contextual factors have on service delivery (Alexander et al., 2015; Hunink et al., 2014; Williamson et al., 2014; Schroy, Mylvaganam, & Davidson, 2014). More research on these types of provider treatment dynamics is needed in the HIV literature. However, though research has been conducted for several decades on the infection, health, lifestyle, and treatment of HIV/AIDS positive clients, little is known about the experiences of HIV/AIDS providers.

Method

Research Approach

Autoethnography is a form of writing that combines elements of autobiography and ethnography, creating a distinct form of work. Increasingly, researchers are using the

approach as a means to explore their personal experiences in the field. The research process is one that facilitates the systematic exploration of the roles and experiences of researchers, positioning all of which, as the subject of inquiry (Ellis, 2011). Through analysis (graphy) of personal experiences (auto), researchers are able to generate an understanding of cultural experiences (ethno) (Ellis, 2011).

Researchers doing autoethnography write, often retrospectively, about realizations born from their experiences participating in particular cultural context, or possessing a specific identity (Ellis, 2011). Writing is often the research tool of choice by researchers, to both collect and analyze data (Wall, 2006). The experiences of researchers are looked at analytically, often through the use of research sources, such as published literature, cultural artifacts, or interviews (Ellis, 2011; Ronai, 1996; Foster, 2006; Denzin, 2006; Anderson, 2012). The analytic process includes the review and identification of patterns from such writings and artifacts and the subsequent capturing of those themes through elements of storytelling or personal narrative. The process allows for researchers to use rich and thick descriptions to present their personal experiences of culture. Thus, allowing them to contribute unique cultural understanding (Ellis, 2011). This is an analytic autoethnographic study, a newer version of the method (Vryan, 2006; Anderson, 2012). The purpose of analytic autoethnography is to provide insight into social phenomena. Data is used to capture personal experiences but also to make general assumptions. The four characteristics of analytic autoethnography, as outlined by Anderson, include:

1. “The researcher is a complete member of the social world under study.
2. The researcher engages in analytic reflexivity, demonstrating an awareness of the reciprocal influence between themselves, their setting and their

informants;

3. The researcher's self is visible within the narrative;
4. The researcher engages in dialogue with informants beyond the self; and,
5. Commitment to theoretical analysis individual life or socio-cultural environment" (Pace, 2012, pg. 5; Anderson, 2006).

In this article, I present my personal experiences practicing in an HIV clinic, as I worked to become a competent and culturally sensitive HIV provider. I situate my experiences in relationship to the available data on HIV provider experiences, and the general HIV literature.

Data Collection

The data for this study are comprised of personal journals and literature on HIV/AIDS providers (Chang, 2008). The journal entries are self-reflective accounts of my personal experiences as an educator, program evaluator, and clinician, and were written over a period of eight months. The journals capture my purposeful attempts to understand and work through the HIV/AIDS treatment dynamics (i.e., interactions, experiences, and events) that I encountered as a provider. More specifically, my writings documented my effort to understand an HIV treatment system by using myself as the subject of study. In so doing, I explored the voiced experiences and displayed behaviors of clients, providers, and administrators in interactions with each other, and with myself. I documented how those interactions shaped me and consequently how I shifted and purposefully tried to shape the treatment system. Though the voices and experience of clients and other providers are not directly quoted in this work, they had a profound

impact on my thinking and actions, and were a powerful instrument in provoking my personal exploration and professional development. A total of 36 journals were written totaling 85 pages of text. Any information that would reveal either the identities of clients or other professionals was excluded from the journals. In addition, I completed a search of published literature on provider treatment experiences when delivering services to HIV/AIDS positive networks. Only a few articles were available that documented the voiced experiences of providers. However, I identified and selected twelve articles for review as part of this study. The articles were acquired through a university library research database and Google Scholar. The database searched included: Academic Search Premier; Eric; PsycArticles; and PsycInfo. The key terms that guided the search included: HIV/AIDS provider experience; HIV/AIDS provider perspectives; HIV/AIDS provider decision-making; HIV/AIDS provider interviews; HIV/AIDS provider characteristics; and HIV/AIDS provider attitudes.

Data Analysis

The data analysis of this study included my careful attention to and exploration of my journals and the published articles. I began my analysis with no preconceived themes or codes. I explored the data and identified important identity, culture, power, and contextual dynamics shaping provider interactions with HIV/AIDS networks. I paid particular attention to how such dynamics interfaced in my interactions with clients, and explored how contextual factors also informed my interactions and my practice. I used Rasado's (2007) Consciousness-in-Action theory during data analysis by engaging in a

reflexive practice while reviewing the data, which allowed me to approach my work with a praxis and insight-oriented process that attended to:

1. Perceiving Oppression
2. Naming, and Acknowledging
3. Understanding: Critical Analysis
4. Responding: Moving to Intentional Action

Also, I completed an ethnographic thematic content analysis to identify salient thoughts, experiences, and interactional patterns or processes. Ethnographic content analysis (ECA), is a research methodology, used to retrieve, identify, analyze, and document meaningful and relevant data (Altheide, 1987, 1996). The approach is used to uncover and describe the meaning, patterns, and processes within data. The approach can be used to understand data and develop meaning, in addition to verifying and developing theory. It is a reflexive and interactive research process in which researchers are central to data analysis and concept development.

I completed the ECA process as outlined by Altheide (1987). I formulated a research focus to investigate. I then engaged in an exploratory phase in which I became familiar with the available literature on provider experiences rendering care to HIV/AIDS positive individuals and networks. I used a library research database and Google Scholar to conduct a literature search using key words. In so doing, I identified twelve documents that met my inclusion criteria and reviewed them for relevant information on provider treatment of HIV/AIDS clients. I then organized the data by giving each document an identifier and I became familiar with each document by rereading each work. I wrote memos documenting impressions and or questions during my reviews and generated

categories and themes. I identified patterns across and within data sources and developed categories by linking similar but distinct ideas and explored whether or not relationships existed between categories. From the categories I identified larger themes encompassing the ideas and then I created a data code sheet and used it to document themes developed from my initial exploratory phase. I continued to explore themes through review of my journals and published literature and engaged in theme verification, termination, and expansion. Finally, I refined my data by amending my code sheet to reflect the emergent themes from my overall data and explored alternative understanding of my ideas by re-viewing the literature of HIV/AIDS treatment.

Autoethnographic Narrative

While performing data analysis, a narrative emerged naturally. It is a storied account of my experiences as a provider working in an HIV/AIDS clinic. The narrative illuminates the prevalent issues, emotions, and choices I experienced as an HIV/AIDS provider, and explores them in context of documented provider experiences. The narrative broadens current understandings of HIV/AIDS provider practice, through my presentation of the pertinent issues I faced and my exploration of similar experiences documented by other providers. Narrative telling is a valued means of representing the personal and social meaning of autoethnographic research (Anderson, 2011; Davis, 2005; Furman, 2005; Liggins, Kearns, & Adams, 2013; Sykes, 2014; Taber, 2005). It is a powerful tool used by leaders to guide their personal growth and work, and a means by which they inspire others to act (Ganz, 2006). I used narrative as the mechanism by which to share the finding of this study because an intimate and accountable account of

provider treatment experiences was needed. I believe such research punctuates the importance of provider awareness, and encourages provider attentiveness to issues of reflexivity, self-mastery, and advocacy when practicing within HIV/AIDS treatment systems.

Results

Primary Themes

Several categories and themes emerged from critical review and analysis of the data. The three categories are as follows: (i) institutional factors, (ii) community professional contextual factors, (iii) direct practice factors, and (v) client treatment factors. In the following narrative, I describe how my practice was informed by these dynamics. I situate my professional experiences in context to the available literature on HIV/AIDS provider treatment experiences. In so doing, I provide insight into the experiences of providers, informing on not only provider behavior, but also of the relational and contextual factors shaping our treatment engagement and decision-making.

Narrative

Review and analysis of my written reflections helped me to identify factors that shaped my professional practice while working in an HIV/AIDS treatment milieu. I found the factors could be broken down into specific categories, institutional, community professional contextual, client treatment, and direct practice. While each factor presented unique issues I had to navigate, the dynamics were not mutually exclusive, but instead interrelated. As a provider, I had to learn how to function within a system with a specific

culture, one of finite resources, but possessing a commitment to improving the health and wellness of positive persons. I had the responsibility of maintaining the continuity of an established treatment culture while also building upon the priorities and practices of the system. I worked to do so in ways that were not only consistent with the treatment needs of HIV/AIDS clients, but also congruent with my identities and training as a provider. Navigating these different prioritizes proved to be challenging, often requiring intentional contemplation of the individual, relational, and contextual implications of my treatment decisions. The practice related issues I faced, and the strategies I employed to resolve them, are summarized in Appendix B and explored with more specificity in the following narrative.

Institutional Factors

Practicing in an HIV/AIDS treatment system required that I learned how to attend to a number of institutional level factors. Balancing was just one of the important issues that I had to navigate. For example, upon joining the HIV treatment system I began to work as an educator, program evaluator, and therapist, often cycling through more than one role during a day. I found doing so often required me to shift my practice based on client or clinic need. In some instances, shifts were routine changes in my professional practice, for example, transitioning from collecting data on client health, to educating clients on HIV/AIDS and substance abuse recovery. In other situations, changes were informed more so by developmental or circumstantial needs, such as shifting my treatment approach to accommodate client growth or cultural needs, or screening and updating charts for an impending audit. Part of balancing, required that I not only

functioned in different capacities and implemented appropriate interventions, but that I did so with time limitations, adhering to clinic policies, while delivering quality care. My initial experiences learning to balance was challenging. I found that my limited awareness of both HIV and the actual treatment system slowed down my ability to take on roles and perform tasks quickly and confidently. I understand now that I was initially self-conscious about my abilities. While I had previously experienced myself as a competent educator, clinician, and evaluator, I found myself hesitant when assuming and balancing roles as an HIV provider. Early interactions with clients and providers, in which I was asked to disclose both my HIV competency and years of experience, heightened my awareness of my limited knowledge of HIV. In addition, learning about the negative treatment experiences of clients heightened my awareness of the need for client centered, informed, and sensitive care. This awareness encouraged me to quickly develop my proficiency as an HIV provider. Consequently, I became very proactive in my work. This pro-activeness was evidenced in my practice, in which I identified and prioritized tasks, worked under pressure, planned ahead, and strategically mapped resources. Balancing several roles helped me to develop a more sophisticated ability to both understand and attend to institutional/organization and client needs. It also prompted me to more quickly increase my understanding of HIV infection and treatment.

Role balancing is a documented issue experienced by HIV/AIDS providers. Mutemwa et al. (2013) found similar findings among HIV/AIDS providers working in an integrated HIV/AIDS and reproductive clinic. Providers had to balance several roles to successfully attend to client needs. In fact, doing so helped to enhance the skills and

competency of providers. Consequently, though balancing may create practice related challenges, it can facilitate provider treatment skill development.

The comfort I experienced while balancing several roles was often influenced by the resources I had access to as a provider. I learned quickly that the availability of resources directly shaped what tasks I could complete, and when. In addition, I found that the type of resource issues I encountered ranged from infrastructure related concerns (i.e. limited treatment space), to limited program material. For example, shortages in workspace and technology shaped dynamics such as when I could treat clients, enter evaluation data, and how many tasks I could complete on a given day. Similarly, infrastructure related issues sometimes shaped whether or not I could provide treatment, and the level of physical comfort experienced during treatment. These limitations were often a source of stress that shaped the ease in which I was able to complete treatment related tasks. In Mutemwa et al. (2013) study, providers reported similar resource challenges. Providers identified space, equipment, and personnel shortages as factors that complicated services delivery. To attend to such issues providers had to deliver multiple services and provide care in limited spaces. Lekas, Siegel, and Leider (2012) and Mutemwa (2013) both found that providers tried to accommodate such resources limitations by adapting their practice to attend to client need. This meant they extended their treatment duration, closely surveyed client health, and increased their accessibility to clients. However, clients were still not always able to acquire the resources or treatment they needed on site (i.e. medication) (Mutemwa et al., 2013; Lekas et al., 2012). Resource limitations have been found to be the byproduct of poor program resource coordination, insufficient funds, and or impractical and poorly articulated

expectations between trainers, providers and funders (Owczarzak & Dickson-Gomez, 2011; Weddle & Hauschild, 2010). I found this to be true in my work. Consequently, as a provider I had to learn how to manage practice expectations without always having the institutional support that I required.

In order to navigate the resource limitations I encountered, I had to negotiate priorities with clients and clinic leadership, collaborate with other providers, and balance demands. Communication among providers and clinic leadership often proved to be instrumental in assessing service delivery abilities and coordinating the best care. To facilitate such conversations, I found approaching dialogues with confidence, a flexible demeanor, and a management attitude was helpful.

I found however, that my ability to adapt my practice was shaped not only by resource availability, organization policy, and role requirements, but also by the quality of communication in the clinic. Communication proved to be both a positive and negative factor shaping my work. I found poorly expressed expectations in the area of treatment protocols and clinic operations made adhering to such requirements incredibly challenging. Limited communication about practice related expectations created time management issues, prompted provider-patient conflict, and contributed to role-strain issues that I had to resolve. Concerns similar to these have been voiced by other HIV/AIDS providers. For example, Owczarzak et al. (2011) found that unclear communication about program modifications made it hard for providers to decide how to approach program revisions and treatment implementation. In addition, Grusky et al. (2005) found that mixed messages about testing protocols resulted in variability in provider treatment. Providers made decisions based on perceived organization

preferences and value based judgments about their clients. Mutemwa et al. (2013) found that in addition to not receiving adequate programmatic direction, providers did not receive adequate psychosocial support to cope with work related stress. These types of communication issues create practice related challenges that providers have to navigate in order to deliver quality services and care for their health.

To address the communication challenges that I experienced, I learned to operate with flexibility and develop creative solutions to meet, to the best of my ability, client and clinic expectations. Doing so, often required strategizing and prioritizing important issues (i.e. how and when tasks would be completed), revising timelines, communicating challenges, and collaborating with other providers to both meet immediate needs, and attend to structural issues that produced the challenges. Communicating with leadership about practice related concerns, setting boundaries, and recognizing my practice limitations was at times required to manage stress, maintain an ethical practice, and generate needed solutions. Communication became a positive strategy to address poorly articulated organization changes and service delivery expectations, and a means to promote improved practice and policy. I am aware that my ability to engage strategically, ethically, and collaboratively to address communication related challenges was very much informed by my level of professional experience and my values. As an African American, woman, family educator/therapist, and researcher conscious of health and treatment disparities among the HIV/AIDS population, I worked intentionally to mitigate the impact of poor communication on service delivery. I realized early when confronted with poor communication treatment related issues that it would have been easy for me to create quick but non client-centered approaches to resolve the challenges. My training

and values as a provider were what motivated me to not cut corners, and to find solutions that would maintain not only the integrity, but quality of my work.

While my practice as a provider was challenged by limited communication, I found that supportive communication was a positive system dynamic that informed my practice. I found clearly communicated expectations in certain service related areas, coupled with an open door discussion policy, facilitated the successful negotiation of practice related issues and contributed to my expanded awareness of HIV/AIDS treatment, and improved service delivery. Being able to both communicate about challenges, and collaborate around the resolution of such issues, was an important form of support.

Though communication in the clinic was not always optimal, a close network of providers existed. Upon starting at the clinic, I was immediately adopted into the established community of caring, funny, intelligent and food sharing professionals. I quickly found that working with a diverse group of professionals whom varied by ethnicity, gender, specialty, role, and time in the field, advanced my professional skills. The team helped to facilitate my acclimation into the treatment system through sharing information, supporting my development of relationships with clients, and co-managing treatment challenges. Even after my adjustment into the system, I continued to experience our team of providers as being instrumental to navigating service delivery binds, coordinating care, and maintaining a sense of community. The connection among providers was often visible during simple interactions in which we debriefed cases, shared cake, or joked about something a member of the team had done. A desire to provide needed and quality HIV/AIDS treatment was often vocalized and evidenced in

the actions of providers. The experience of being part of group of providers invested in connecting and managing the health of HIV/AIDS clients buffered against clinic operations related stress.

The importance of good communication and social support is a documented issue in the HIV/AIDS provider literature. Myers et al (2007) found humorous communication among HIV/AIDS providers helped them to alleviate tension. Clinical humor, joking about encounters with clients, helped providers to emotionally and cognitively cope after having had sensitive interactions with HIV/AIDS positive clients. Similarly, Mutemwa (2013) found that when communication improved among HIV/AIDS providers that work place relationships and sense of support increased. In essence, providers were better able to coordinate care and felt less alone. These sentiments were similarly articulated by Owczarzak et al. (2011) who found communication among providers and upper level management was a contributor to provider successful intervention implementation. Good communication among providers in a treatment network is a particularly important issues as it allows for providers to effectively coordinate client care (Wagner et al., 2009).

Professional-Contextual Factors

As a new provider, I had to learn how to navigate the personal, contextual, and relational issues that I encountered in the treatment system. I started to do so by collaborating with other providers in the treatment network, consulting with my immediate supervisor, and by delivering services. Engaging in the system in this way helped me to develop a deeper understanding of the clinic's treatment culture, and the interpersonal dynamics shaping care. However, I continued to have questions about how

to proactively and sensitively work through the intersecting issues that I faced as a provider. My value of evidenced informed practices prompted my review of available literature on provider decision-making. At the time, I viewed researching HIV/AIDS treatment as a means to further improve my relationships with clients, navigate practice related issues, and increase my treatment competency. However, I found limited literature documenting HIV/AIDS provider experiences. The absence of literature made increasing my awareness on provider decision-making challenging. Lekas et al (2012) similarly found that limited literature on HIV/AIDS treatment with co-infected patients impacted the practice of HIV/AIDS providers. Providers reported not being able to acquire trustworthy direction from the available writings. The absence of information prompted providers to strategically make treatment decisions. Similar to the approach I took, providers felt their way through treatment, consulted with other providers, collaborated with experienced providers, and monitored client health. Because I continued to have unanswered questions however, I began to intentionally investigate more my professional practice. I reflected on my experiences and wrote about them. I evaluated my decisions and the logic behind them. I documented the issues I encountered, contextual and relational, and looked at the factors informing them. I often posed questions to myself and identified possible courses of action to attend to the issues I faced.

Through my investigation I become more aware of the treatment discomfort I occasionally experienced, service binds I encountered, and of personal biases I held. I learned my identities both supported and inhibited my work at times. For example, being an African American and woman made it easier to build rapport and collaborate with clients in some treatment setting. However, not living with a chronic infection or

addiction, and my perceived youthfulness seemed to raise questions about my ability to understand and attend to the needs of clients. Also, I experienced discomfort working to maintain the established treatment culture, while broadening and improving treatment interventions. I learned to grapple with holding the tension of advocating for client needs while also being identified at times as being part of the system that was invalidating their needs and requests. Identifying and exploring these types of issues helped me to become conscious of the contextual factors shaping my treatment decisions and more sensitive to the identity, relationship, and health concerns of HIV/AIDS clients. My heightened awareness of personal, relational, and contextual factors shaping my practice made navigating such issues easier.

Provider shortages was an additional professional contextual factor I identified as impacting HIV/AIDS provider services. Providers in Lekas et al. (2012) reported not having the needed health specialists onsite to help clients receive the comprehensive care they required. The onsite provider shortage required providers to try their best to manage client health concerns, but it also prompted their provision of referrals to offsite agencies and providers. Similarly, the HIV/AIDS system I practiced in had developed a network of provider/organization referrals that supported the clinics efforts to help clients access the care they required. Consequently, when clients needed resources that we did not have in the office, we provided referrals to professionals/organizations. The established referral base, coupled with resource competent case managers, public health professionals, educators, and therapists made helping clients to acquire the services they needed easier. Thus, though we did not have all specialties on had to attend to client needs, the system that was in place allowed for the strategic support of clients through extended treatment

networks. Collaborating with HIV/AIDS clients in the management of their health and lifestyle helped me to understand on a very tangible level the importance of treatment networks in the health management of HIV/AIDS clients.

Client Treatment Factors

There were several client specific issues that I had to navigate as an HIV/AIDS provider. To practice effectively and sensitively, I had to acknowledge, come to understand, and learn how to address them. For example, client readiness was an important treatment issue that I had to attend to as a provider. I found client preparedness to engage in treatment could vary from one-time point to another. Transportation issues, depression, personal or relational crisis, conflicting appointments, substance relapse, complicated health issues, improved health, engagement in community projects, and employment, were typical factors that shaped client engagement. Similar challenges were identified by providers in Owczarzak et al. (2011) study. Schedule conflicts and crisis were identified as issues impacting client treatment retention. Providers reported revising programs and using incentives such as gifts, prizes, and food to improve the situation. However, the interventions were not enough to substantially improve engagement.

To improve client engagement, I explicitly addressed motivation and treatment readiness consistently with clients. Also, I supported clients in identifying discrepancies in their behavior, naming priorities, and attending to reoccurring crisis. The conversations had to happen frequently, were done in both one-on-one, and in group meetings and were not always easy.

The process required that I respect client positions, direct them to other clinic staff to acquire needed resources, and that I helped them to track their behavior overtime. Tracking client behavior allowed me to notice shifts in client engagement, and subsequently verbally acknowledge positive change. I was then able to adapt treatment to accommodate their growth.

An additional client factor that I navigated as a provider, was client health management. To help clients manage their health, I had to first identify their concerns, and then subsequently work to systemically treatment them. In doing so, I supported clients in naming and managing multiple, chronic, and often interrelated issues. Health, legal, economic, relationship, and identity (i.e. gender, race, sexual orientation, and disability) concerns were typical issues raised in treatment. Client health management is a documented practice issue navigated by HIV/AIDS providers. In Freedman et al. (2006) study, providers identified individual, community, and structural factors as important clinical issues to address when treating clients. They named skill building, networking, prevention interventions, and peer-led interventions as critical means to facilitating client change. Likewise, providers in Tripathi et al. (2013) and Myers et al. (2003) studies described an individual level intervention, education, as an appropriate means to help clients raise awareness about HIV/AIDS and risk behavior.

To adequately attend to client treatment needs, I coordinated care with other providers, I increased my understanding of physical illnesses, medications, disabilities, and structural inequality, worked persistently to create a safe and comfortable treatment environment, and encouraged client leadership. I conducted research to increase my awareness of a number of illnesses and treatments. By increasing my awareness, I was

able to better communicate with clients about their health, and was able to conduct comprehensive biopsychosocial assessments. I assessed client functioning at the start of treatment and briefly at each subsequent encounter. Ongoing assessments helped me to attend to the developmental needs of clients which allowed me to identify the level of care they required. This helped me to meet them where they were. The assessments also allowed me to update treatment practices while maintaining a client focused treatment culture, and helped me to empower clients to take on leadership roles with peers. Assessments are a documented strategy used by HIV/AIDS providers to successfully target and attend to client needs. In Myers et al. (2003) study, providers described individualized assessments as an appropriate means of understanding the needs of clients. Assessments were described as a strategy to acquire information on individual and contextual factors shaping client health.

Being both a therapist and educator allowed me to easily shift from one level of care to another based on client need. Yet, meeting clients where they were emotionally, physically, and cognitively often meant that I had to adapt or discard the evidenced-based educational curriculum I was advised to use. I shared discerning the appropriateness of daily treatment interventions with the providers I coordinated care with, but the choice between following program instructions or attending to client need was an ongoing tension. However, I typically chose to attend to client needs, weaving as much of the structured program into treatment that I could. Doing so helped me to remain in program compliance as much as possible.

Part of providing services required that I worked to create a safe and comfortable environment. I did so by aligning my practice with the specific needs of clients. This

meant that I coordinated the availability of client approved food for meetings, actively addressed relational issues (i.e. provider-client conflicts, client-client disagreements), promoted intimacy (i.e. authentic sharing, support), and maintained hope. An important part of creating a meaningful environment was making sure that the services I provided were client-centered.

My ability to attend to the treatment needs of clients extended beyond my awareness of their health concerns and delivery of appropriate levels of care, however. An additional client factor that I had to attend to as a provider was power. Power was an issue that shaped the patient-provider relationship and consequently the level of influence I had in treatment. I learned early that power could be extended from one provider to another or earned by nurturing relationships with clients. Though borrowed power is a relational intervention that makes the transition into practice easier for providers, it is used primarily to help clients adapt to staff changes. Initially, I was able to borrow power by allowing providers to introduce me and vouch for my work. Being endorsed resulted in the extension of trust between providers and myself, which made it easier to build relationships with clients. It is important to note that borrowed power is not something a provider asks for. It is bestowed from one provider to another, upon assessing competency and witnessing a common investment in client health. I borrowed power initially to begin to build relationships with clients and then began to use my own personality and skills to establish strong relationships. This meant that I initially allowed providers to introduce me and take the lead in interactions with clients. I provided supportive feedback, asked questions, and shared information about myself to build relationships. I was sensitive to the type of feedback I provided and my timing. I was also

very intentional about my level of personal disclosure. I learned that power could be earned quickly through disclosure of life hardships, especially if the challenges resonated with the experiences of clients. Though I understood substantive disclosure of life challenges would expedite my earning of credibility as a provider, I chose to minimally disclose. My decision was based on my professional socialization, values, and personal boundaries. I also understood however, that my life experiences may not have been aligned enough with my clients to be able to earn credibility that way. Consequently, I continued to earn power through consistent, thoughtful, informed, and respectful engagement with clients around their health.

Distrust, guard, and treatment hesitancy was another client factor that I had to address in treatment. I learned quickly that negative past treatment experiences informed how clients interacted with me. This meant that even though clients had consented to treatment, and were open to developing a relationship with me, that I had to be very honest, transparent, and collaborative in my work. I learned to disclose more frequently about my behavior and intentions to address client anxieties. This meant that I consistently assessed client need, explained my treatment intent, clarified as much as possible my behavior, and asked for permission to move forward as discussed. Instead of pathologizing the guard I encountered with clients, I normalized the situation and tried to create opportunities for them to share their experiences, ask questions, and influence treatment. Having been trained as an educator and therapist to respect client boundaries and meet them where they were, I was comfortable working with clients to navigate their treatment concerns. In addition, I believe having experienced discrimination and marginalization in health systems, helped me to engage sensitively with clients around

such issues. However, I found that sometimes even when I worked with the best intentions, that my actions and behaviors were still questioned. Consequently, I learned that my relationship with clients were not only shaped by what I said and did, but were also informed by the actions of other providers and clinic leadership. I had to work hard in such moments to not become defensive and authoritative, and tried to maintain a discussion that would permit the processing of issues. I learned that the best remedy to attend to client concerns in those moments was to listen, communicate openly and honestly, negotiate, and maintain a dialogue until resolution occurred. With time, good intentions, and compromise issues were typically resolved.

Normalcy was a particularly sensitive client factor that I addressed as a provider. While helping clients to attend to health and lifestyle concerns, I became increasingly conscious of the chronic stressors they navigated daily and the strategies they used to resolve them. I found that some of the behaviors clients had adopted to overcome adversity had become impediments to their growth. Consequently, I explored with clients the appropriateness of their “normal” or resilient behaviors in relationship to their new goals. In essence, I helped clients meet new goals by challenging old ways of surviving. In so doing, I listened intently and explored with clients their current behaviors in the context of past struggles and current goals. I worked with client to identify barriers to healing and supported them in exploring their ability to change. While working with clients in this way, I frequently critiqued my behavior and thoughts. I felt uneasy at times challenging practices of client strength, however, doing so appeared to be the right course of action to appropriately assist clients in reaching their goals. I was particularly sensitive about challenging “normal” resilient behaviors because I had grown up hearing about

them and witnessing people use them in the African American community. I believe my familiarity with such issues allowed me to acknowledge the utility of such practices while challenging their continued use.

Direct Practice Personal Factors

In addition to client, institutional, and contextual factors, there were also a number of personal professional dynamics that informed my work as a provider. One dynamic that I had to address was identifying how to use my experiences and training in an HIV/AIDS treatment system. Though I had experience as an educator, therapist, and evaluator, the system presented with unique organization and client issues that I had to learn to navigate. I approached my new roles intentionally and worked to create a working process that would help me to not only address HIV/AIDS client treatment issues, but also support organizational operations, and develop as an HIV/AIDS provider. Part of the process included my development of collaborative relationships. I developed relationships with clients, providers, and clinic administration that allowed for the co-construction of priorities and interventions. I learned to alternate between attending to client needs at the individual and group levels, and priorities at organization and patient levels. I was able to develop as a professional in these ways because I was very intentional in reflecting on my practice. Reflexivity also helped me to become conscious of the power dynamics in the treatment system, and my responses to them. I became increasingly sensitive to interactions between systems (i.e. client, clinic). My awareness grew due to having to navigate power binds between systems (for example, who extends an invitation to a group clients or clinic supervisor). I evaluated my behavior during

interaction with clients and clinic personnel and learned to better listen for needs, coordinate priorities, identify approaches to attend to needs, and accept feedback. This meant that I would listen intently for client concerns, pause to allow clients to present preference and frame issues, negotiate client priorities with institutional treatment expectations, collaborate with clients and other providers in identifying the best course of action, outline how providers and patients could jointly participate in reaching goals, and maintain an openness to receiving client feedback.

Part of attending to the needs of multiple systems required that I developed healthy boundaries. Identifying appropriate boundaries and then actually implementing them was one of the personal professional dynamics that I had to attend to as a provider. I felt the need to do so after witnessing and experiencing a few provider-organization challenges, and patient-provider conflicts. First, I began to observe providers, studying how they took directions, managed priorities, and self-disclosed. I found that providers differed substantially in how and what boundaries they set. Providers varied on issues such as how late to take work calls, how much personal information to disclose with clients, and how to manage multiple tasks. I engaged in ethical contemplation to explore my opinions on appropriate navigation of treatment binds. I reviewed my values, typical norms among therapists and educators, and standards among providers in the clinic. I then worked to set limits. Once I had mentally established boundaries, I found navigating relationship and priorities more manageable. One positive affect, was that I was better able to understand how my behavior shaped my interactions with clients. For example, minimal personal disclosure meant I had to work harder and longer to earn trust and build collaborative relationships. Yet, once a strong patient-provider relationship had been

built, it appeared to allow for complex and sensitive conversations. Boundaries also helped me to understand more how my clients impacted me. Overtime I found my commitment to delivering sensitive, informed, and effective care increased. My investment increased and I began to view my work as a form of advocacy and as my personal art.

Discussion

The National HIV/AIDS/AIDS Strategy for the United States: Updated to 20:20 is shifting how our community talks about and addresses the HIV/AIDS epidemic. At the core of the strategy, is a commitment to decrease the prevalence of HIV/AIDS across communities (i.e. ethnic, geographic, gender identity), ensure the availability and accessibility of high quality, life lengthening, and stigma and discrimination free treatment (National HIV/AIDS/AIDS Strategy: Updated 2020, 2015). While the strategy is focused on increasing access to care (i.e HIV/AIDS testing), making available quality care (i.e. full access to comprehensive pre-exposure prophylaxis), and funding treatment (i.e. Ryan White, and Affordable Care Act), more needs to be done to improve the systems of care treating HIV/AIDS clients (National HIV/AIDS/AIDS Strategy: Updated 2020, 2015). To improve the health outcomes of HIV/AIDS clients, it is important that the full spectrum of issues shaping HIV/AIDS treatment be adequately addressed. Doing so would require researchers and interventionist to continue to build upon the continuum of care framework to attend to provider, program, funding, and institution dynamics that shape HIV/AIDS treatment, and its related client outcomes.

In this work, performing an autoethnography allowed me to present a detailed personal account of the experiences I encountered while working in an HIV/AIDS treatment system. I identified several institutional, client, and provider related dynamics that shaped my professional decision-making. I demonstrated that even when I approached my work intentionally, that I had to navigate interacting contextual, relational, and personal issues. This meant that I had to manage multiple and often competing priorities, and negotiate treatment compliance among multiple stakeholders. Navigating these issues directly shaped the treatment I provided and the level of comfort I experienced as a provider.

Beyond providing a personal account of HIV/AIDS provider decision-making, this study increased awareness of some of the intricacies of HIV/AIDS delivery systems. The implications of this study are relevant for providers, administrators, researchers, and funders of HIV/AIDS treatment. Challenging service delivery conditions such as, poorly articulated or infeasible treatment guidelines, and limited resources, can create service challenges for providers. These issues may perpetuate service ambiguity and may require providers to cut corners to complete tasks, and rely on personal biases when making decisions. Consequently, clear and feasible priorities between funders, clinic administrators, and providers could improve the development and implementation of effective HIV/AIDS services. In addition, training on the HIV/AIDS infection, and client related treatment factors may help providers to be better prepared to connect and attend to needs of HIV/AIDS clients.

Additional research is needed to understand provider decision-making. Studies that increase understanding of the personal and contextual factors that shape provider

treatment decisions, identify training and service delivery strategies, and that inform of clinic best practices are needed. A combination of quantitative, qualitative, or mixed methods studies may be needed to develop a descriptive and comprehensive understanding of these issues. The findings of such research could be instrumental in improving provider trainings and facilitating the development of more effective and cost efficient systems of care. The outcome of which would most likely translate into improved HIV/AIDS client health outcomes.

Study Rigor, Limitations and Integrity

The available literature on HIV provider treatment practices makes it clear that how HIV services are delivered matters. As outlined in this study, there are a number of factors that shape how providers make treatment decisions and render care. Important issues such as provider HIV competency, resource availability, and treatment networks were among the issues identified in the literature and in this study as shaping provider treatment practices (Freedman, 2006, Tripathi et al. 2013, Myers et al. 2003. This study is timely, as the agenda for addressing HIV/AIDS has just been updated, and treatment and research strategies are shifting (National HIV/AIDS/AIDS Strategic Plan: Updated 2020, 2015). I believe this topic is an interesting and significant issue given the critical role providers play in shaping client treatment behavior and outcomes (Amed et al., 2009; Breitbart, et al., 1999; Mall, et al., 2012; van Ryan, 2002).

In this study, I engaged in reflexive processes to sensitively and ethical address my personal experiences working in an HIV/AIDS treatment system. In presenting the findings of this study, I was very intentional in the presentation of my

experiences, working to exclude identifiable information, being clear enough to communicate findings, but vague enough to maintain confidentiality. I used Finlay (2006) five criteria for evaluating qualitative research to develop this study. In so doing, I developed this work sensitive to the following: (a) clarity (b) credibility, (c) contribution, (d) communicative resonance, and (e) caring. More specifically, I made both my research process and findings clear by detailing the aim, methodology, findings, implications, and limitations of this study. I achieved credibility by clearly naming and presenting my findings, providing detailed examples, and linking when appropriate my personal findings to available literature. I make a contribution with this study, as I am increasing understanding of the treatment experiences of HIV/AIDS providers. As previously mentioned, the experiences of providers have been understudied and much is still unknown about the issues we navigate when rendering care. I contribute in this area by providing an insiders perspective about the types of issues that can arise in treatment. I presented the findings of this study as a narrative to try to achieve communicative resonance. By writing in an intimate, informed, and intentional way I hope that readers may connect to or learn from my written experiences. I demonstrated that I cared by studying my work to ensure my delivery of quality services. I intentionally explored my experiences as a provider in order to generate awareness of provider HIV treatment experiences. I focused on my personal experiences, in addition to the perspectives, and behaviors of the clients and providers I encountered, and or observed in an HIV treatment system. Consequently, the findings of this study represents my experiences in interaction with HIV clients, providers, and administrators in an HIV treatment context. In this way, I studied myself (auto), with others, as situated in an HIV context (ethnos), and was able

to develop an understanding of the world, from the position of interacting with participants (Spry, 2001). Finally, I also demonstrated caring in this work by being systemic in my descriptions of the impact of the aforementioned treatment issues on clients, clinic culture, and on provider functioning.

The use of autoethnography allowed for an intimate and honest account of my experience as a provider. In this study, I have made the case for making provider experiences an area of research, as more literature is needed to appropriately train providers, and adequately design and fund HIV/AIDS treatment systems. Though I shared my experiences, and tied my findings to the available literature of provider treatment experiences, I recognize this study does not capture the full spectrum of issues faced by providers, and that other providers might not face the same issues I have outlined. Yet, I am hopeful that by having contributed findings beyond what has previously been covered in provider studies that this work will help to increase the study of HIV/AIDS provider treatment experiences.

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CHAPTER SIX

IMPLICATIONS

Providers have a critical role in shaping the treatment retention and adherence behaviors of HIV clients. Given the influence that providers have on HIV treatment, it is important to understand the factors that shape our delivery of services. Though much research has been conducted on the HIV infection and treatment, little continues to be known about the experiences of HIV providers (CDC, 2014). More research is needed in this area to fully understand the range of factors shaping HIV treatment and its related health outcomes. Understanding HIV provider experiences is critical to understanding HIV treatment quality and effectiveness. This study increased awareness of factors shaping HIV provider decision-making.

The findings of this study demonstrated that institutional, client, contextual, and provider level factors can inform provider decision-making in HIV treatment systems. The practice implications of these findings are relevant for HIV treatment facilities and funders, providers, and researchers.

First, in this study I found that HIV treatment contexts can impact provider decision-making. The quality of clinic infrastructure, availability of treatment resources, and comprehensiveness of communication within HIV health systems can have a direct impact on how services are provided, what services are provided, and when they are provided. The struggle I encountered as a provider to complete service related tasks without clear and feasible direction, and without the resources needed to deliver quality care, illuminates the need for better coordination of HIV services. Improvements in this area would require more feasible and clear treatment guidelines and service expectations

between funders and programs. This would mean adequate funding to appropriately fund treatment, and the coordination of realistic and practical treatment objectives. Improved communication could translate into more practical service expectations between clinic administrators and providers. Consequently, while balancing roles and coordinating care, providers would spend less time addressing role conflicts and service related binds, and be able to focus more appropriately on delivering quality services.

In situations where funding challenges cannot be easily rectified at the agency level, it is critical that clinic leadership develop a clear vision and plan about how to navigate resource limitations and successfully communicate them to providers. The delivery of quality services requires good, timely, and comprehensive communication about service related expectations. Early and clear communication would permit providers to communicate about the feasibility of expectations and allow them to negotiate treatment course of action. In addition, development of a supportive treatment environment within treatment agencies can help providers to navigate service related binds. Such a system of support can buffer against provider related stress when addressing other institution related challenges.

Second, I found that contextual level issues can have an impact on provider professional practice. Increasing the availability of professional resources across treatment systems and within the professional literature can support providers in navigating clinical issues. Literature on HIV treatment best practices and provider decision-making can support providers in making clear and informed decisions, in what may sometimes feel like unclear treatment conditions. It could also provide providers with a language to communicate treatment issues with other professionals and clinic

administrators. Until substantive information is available on these issues in the literature, clinic level interventions could be of some support for providers. Brief agency assessments that identify the intellectual resource needs of providers may be a proactive means of attending to provider concerns. The completion of such assessments could be used to plan didactics or facilitate dialogue among professionals.

Third, being an HIV provider requires professionals to navigate client related treatment issues. Professionals working with HIV clients need to be prepared to collaborate with clients with multiple treatments needs and differing levels of treatment readiness. Building relationships with clients is an important requirement that sets the stage for need identification and treatment. Until providers have built meaningful relationships with clients, borrowing power from other providers may be an important means to being able to work effectively with clients in the short-term. This would require a trusted provider to help facilitate the treatment connection of new providers with existing clients. Doing so could help providers navigate client treatment hesitancy and mistrust. While this may require the use of additional resources and time upfront, it is may decrease the amount of resources used in the long-term.

In addition, while rendering care providers may need to identify how to strategically maintain culture, while also appropriately shifting culture. To build meaningful treatment relationships with long-term clients, providers can not immediately change contextual treatment norms. However, when such norms need to be updated, coordinating such changes with clinic administrators and clients is very important. This is also the case when helping clients to shed long standing behavioral coping strategies. While such institutional or individual behavioral strategies may have been helpful at one point in

time, it is important that administrators and clients make programmatic and behavioral changes that are in line with the developmental needs of clients. Consequently, challenging normal practices, and collaborating in the construction of a new normal may be an important issue to be addressed by HIV providers.

Finally, providers new to working in an HIV system may need to create a new treatment process. Providers may need to identify how to do the following: (a) use self, (b) set boundaries, (c) collaborate with clients and other providers, and (d) navigate functioning in multiple roles. Provider may find attending to these issues easy or complicated based on their past experiences. However, given the unique treatment needs of HIV clients providers may need to explore subtle treatment nuances that exist in HIV treatment setting and explore if practicing as normal is really appropriate. Engaging in reflexivity can be a critical means of exploring the congruence of treatment practices in the context of client needs and expectations. Doing so could verify the appropriateness of treatment approach, or could promote provider shifts in practice to better accommodate client treatment needs. Reflexivity can be a powerful means of self-evaluation for providers new to providing HIV services. It may help providers to learn how to effectively engage in treatment.

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APPENDIX A
LITERATURE THEMES

Treatment Dynamic: Institutional Factors	Descriptors Impact/Influence on my Professional Practice	Data Source
<p>Theme I: Multiple Roles (i.e. Provide more than one service)</p> <p>Theme II: Communication Collaboration/social support/mentors Limited Direction and support</p> <p>Theme III: Resources Limited Resources (i.e. time, funds, space, supplies, mental health)</p>	<p>Broaden provider: “skill, awareness, competence”</p> <p>Decrease isolation (feeling alone) and burn out; seek counseling, team approach, debriefing to cope, increase consciousness of effects of work. Provide emotional support, informational support, procedural support, guidance on program changes, allows for coordination around services</p> <p>Burnout, disconnect/lacking information and guidance, communication breakdown; interpret best practice to best of ability. Make best decision with mixed messages, develop personal criteria to decide (client looks, assessed risk, informing client and allowing to decide, operate from a business perspective, refer. Provider adaption- Evaluate fit of intervention (against population dynamics-access-behaviors(drugs)-transient population-pop can actually use), face a choice (abandon project or implement or modify it, don’t deliver), attend trainings to learn how to modify interventions, consult directors. Operate with flexibility when interacting with clients and other providers. Make best decision, and deal with ambiguity). Decision based on fit, experiences/values/ and relevant treatment related dynamics (population, resources)</p>	<p>DS#2</p> <p>DS#2; DS#3; DS#1:DS#9</p> <p>DS#2; DS#1; DS#4; DS#12</p> <p>DS#1; DS#2; DS#4; DS#12</p> <p>DS#1; DS#2; DS#4, DS#6</p>

services, providers, payment)	Evaluate resources, prioritize services, adapt service implementation, investigate what fits and what works, shifts priorities, cut back on innovation/new programming, more frequent and longer appointments, closely monitor client health, make self more available, leave job, experience burden/out.	
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Treatment Dynamic: Professional-Contextual Factors	Descriptors Impact/Influence on my Professional Practice	Data Source
<p>Theme I: Limited Resources (literature/lack of consensus/ambiguity/lack of clarity; specialty services; service guidelines)</p> <p>Theme II: Limited Intra-organization Collaboration Other professionals refusing to accept client referrals</p>	<p>Skepticism about treatment recommendations; Work through with limited clarity; Feel way through Consult (physician); Collaborate in service delivery; Monitor clients; Carefully consider options;</p> <p>Get providers in house</p>	<p>DS#4</p> <p>DS#4</p>

Treatment Dynamic: Client Treatment Factors	Descriptors Impact/Influence on my Professional Practice	Data Source

Theme I: Client Distrust, Guard, and Treatment Hesitancy	Recognize limitations, create incentives (small gifts, food and beverages). Create a system to track (certificate of participation instead of completion)	DS#1
Theme II: Multiple Treatment Needs and Concerns (side effects / treatment concerns, denial, resistant, mental, emotional, economic; physical, social)	Help client manage, educate clients, help them make treatment decisions, provide, referrals and help them get needed resources, assess mental health and social needs. Attend to all needs; Empower clients; provide correct education (offer trainings HIV, educate during session on health specific issue/treatment; prevention); Help clients process how to apply information and provided recommendations; Conduct testing; Establish boundaries (mixed sometimes cross to provide level of care but balanced for burn out); Distance emotionally	DS#4; DS#5; DS#11; DS#6; DS#7; DS#8; DS#9
Client Awareness	Clients not informed on health concerns; increase client awareness, help client make treatment Decision	DS#4

Treatment Dynamic: Direct Practice factors	Descriptors Impact/Influence on my Professional Practice	Data Source
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<p>Theme I: Reflexivity and Awareness Informed Action</p>	<p>Assess hesitancy to perform screening; Identify areas of confidence/competency and insecurity; understand scope of practice; Fear of harming client; Refer client: Engage other professionals; Use experience to guide decisions</p>	<p>DS#10; DS#8</p>
<p>Theme II: Coping</p>	<p>Sense of responsibility to client, Increased emotional investment, promote greater investment when connected/can relate/ have history with clients. Little investment (when little information is not known). Emotionally/psychologically stressed about client issues. Limit clients seen, take issues home, promotes personal reflection and appreciation. Employ coping mechanisms, “coated armour,” go through phases (shut down as means of self care), shut off part of self, depersonalize, eat, go home, self care, humor.</p>	<p>DS#7; DS#3; DS#2</p>

APPENDIX B

ARCHIVED DATA THEMES

Treatment Dynamic (Institutional Factors)	Descriptors Impact/Influence on my Professional Practice
<p>Theme I: Balancing</p> <p>Theme II: Communication</p> <p>Poorly Communicated Expectations (Treatment Protocols, Service Related Expectations)</p> <p>Clear Communication and Treatment Expectations</p> <p>Theme III: Resource Limitations (i.e. time, structural issues such as air conditioning and water)</p> <p>Theme IV: Professional Community</p>	<p>Mange pressure and stress of having multiple roles, time limitations, rendering quality client care, and adherence to clinic policies</p> <p>Operate with flexibility, create creative solutions, strategies issues course of action based on experience, prioritizing, addressing service delivery program operating binds, manage stress, time, and client and organization need. Communicate issue to leadership, collaborate in addressing structural issues, improvise, seek additional support, communicate boundaries, understand personal limitations</p> <p>Debrief, share professional experiences (process, negotiate, revise practice), review best practices, receive guidance and support</p> <p>Adapt service delivery and communicate practice limits to clients/organization. Hold tension of opposing demands/values, rank priority based on best practice, engage based on need ad priority, draw on personal skill and resources to decide best practice, operate with flexibility and confidence, seek guidance when appropriate.</p> <p>Accepted into network, collaborate in the coordination and delivery of care, offer support, share experience.</p>
Treatment Dynamic: Professional-Contextual Factors	Descriptors Impact/Influence on my Professional Practice

Theme I: Limited Provider Testimony -	Seek out available resources literature. Promote reflection and observation to attend to biases, blind spots, discomfort. Explore such issues in the context of my identities and experiences. Commit to a professional practice that is sensitive to identity, stigma, and health
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Treatment Dynamic: Client Treatment Factors	Descriptors Impact/Influence on my Professional Practice
<p>Theme I: Client Readiness</p> <p>Theme II: Multiple treatment needs and concerns (crisis management, health management, economic strain, relational concerns, chronic health issues)</p> <p>Assessment and Engagement</p> <p>Theme III: Borrowed Power</p>	<p>Attend to client treatment consistency, assess client treatment readiness and meet where they are attending to persistent crisis, address group dynamics/values about treatment, engagement, and wellness. Follow up with client/group and encourage to return. Look at discrepancies in language and treatment engagement, engage more meaningfully as client readiness increases, notice client growth and punctuate, recommend opportunities for leadership. Respect, track, and attend appropriately to progressive level of client disclosure and engagement. Notice client sensitivity verbally/non verbally</p> <p>Meet client where they are daily, assess resources and need, accommodate presenting treatment needs while trying to promote movement away from crisis, commit time and energy, make conscious decisions based on client presentation, work through stuckness, confrontation, low motivation. Prioritize treatment based on client need, development, resources, ability, allow myself to be influenced and try to influence client.</p> <p>Assess client motivation, identify range of client concerns (i.e. health, legal, relational, economic), attend quickly to need. Understand and attend to layered issues and trauma, explore issues in context, attend to spectrum of substance abuse, and mental and physical health issues. Identify behavioral patterns and weave together issues/experiences. Storytelling (pulling client histories). Assess for resources, energy, stuckness, willingness to confront.</p>

Treatment Dynamic: Direct Practice Factors	Descriptors Impact/Influence on my Professional Practice
<p>Theme III: Creating a Working Process</p> <p>Reflexivity/Shifting</p> <p>Boundaries</p> <p>Ethical Contemplation</p>	<p>Collaborate with client (i.e. co-create goals, incorporate client feedback, allow dialogue to evolve as appropriate with client developed), read emotional energy in room and attend to it, Pause and assess appropriateness of my engagement (i.e. do I understand the issues, where is the client/group emotionally/cognitively, what is in the best interest of the individual and group, what would be a good entry point), integration of changes early, build upon change and new goals; challenge patterns (resiliency), strategize use of power, promote shifting power among all group members, increase personal awareness of HIV, promote sharing and connectedness, connect themes. Create opportunities for client to confront, to feel. Allowing/promote witnessing (disclosure and support). Assess client need, evaluate need in context of agency service expectations, explore appropriateness of evidenced based intervention, create care plans and back up plans to attend to treatment dynamics</p> <p>Evaluate my behavior in relationship to client response, identify potential course of action, assess for alternative solutions, evaluate values informing my behavior. Explore feedback provided by clients and colleagues. Shift attention from focus on client, focus on me, focus on client and I. Identify when shifts in focus occur. Exploration of use of power.</p> <p>Explore provider boundary differences, accept outsider status and earn trust slowly, navigate sharing in context of professional norms, personal values, contextual/relational expectations. Notice respect client boundaries (trust/distrust), name boundaries by highlighting behaviors/ language, ask questions, assess interests. Navigate client extended power with institutional level power, acknowledge errors, attend to power related binds.</p> <p>Identify binds, communicate issues, don't do something I am not comfortable with. Explore discomfort and</p>

	<p>issues in context of identity and training. Value of social justice rubric for professional action.</p>
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