

A MIXED METHODS STUDY OF PERCEIVED SOCIAL SUPPORT
BASED ON THE MEDICAL OUTCOMES STUDY
SOCIAL SUPPORT SURVEY IN ADULTS WITH REPEATED CHALLENGES
WITH HIV MEDICATION ADHERENCE

A Dissertation
presented to
the Faculty of the Graduate School
at the University of Missouri-Columbia

In Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy

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DECEMBER 2016

The undersigned, appointed by the dean of the Graduate School, have examined the dissertation entitled

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ACKNOWLEDGEMENTS

My journey to completion of this dissertation has been many things---challenging, exhilarating, sometimes frustrating, at times lonely, and certainly a test of my perseverance. It was accomplished with the support of amazing people in my life, both personally and professionally.

To Maithe Enriquez, my dissertation chair, who possesses not only clinical and research expertise, but also the qualities of a true mentor...patience and wisdom. She never gave up on me even in my darkest moments when I wanted to walk away and quit. She was always there when I needed her and knew exactly what to say to calm me down, make me feel better and get back on track.

To my husband, Jim Mercier, for his love, support, patience, and assistance with holding our world together so I could see this dissertation through to completion. To my adult children, Sarah and Brian, for their love, support, and encouragement that was so needed along the way. It is difficult for me to express the emotions I feel about the sacrifices my family has endured during my dissertation journey. I could not have done this without them in my corner.

I am also grateful for the assistance of my committee members. A special thanks to Dr. Michelle Teti, whose inspirational words at last year's APHA conference helped me focus and move forward with my dissertation work. To Dr. An-Lin Cheng for her guidance and mentorship with my quantitative work and Dr. Todd Rupp for his unwavering support from the beginning of my doctoral journey.

I would like to acknowledge and thank the Sinclair School of Nursing faculty and staff for their significant contribution to my doctoral education. To Dr. Diedre Wipke-

Tevis for her vision and leadership of the PhD program, Dr. Vicki Conn for her knowledge and guidance during my doctoral coursework and comprehensive exam, and Dr. Lori Popejoy for her mentorship during my qualitative practicum.

To my classmates, those inspirational individuals, who participated in the experience of completing requirements for this doctorate degree. The memories of our intellectual discussions, sharing of knowledge, frustrations, excitement, and especially our time together at The Gathering Place during on campus intensive weeks will last a lifetime. To my nursing and public health colleagues who supported me in many ways throughout this journey. Your words of inspiration kept me going when I wanted to give up and for that I will be forever grateful.

Finally, and especially to my mom, Anne Leachman, and my other parents who are no longer with us, for giving me the necessary skills early in life to be able to succeed, to be a productive, hardworking wife, mother and professional, and to value what is most important in my life.....family.

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ABSTRACT

Numerous research studies in the HIV literature have documented social support as a key factor influencing adherence to antiretroviral therapy (ART). This is one of only a few studies to examine perceived social support among adults living with HIV who have had repeated challenges with medication adherence. A secondary analysis of quantitative and qualitative data from two intervention studies was conducted using a mixed methods design. Two overarching themes were associated with the lack of social support: extreme isolation and constant turmoil. Subthemes, included loneliness, structural vulnerability, and emotional distress. Overall social support was low in this vulnerable group, especially when compared to the general population and to adults living with other chronic health conditions. Strong correlations existed between all social support subscales of the Medical Outcomes Study Social Support Survey (MOS-SSS). The strongest positive correlation was found between affectionate support and positive social interaction ($r = .870, p = < .0001$). These data suggest that participants who frequently self-reported a lack of persons to spend time with socially often lacked positive, supportive relationships in their lives. No significant variation was found between self-reported overall social support or subscale scores based on age or health variables. Convergent qualitative data excerpts corresponded with low quantitative social support scores in every dimension, confirming that adults living with HIV who repeatedly struggle with taking life-long HIV medications lack social support in many areas of their lives.

CHAPTER 1

Introduction

The problem of medication adherence remains a common topic in medical, nursing, and public health literature (Conn, Ruppap, Enriquez, & Cooper, 2015) as is the importance of social support to individuals' health and well-being (McColl, Rideout, Parmar, & Abba-Aji, 2014; Uchino, Cacioppo, & Kiecolt-Glaser, 1996). Although social support has been shown to affect medication adherence in general populations (DiMatteo, 2004; Scheurer, Choudhry, Swanton, Matlin, & Shrank, 2012), work remains to improve social support interventions that improve medication adherence (Ruppap, Delgado, & Temple, 2015). Within the HIV population, the literature contains numerous adherence studies with a social support component (Edwards, 2006; Gardenier, Andrews, Thomas, Bookhardt-Murray, & Fitzpatrick, 2010; Gonzalez et al., 2004; Gray, Muiruri, Gould, Knight, & Flynn, 2014; Huynh, Kinsler, Cunningham, & Sayles, 2013; Lehavot et al., 2011; Simoni, Frick, & Huang, 2006; Woodward & Pantalone, 2012). However, only one published study reported the relationships of specific social support dimensions [measured by the Medical Outcomes Study Social Support Survey (MOS-SSS)] and their relationships to HIV medication adherence. This study was completed with a treatment naive population (Kelly, Hartman, Graham, Kallen, & Giordano, 2014). Few published medication adherence studies appear in the literature with patients who have experienced repeated challenges with adhering to HIV medication and no studies offer this population's perspective of social support as it relates to medication adherence. This mixed methodology study helps fill such gaps in the literature through use of the social support dimensions within the MOS Social Support Survey, theoretical underpinnings

from Stress-Buffering Theory and House's Conceptualization of Social Support as a conceptual framework. This study's results will inform interventions to improve HIV medication adherence in adults with repeated adherence challenges.

Background of the Problem

Numerous intervention studies have sought to improve medication adherence across multiple disease states (Conn et al., 2009; Conn et al., 2015; Haynes, Ackloo, Sahota, McDonald, & Yao, 2008; Peterson, Takiya, & Finley, 2003; Ruanjahn, Roberts, & Monterosso, 2010; Ruppap, Conn, & Russell, 2008; Viswanathan et al., 2012). Literature in the past decade contains medication adherence studies focused on antiretroviral therapy (ART) in adults living with HIV (Attonito, Dévieux, Lerner, Hospital, & Rosenberg, 2014; Chandwani et al., 2012; Davis, Thornton, Oslin, & Zanjani, 2014; Enriquez et al., 2015; Fogarty et al., 2002; Genberg et al., 2016; Ruanjahn et al., 2010; Simoni, Pearson, Pantalone, Marks, & Crepaz, 2006). An estimated 23% of all HIV drug resistance occurs in the top quintile of adherence (92-100%), and over 50% of adults experiencing resistance to their HIV medications fall within the top two quintiles of HIV medication adherence (79-100%) (Bangsberg, 2006). A landmark HIV prevention study recently concluded that virologic suppression associated with ART reduced rates of sexual transmission of HIV-1 by 96%, indicating both personal and public health benefits from adherence to HIV treatment (M. S. Cohen, McCauley, & Gamble, 2012).

The literature is replete with studies reporting the positive association between social support and HIV medication adherence (Edwards, 2006; Gonzalez et al., 2004; Kelly et al., 2014; Ncama et al., 2008; Qiao, Li, & Stanton, 2014; Rungruangsiripan,

Sitthimongkol, Maneesriwongul, Talley, & Vorapongsathorn, 2011; Simoni, Frick, et al., 2006; Takada et al., 2014; Woodward & Pantalone, 2012). As an important determinant of health, the role of social support in adults living with HIV has been studied across the domains of mental health functioning, neurocognitive functioning, physical function and employment (Hergenrather, Zeglin, Conyers, Misrok, & Rhodes, 2016).

Medication adherence studies with the HIV population often contain a social support component (Edwards, 2006; Gardenier et al., 2010; Gonzalez et al., 2004; Gray et al., 2014; Huynh et al., 2013; Lehavot et al., 2011; Simoni, Frick, et al., 2006; Woodward & Pantalone, 2012). However, only one published study reported the relationships of specific social support dimensions (measured by the MOS-SSS) and their relationships to HIV medication adherence. That study was completed with a treatment naive population (Kelly et al., 2014).

In adults living with HIV, optimal adherence to HIV medication is essential to maintaining good health. ART reduces morbidity and mortality and slows HIV disease progression by suppressing viral replication (Cohen et al., 2011; Rayment, 2012). Optimal adherence is significant to public health because it can reduce the risk of HIV transmission (AIDS.gov, 2015; Cohen et al., 2011; DHHS, 2011; Jain, Maulsby, Kinsky, Charles, & Holtgrave, 2016). However, despite the past quarter century's advances in ART, adherence remains a problem in the fight against HIV (Rivera, Madera, Díaz, & Pacheco, 2013). Studies of adults living with HIV have demonstrated that only 55-65% of patients have high levels of adherence to HIV medication (Mills et al., 2006; Ortego et al., 2011). These findings are significant because poor adherence to ART strongly predicts disease progression (Bangsberg, 2006).

Study Purpose and Specific Aim

A growing consensus favors the idea that increased social support is often a protective factor in coping with challenges imposed by HIV, including medication adherence (Rivera et al., 2013). Many studies have documented that among numerous factors influencing adherence to HIV medication, psychosocial factors such as social support are among the most important (Benoit, 2015; Garcia et al., 2015; Mills et al., 2006; Rao et al., 2012; Simoni, Frick, et al., 2006; Simoni, Pearson, et al., 2006; Vyavaharkar, Moneyham, Murdaugh, & Tavakoli, 2012).

This study's two-fold purpose was 1) to better understand how adults living with HIV who have experienced repeated challenges with HIV medication adherence describe perceived social support in relationship to medication adherence and 2) to determine whether self-reported total social support or the dimensions of social support described by the MOS-SSS varied by demographic and health variables (i.e. age, gender, race/ethnicity, education, length of time living with HIV, and number of previous HIV medication regimens). The following specific aims were achieved:

- Exploration and description of perceived social support in a sample of adults living with HIV who had experienced repeated challenges taking HIV medications;
- Identification of correlates among adults living with HIV who had experienced repeated challenges with HIV medication adherence related to the MOS-SSS dimensions of social support (emotional/informational, tangible, affectionate, and positive social interaction) and demographic and health

variables (i.e. age, gender, race/ethnicity, education, length of time living with HIV, and number of previous HIV medication regimens);

- Convergence of results from the qualitative data analysis and the quantitative data analysis to better understand perceived social support in relationship to HIV medication adherence.

Significance of the Proposed Study

Although HIV has become a chronic disease, it remains a public health concern (AIDS.gov, 2015; WHO, 2016). Medication adherence is a common area of inquiry because poor adherence to ART has been linked to disease transmission, disease progression, and increased mortality and morbidity (AIDS.gov, 2015; DHHS, 2011; Genberg et al., 2016; Jain et al., 2016). Developing effective, practical, and cost-effective interventions to increase medication adherence in adults living with HIV remains a priority (Enriquez et al., 2015). One study published to date that has examined the particular dimensions of the MOS-SSS and their impact on HIV medication adherence (Kelly et al., 2014). This study sample consisted of treatment naive, newly diagnosed patients with social support as a predictor of success through the cascade of HIV care (Kelly et al., 2014). Kelly et al. (2014) found that increased social support, tangible social support, in particular, and affectional support to lesser degree predicted high adherence to ART. The authors concluded that further research assessing the dimensions of perceived social support would contribute to an improved understanding how certain dimensions of social support play a role in optimizing HIV medication adherence. This dissertation study provides further insight for investigators when

developing HIV and/or medication adherence interventions for other chronic illnesses as well.

Although medication adherence interventions have been shown to improve medication-taking behaviors in some populations with adherence challenges (Conn et al., 2015), very little data exists regarding adherence in adults living with HIV who have had repeated challenges with medication adherence (Enriquez et al., 2015). Conn et al. (2015) discussed the importance of recruiting intervention study subjects who have had medication adherence challenges to better understand how interventions may help increase adherence scores and improve health outcomes. However, recruiting adults living with HIV who have had repeated challenges with medication adherence to clinical trials is difficult not only due to socioeconomic issues but also to stigma associated with HIV (Enriquez & Cheng, 2016). The only published study regarding social support and adherence in a population of adults living with HIV who had challenges to medication adherence found no change in adherence when providing patients with HIV-treatment specific support (Taylor, Neilands, Dilworth, & Johnson, 2010). The study measured *received* social support as a predictor of medication adherence rather than measuring *perceived* social support (Taylor et al., 2010).

Knowledge gained from this dissertation study adds to the literature informing researchers and providers how to improve health outcomes in this understudied, vulnerable population. This study informs future cost-effective intervention studies to improve HIV medication adherence. It does so by elucidating the patient perspective of specific dimensions of perceived social support and by analyzing empirical data on relationships among social support dimensions based on the MOS-SSS and selected

demographic and health variables. This study also provides information to improve current and future adherence interventions with this challenging, vulnerable patient population. The research questions addressed, using a mixture of quantitative and qualitative methods, were:

Research Questions

Research Question 1 (Qualitative): What is the role of perceived social support in adults living with HIV who have experienced repeated challenges with medication adherence?

Research Question 2 (Quantitative): How do adults living with HIV who have experienced repeated medication adherence challenges self-report total social support and social support within specific dimensions as measured by the MOS-SSS (emotional/informational, tangible, affectionate, and positive social interaction)?

Research Question 3 (Quantitative): Does the self-reported total social support score and/or social support score within specific dimensions as measured by the MOS-SSS (emotional/informational, tangible, affectionate, and positive social interaction) vary based on sociodemographic and health variables (i.e. age, gender, race/ethnicity, education, length of time living with HIV, or number of previous HIV medication regimens) in adults living with HIV who have experienced repeated medication adherence challenges?

Research Question 4 (Mixed Methods): What is the relationship between self-reported total social support, social support within the specific dimensions of the MOS-SSS and the perceptions of perceived social support in relationship in adults living with HIV who have experienced repeated medication adherence challenges?

Assumptions

Prior to this study, no clear evidence showed which type of social support adults living with HIV who have experienced repeated challenges with medication adherence perceived to be most helpful, needed, available, or lacking in their lives. It was also unclear whether certain dimensions of social support within the MOS-SSS were perceived as higher or lower in this vulnerable population based on demographic or health variables. This study is significant because it provides answers to these questions.

The literature supports the assumption that demographic and health variables affect HIV medication adherence (Kelly et al., 2014). Several researchers have assumed that certain demographic and health variables may also influence social support, which has been reported to be a predictor of HIV medication adherence (Edwards, 2006; Huynh et al., 2013; Mills et al., 2006; Simoni, Frick, et al., 2006; Simoni, Frick, Lockhart, & Liebovitz, 2002; Simoni, Pantalone, Plummer, & Huang, 2007; Vyavaharkar et al., 2012).

Limitations

This study is a secondary analysis of existing data from two non-publicly available datasets from medication adherence intervention studies. Qualitative data for this secondary analysis were from field notes written by peer interventionists in the parent studies (Enriquez & Cheng, 2016; Enriquez et al., 2015). Field note data are not as reliable nor valid as audio or video-taped data. Peer interventionists took field notes about what the participants said during the study visits and it is conceivable that pertinent information could have been lost in translation from participant to interventionist when writing field notes (Enriquez & Cheng, 2016; Enriquez et al., 2015). The quantitative

data from the parent studies (MOS-SSS data) was self-reported patient data and thus may have introduced threats to validity.

The data from the parent studies for this secondary analysis was collected from a population of adults living with HIV in the Midwest near a metropolitan area. The sample included only adults who had experienced repeated challenges with HIV medication adherence. As such, the generalizability of the results of this study is limited to similar populations experiencing repeated challenges to medication adherence.

Delimitations

This study analyzed data from the MOS-SSS, which measures *perceived*, functional social support. Therefore, the study did not focus on *structural* social support. The study did not include research questions designed to better understand or test *received* social support, an important concept for future measurement.

Operational Definitions and Terminology

The following definitions provided uniformity and understanding of terms throughout the study:

Age: Measured in parent studies on demographic survey as a categorical variable with six age categories (Enriquez & Cheng, 2016; Enriquez et al., 2015).

CD4+ cell count: Used in parent studies as a proxy for HIV medication adherence (Enriquez & Cheng, 2016; Enriquez et al., 2015). Measures the number of CD4+ T lymphocytes in blood. It is the most important laboratory indicator of how well the immune system is working and the strongest predictor of HIV progression (Bangsberg, 2006).

Education: Measured in parent studies on demographic survey as a categorical variable with “did not finish high school”, “high school graduate/GED”, “some college”, or “college graduate as choices” (Enriquez & Cheng, 2016; Enriquez et al., 2015).

Ethnicity/Race: Measured in parent studies on demographic survey as a categorical variable with six age categories including “Other” (Enriquez & Cheng, 2016; Enriquez et al., 2015).

Functional social support: Emotional, informational, or practical assistance from significant others, such as family members, friends, or coworkers. Support may be received from others or perceived to be available when needed (Thoits, 1986).

Gender: Measured in parent studies on demographic survey as a categorical variable with “male”, “female”, or “transgender” as choices (Enriquez & Cheng, 2016; Enriquez et al., 2015).

HIV-1 RNA by PCR: Used in parent studies as a proxy for HIV medication adherence (Enriquez & Cheng, 2016; Enriquez et al., 2015). Viral load assessment tracks progression of the infection and is the most important indicator of antiretroviral treatment response. In the parent studies, a viral load of < 200 copies/mL was used as the cutoff point for viral load suppression based on the U.S. Department of Health and Human Resources HIV/AIDS Bureau Performance Measures for HIV viral load suppression (Valdiserri, Forsyth, Yakovchenko, & Koh, 2013). High levels of medication adherence are directly correlated with the suppression of HIV viral load (Bangsberg, 2006).

MOS-SSS Dimensions of Social Support: Medical Outcomes Study Social Support Survey (Sherbourne & Stewart, 1991).

Emotional/Informational Support: the expression of positive affect, empathetic understanding, the encouragement of expressions of feelings, the offering of advice, information, guidance, or feedback;

Tangible Support: the provision of material aid or behavioral assistance;

Affectionate Support: involving expressions of love and affection;

Positive Social Interaction: the availability of other persons to do fun things with you (Sherbourne & Stewart, 1991).

Perceived social support: A recipient's subjective judgment that providers will offer (or have offered) effective help during times of need (Haber, Cohen, Lucas, & Baltes, 2007).

Previous HIV medication regimens: Measured in parent studies on demographic survey as a discrete variable. Mean number for study participants in parent studies was three previous regimens (Enriquez & Cheng, 2016; Enriquez et al., 2015).

Received social support: Specific supportive behaviors offered during times of need (Haber et al., 2007).

Repeated challenges with HIV medication adherence: Inclusion criteria in parent studies was documentation of nonadherence to ART in the medical record. The mean number of previous regimens for study participants in parent studies was three (Enriquez & Cheng, 2016; Enriquez et al., 2015).

Structural social support: Social integration, social isolation, and social network characteristics. Structural support is the size of the social network available, while functional support, mentioned above, refers to certain types of support the network can provide (Garcia et al., 2015).

Years living with HIV: Measured in parent studies on demographic survey as a discrete variable (Enriquez & Cheng, 2016; Enriquez et al., 2015).

Theoretical Framework of the Study

Stress Buffering Model

The Stress Buffering Model often has been used to describe relationships between social support functions and health outcomes (Cohen & Wills, 1985). According to the model, social support is only needed when stress is apparent because it protects against the damaging effects of stress (Aronson, Wilson, & Akert, 2007). It does so by helping with coping and with interpreting events as less stressful than otherwise thought (Aronson et al., 2007). Research has suggested that social support “buffers” the impact of stress on the individual and thus indirectly affects emotional well-being (Cohen & Wills, 1985).

According to the model, social support acts also buffers against the deleterious effects of stress on physical health (Cohen & Wills, 1985). The buffering hypothesis predicted that social support is beneficial during stressful times, such as during a chronic illness including HIV. Cohen & Wills (1985) write that a correlation exists between stressful events and poor health, noting in that the long-term effect of stress is weaker for people with high social support than for people with low social support.

Stress buffering has been used as a theoretical base in several studies of HIV medication adherence (DiMatteo, 2004; Lehavot et al., 2011) including the theoretical work and further conceptualization of social support by Dr. James House and colleagues in the mid-to-late 1980s (House, 1987; House, Kahn, McLeod, & Williams, 1985; House, Landis, & Umberson, 1988; House, Umberson, & Landis, 1988). The model best describes the relationship between perceived rather than received social support, such as that which is measured by the MOS-SSS (Sherbourne & Stewart, 1991) and is the basis for the study of the dimensions of social support in the proposed study.

House's Conceptualization of Social Support

The MOS-SSS (Sherbourne & Stewart, 1991) was developed using available data on social support measurement, with emphasis on the function aspects of support (Cohen & Syme, 1985; Cohen & Wills, 1985; House et al., 1985). Before the MOS-SSS was developed, the first major prospective study on social relationships and mortality was completed. The study examined four types of social relationships and found that intimate ties of marriage and contacts with family/friends were stronger predictors of mortality rates than were other community memberships (Berkman & Syme, 1979). House et al. (1985) replicated and extended this work and through several studies with colleagues (House, 1987; House et al., 1985; House, Landis, et al., 1988) suggested that social relationships were consequential for health (House, Umberson, et al., 1988).

House, Umberson, et al. (1988) reported that conceptual definitions of terms such as social support, social networks, social integration, and social relationships were being used interchangeably in the literature. The authors drew distinctions among the concepts to delineate which aspects of social support, what kind of affects, and under what

conditions social support affects health. They differentiated three interrelated classes or variables of social support (House, Umberson, et al., 1988):

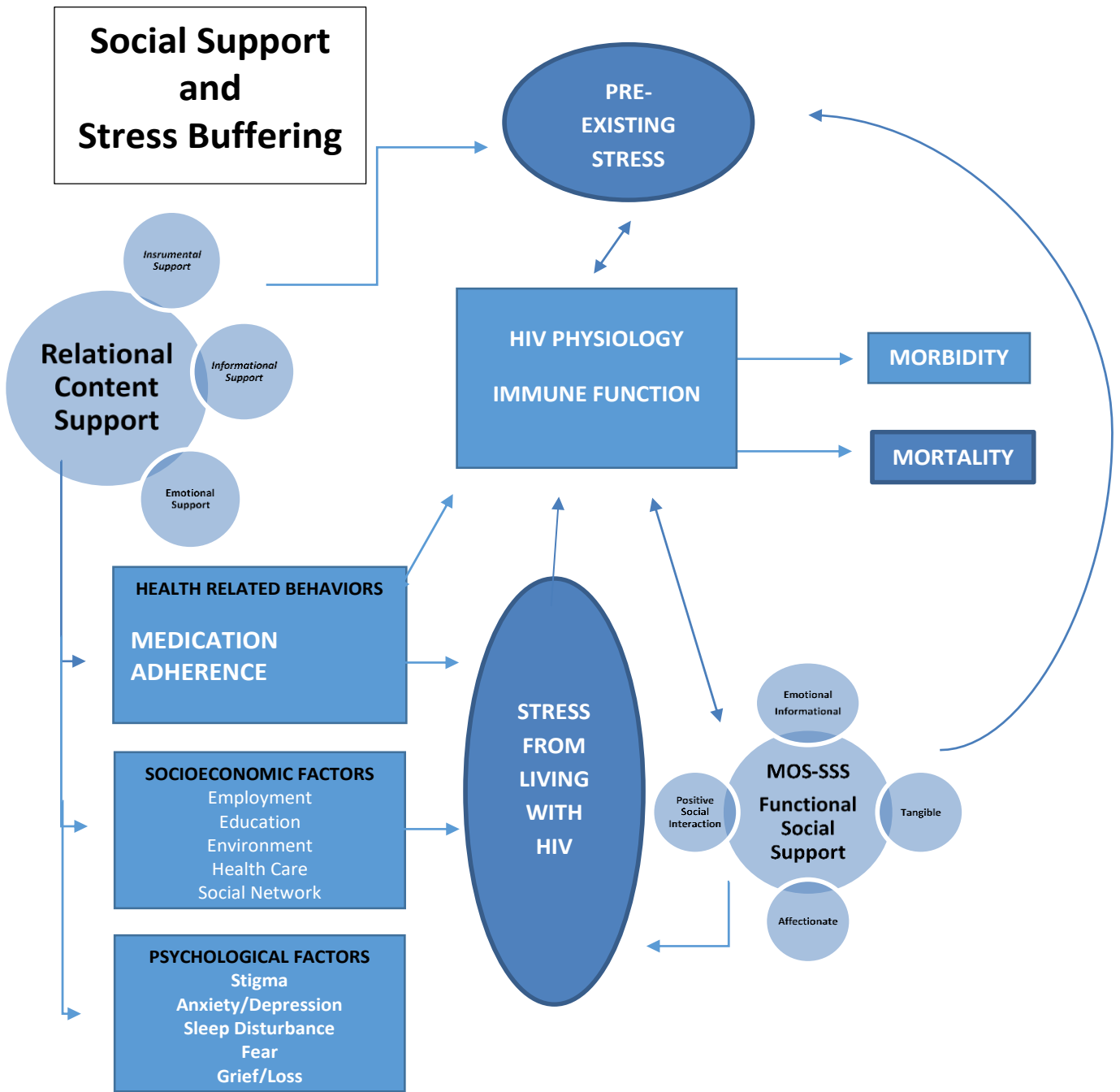
- *Social integration/isolation* refers to the existence or quantity of social ties or relationships, which may in turn be distinguished by type and frequency of contact. It does not speak to the relationships' structure or functional content;
- *Social network structure* refers to the structure characterizing a set of relationships, such as between two people or between a person and a network of people;
- *Relational content* refers to the functional nature of social support, which may be distinguished in terms of the source. This refers to the positive, potentially health promoting or stress-buffering aspects of relationships, including instrumental aid, emotional caring or concern, and giving of information (House, Umberson, et al., 1988).

Sherbourne and Stewart (1991) used information from the third area of social support, *relational content*, to design of the MOS-SSS. The selection of the pool of items was guided by this strong *a priori* conceptual underpinning that Dr. House and his colleagues proposed (House, 1987; House et al., 1985; House, Landis, et al., 1988; House, Umberson, et al., 1988). The focus of the MOS-SSS on perceived availability of functional support was therefore based on House's Conceptualization of Social Support (House, Umberson, et al., 1988). Reliability scores for the MOS-SSS have been documented in the HIV literature (Mak et al., 2007). The four MOS-SSS subscales (emotional/informational, tangible, affectionate, and positive social interaction) achieved

satisfactory to excellent internal consistencies with Cronbach's alphas of 0.88, 0.74, 0.90 and 0.94, respectively.

This study's theoretical base comes from Cohen and Wills (1985) stress buffering effect model based on House's Conceptualization of Social Support. The model applied House's original theoretical social support components (House et al., 1985; House, Umberson, et al., 1988) as a buffer to the stress of living with HIV (Cohen, Mermelstein, Kamarck, & Hoberman, 1985; Cohen & Wills, 1985). The model (Figure 1) proposed that in the presence of ongoing socioeconomic and psychological stressors, functional social support buffers the stress of health related behavioral issues such as repeated challenges with medication adherence. This, in turn, has the potential to affect HIV disease progression in the form of immune function and eventually morbidity and mortality.

Figure 1. Social Support and Stress Buffering in HIV



CHAPTER 2

Review of the Literature

The purpose of Chapter 2 was to review the literature concerning social support and medication adherence regarding these topics of interest: Social Support and Health, Social Support and Medication Adherence in Chronic Disease, Social Support in HIV Medication Adherence, MOS-SSS as Measurement of Social Support in HIV Medication Adherence.

Social Support and Health

Social support has been identified as a social determinant of health (Braveman, Egerter, & Williams, 2011; DHHS, 2011) and studied across multiple disciplines. Greater social support has been shown to be associated with healthier behavior and improved health outcomes (Cohen & Wills, 1985; Wang, Wu, & Liu, 2003). This review uncovered no universally agreed upon definition of social support among researchers. Clarity around nomenclature for the dimensions of social support would add to the literature and the overall state of social support research (Uchino et al., 1996).

Generally, social support was described as a construct that includes the structural component of an individual's social relationships and the functional components the relationships provide (Uchino, 2004). Most social support studies in the general literature further define or discuss structural and functional social support as having multiple dimensions, though the dimensions vary depending on the source. Structural social support was often defined in terms of social integration, social isolation, and social network characteristics (Garcia et al., 2015). Examples of structural support included

living arrangements, social networks and marital status. Although important, structural support was outside the scope of this study.

Definitions of functional social support also varied in the literature. For example, Cobb (1976) defined social support as information that results in feeling either cared for, valued, or belonging to a network, with each type serving a distinct function. Cohen (2004) noted three main types of functional support: instrumental, informational, and emotional. Instrumental support, which has also been referred to as physical or non-psychological support, involved the facility of material aid, such as financial assistance (e.g. help with childcare or housekeeping, provision of transportation or money). Informational support such as advice-giving was relevant to the individual's dilemma and referred to the help that others gave by providing information. In contrast, emotional support focused on meeting social-emotional needs, often through expression of empathy, caring or understanding. Emotional support also referred to things people do that make a person feel loved and cared for and that bolster a sense of self-worth (e.g. talking over a problem, providing encouragement, giving positive feedback). In the Stress Buffering Model, the type of support received should match the recipient's perceived need in order to be effective (Cohen, 2004; Cohen et al., 1985; Cohen & Wills, 1985).

According to the MOS-SSS, functional support was defined and measured within the dimensions of emotional/informational support, tangible support, affectionate support, and positive social interaction (Sherbourne & Stewart, 1991). The theoretical underpinning of the MOS-SSS was based on the Stress Buffering Model (Cohen & Wills, 1985) and House's Conceptualization of Social Support (House et al., 1985; House, Umberson, et al., 1988). House's conceptualization of support included three dimensions

of social support. Emotional support related to the amount of love and caring, sympathy and understanding and/or esteem or value available from others. Emotional support which also involved verbal and nonverbal communication of caring and concern, was believed to enhance perceptions of control over stress by reducing confusion and providing patients with strategies to cope with their illness. This type of support was most often provided by a confidant or intimate relation, although less intimate persons could provide such support under circumscribed conditions (House, Landis, et al., 1988). Instrumental support referred to help, aid such as money or physical help, the provision of material goods or assistance with physical needs such as getting to appointments, getting groceries, cooking, cleaning, or paying bills. According to House, Landis, et al. (1988), instrumental support helped decrease the feeling of chaos during the stress of illness and appraisal support related to help in decision-making, giving appropriate feedback, or providing information in the service of particular needs.

A large body of literature dating back to Berkman and Syme (1979) identified that social support offered powerful health benefits and social isolation was a significant risk factor for mortality. Social support also fosters psychological well-being, enhances self-esteem and self-efficacy, reduces physiological arousal, and promotes functional and adaptive coping with stressors (Cohen, 2004; Uchino, 2004; Umberson, Crosnoe, & Reczek, 2010). The mechanisms underlying the health benefits of social support have been attributed to its various functional components (Cohen et al., 1985; Sherbourne & Stewart, 1991; Stangl, Bunnell, Wamai, Masaba, & Mermin, 2012; Takada et al., 2014), although a thorough understanding of the components and their relationship to other variables did not exist in the literature.

Empirical studies of social support tended to focus more on perceived availability of support as well as the quality of support rather than the receipt of such support (Nurullah, 2012; Sherbourne & Stewart, 1991). Perceived social support (particularly emotional support) has consistently been shown to be associated with reduced stress and improved physical and mental health (Dunkel-Schetter & Bennett, 1990; Haber et al., 2007; House, Landis, et al., 1988; Thoits, 1986; Uchino, 2004). However, research suggested that the need for a paradigm shift in research to consider both perceived and received social support. The optimal match may be found in a better understanding of support *need* (perceived) along with support *provision* (received) (Nurullah, 2012).

Social Support and Medication Adherence in Chronic Disease

The World Health Organization defined adherence as “the extent to which a person’s behavior such as taking medications, following diet and/or executing lifestyle changes corresponds with agreed upon recommendations from a health care provider” (WHO, 2016). Long-term medication adherence for chronic illness in developed countries averages 50% and is even lower in developing countries (WHO, 2014). Non-adherence to medications in chronic conditions, including HIV, imposes a substantial clinical and financial burden on the U.S. healthcare system (Iuga & McGuire, 2014). Studies demonstrated repeatedly that medication non-adherence is a common source of hospitalization, morbidity, and mortality across varied populations and disease states (Botelho & Dudrak, 1992; Chandwani et al., 2012; Conn et al., 2009; Conn et al., 2015; Ruppar et al., 2008; WHO, 2014). Of all U. S. medication-related hospitalizations, between one-third and two-thirds resulted from suboptimal medication adherence (Brown & Bussell, 2011; Iuga & McGuire, 2014; Osterberg & Blaschke, 2005). As a health

policy issue, medication adherence had strong implications for population health and system outcomes. Brown & Bussell (2011) felt it was imperative to find new ways to improve medication adherence because poor adherence compromises these outcomes.

Scheurer et al. (2012) assessed the direction and strength of the association between social support and medication adherence in disease states such as HIV, diabetes, tuberculosis, asthma, hypertension, and congestive heart failure. She concluded that, across disease states, greater practical support of medication taking habits was most consistently associated with medication adherence. Structural support, defined by cohabitation or support from a spouse or significant other, was not consistently associated with medication adherence, implying the mere presence of a partner is not sufficient to affect medication taking behavior (Scheurer et al., 2012). Similarly, only half of the emotional support studies demonstrated a relationship between examples of emotional support and medication adherence. Emotional support was found to correlate best with adherence when it involved meeting specific identified unmet needs by a peer or friend (Scheurer et al., 2012).

In a more recent systematic review of 53 intervention studies involving adults with adherence challenges, Conn et al. (2015) determined that medication adherence interventions improve medication-taking behaviors in patients with a history of repeated medication adherence challenges. However, the authors found that the interventions generally did not adequately address the underlying reasons for participants' nonadherence. The analysis showed that, for people with adherence challenges, behavioral interventions may help more than cognitive interventions. This adult vulnerable population doesn't necessarily need to be persuaded of the importance of

taking medications. Instead, improved adherence interventions may require strategies to help them remember to take them (Conn et al., 2015).

Social Support in HIV Medication Adherence

ART requires adherence rates of 95% or greater to achieve virologic suppression (Chernoff, 2007). However, less one-than half of adults prescribed ART achieved adherence in the optimal range despite being linked to care and having access to medication (Enriquez et al., 2015; Houston, Osborn, Lyons, Masvawure, & Raja, 2015). This study was designed to review social support in relation to medication adherence in adults with a history of repeated HIV medication adherence challenges. Although medication adherence interventions have improved medication-taking behaviors in some populations with adherence challenges (Conn et al., 2015), very little extant data related to adherence in adults living with HIV who have had repeated challenges with medication adherence exists (Enriquez et al., 2015). A study conducted in San Francisco identified a population with poor adherence and provided them with HIV-treatment specific support (Taylor et al., 2010). The authors found no change in overall social support or adherence to ART. However, this study's measure of social support as an independent variable associated with HIV medication adherence was perceived support versus received support.

Despite the lack of specific evidence in patients struggling with repeated adherence challenges, numerous research studies in the HIV literature documented social support as a key factor influencing antiretroviral adherence (Edwards, 2006; Huynh et al., 2013; Mills et al., 2006; Simoni, Frick, et al., 2006; Simoni et al., 2002; Simoni et al., 2007; Vyavaharkar et al., 2012). Lack of social support has been associated with a lower

level of adherence to ART (Atkinson, Nilsson Schönnesson, Williams, & Timpson, 2008; Catz, Kelly, Bogart, Benotsch, & McAuliffe, 2000). Numerous studies suggested that social support may improve quality of life, influence adherence to HIV medication and lead to improved outcomes in adults living with HIV (DiMatteo, 2004; Ncama et al., 2008).

Several studies examined the association between social support and adherence to HIV medication, as well as mediators of the relationship between these variables (Simoni, Frick, et al., 2006; Simoni et al., 2002; Vyavaharkar et al., 2012). Simoni et al. (2002) reported that the need for social support was positively correlated with adherence to ART and that this relationship was mediated by self-efficacy and depression. In general, research findings indicated that access to overall social support promoted adherence to ART in adults living with HIV (Lehavot et al., 2011; Ruanjahn et al., 2010). Huynh et al. (2013) suggested that although social support correlated with increased adherence, future adherence interventions should consider adding a mental health treatment component along with social support dimensions for best effect.

Some studies suggested a relationship between tangible support and antiretroviral adherence in the literature (Gonzalez et al., 2004; Ulett et al., 2009; Vyavaharkar et al., 2012). In a longitudinal study by Kelly et al. (2014), baseline tangible support scores were statistically significantly higher ($p = .02$) in adults newly diagnosed with HIV who subsequently had at least 95% adherence to ART. Overall social support scores greater than 50 (OR 2.36, $p = .05$) and tangible support scores greater than 50 (OR 3.01, $p = .02$) predicted adherence equal to or greater than 95% (Kelly et al., 2014). The literature regarding social support and HIV medication adherence contains mixed results, leaving

unanswered questions about how and in what contexts to best approach social support. An analysis of social support from institutions, such as a church, rather than from close relations found a high rate of nonadherence, even though 80% of participants felt their social support needs were being met (Pichon, Rossi, Ogg, Krull, & Griffin, 2015). In a large sample of HIV patients identified as having the unmet need of counseling, significantly reduced odds of being adherent were found (OR 0.32, $p < .01$), and having the unmet need of a support group significantly increased the odds of not taking ART (OR 3, $p < .05$) (Scheurer et al., 2012).

A growing body of research has investigated the use of interventions that included a social support component or measure of social support within an intervention study aimed at improving adherence to HIV medication. These studies provided mixed results. Of three interventional studies that evaluated the effect of emotional support on HIV medication adherence, two reported no significant difference in overall medication adherence (Jones et al., 2007; Simoni et al., 2007). Simoni et al. (2007) found no effect of a peer support group. Jones et al. (2007) reported that a cognitive-behavioral stress management expressive-supportive therapy intervention (10 weekly sessions) also had no overall effect on HIV medication adherence though a subgroup of low adherers did increase their mean self-reported adherence. A third intervention study of emotional social support engaged patients and their HIV-serodiscordant partners in four, 1-hour educational sessions (focused on medication adherence, barriers, support, and confidence building) significantly increased the percentage of patients who achieved at least 95% adherence with their HIV regimen ($p = .02$) (Remien et al., 2005).

Enriquez et al. (2015) showed a statistically significant difference in viral load suppression (a proxy for HIV medication adherence) between adults living with HIV who received a peer-led medication adherence intervention and those who received a control comparison healthy eating intervention. Results indicated that 90% of the intervention-group participants had suppressed viral loads at the 24-week follow-up time point, compared to 30% of control-group participants ($p = < .01$). In a qualitative study of social support in a population of injection drug users with HIV, many participants mentioned that being around others who shared their histories of drug abuse and HIV decreased their sense of isolation (Mitchell et al., 2007). Participants referred to the INSPIRE Project intervention as a “support group”, adding evidence of the strength of peer social support interventions for HIV medication adherence. Houston et al. (2015) built on the work of Mitchell et al. (2007) by examining the nature of perceived social support from peer facilitators to participants. His qualitative study focused on four types of social support and determined that instrumental (tangible) support was not perceived as frequently as informational/emotional support. Houston et al. (2015) concluded for many adults living with HIV, social support of any type was scarce or nonexistent (Houston et al., 2015).

MOS-SSS as Measurement of Social Support in HIV Medication Adherence

In order to study the effects of social support on HIV medication adherence, the ability to gather empirical evidence from reliable measurement is paramount. Methods of measuring social support varied due to different definitions of social support and to the lack of a clear conceptualization in the literature. One of the most commonly used instruments with strong reliability was the MOS-SSS (Sherbourne & Stewart, 1991).

Although this tool provides for measurement of four social support dimensions as well as an overall social support score, the dimensions were rarely measured and reported in the literature regarding the HIV population. Of the 16 studies using the MOS-SSS to measure of social support in relationship to HIV medication adherence, only one reported scores on the four social support dimensions (emotional/informational, tangible, affectionate, and positive social interaction) (Kelly et al., 2014). In a prospective observational cohort study, Kelly et al. (2014) reported that baseline tangible social support scores were higher in participants who subsequently had at least 95% adherence to ART ($p = .04$). Positive social interaction sub scores greater than 50 (OR 2.86, $p < .01$) were associated with CD4+ T cell counts ≥ 200 cells/mm³ at diagnosis. It was reported assumption by the author that these two social support subscores (tangible support and positive social interaction) drove the overall significant social support findings related to HIV medication adherence (OR 2.36, $p = .05$) (Kelly et al., 2014).

Studies of social support and HIV medication adherence showed mixed results. Of 16 studies reporting statistically significant results for social support's association with medication adherence, seven demonstrated no association between the two variables, and two measured social support, but did not report the results. Using the modified 5-question version of the MOS-SSS, Huynh et al. (2013) observed that optimal HIV medication adherence was associated both with overall social support and favorable mental health status. They suggested exploring the combination of social support and mental health components of adherence interventions because mental health appeared to moderate the relationship between social support and medication adherence (Huynh et al., 2013). Congruent with the reported literature, several studies found that despite the

presence of significant social support high levels of non-adherence still existed (Huynh et al., 2013; Raboud et al., 2011; Vyavaharkar et al., 2012).

Perceptions of general social support were higher in what one study compared to “medication-specific support” (Lehavot et al., 2011) suggesting a personalized approach to social support-driven medication interventions. Vyavaharkar et al. (2012) did not measure sub scales, but observed that satisfaction with perceived available social support ($p .04$) and coping by managing HIV disease ($p = .002$) were the best positive predictors of medication adherence. Although Vyavaharkar et al. (2012) reported that satisfaction with social support is a good predictor of adherence, they did not provide insight into which types of social support may promote increased adherence. Raboud et al. (2011) suggested that interventions promoting positive social interaction might provide the best opportunity because suboptimal social support in this area strongly predicted medication adherence.

Social support was reported to be associated with medication adherence through mediation (Golin et al., 2006; Turan, Smith, Cohen, Wilson, & Adimora, 2016; Woodward & Pantalone, 2012). In a serial mediation model, Turan et al. (2016) suggested that stigma decreases perceived social support which in turn increases depression. Depression predicted suboptimal medication adherence in this multicenter cohort study. In the model, each association between stigma, social support, depression, and medication adherence on the path was statistically significant at ($p < .01$). An additional strength of this study was the population, which consisted of 88% racial and ethnic minorities, which have been shown to have high rates of adherence challenges (Turan et al., 2016). Woodward and Pantalone (2012) found that although social support

did not have a statistically significant relationship with medication adherence, a significant inverse relationship existed between depression and medication adherence and that social support appeared to mediate that relationship. However, Golin et al. (2006) found the mediating relationship of social support perplexing in their study of a motivational interviewing-based intervention study to improve medication adherence to ART among patients failing or initiating the therapy. Social support, among other variables, had statistically significant changes in an unexpected direction in the intervention group compared with the control group, with the motivational interviewing group having a greater decrease in social support than did the control group ($p = 0.02$). This may have been because the motivational interviewing counselor potentially reduced patients' needs for additional support during the time they saw the counselor (Golin et al., 2006).

Many studies in the literature measuring the association between social support and HIV medication adherence observed no significant association between social support and adherence as measured by the MOS-SSS. Corless et al. (2009) investigated factors affecting medication adherence in one sample of patients initially diagnosed with HIV and a second sample initially diagnosed with tuberculosis. However, both groups had a coinfection of rate 16-20%. Despite the sample differences, no significant difference appeared between groups or within groups regarding medication adherence scores related to social support (Corless et al., 2009). In two separate observational cohort studies, psychosocial support was measured in relationship to ART discontinuation, virologic failure, and HIV disease progression as surrogates for medication adherence. No evidence of statistically significant associations was found

(Pence et al., 2012; Pence et al., 2008). Likewise, Trejos, Reyes, Bahamon, Alarcon, and Gaviria (2015) confirmed the findings of other studies, reporting no significant differences in adherence to treatment based on a psychosocial clinical model referred to as “DIRE”.

This review found mixed results concerning the relationship between social support and HIV medication adherence. However, studies across varied settings provided evidence of the reliability of the MOS-SSS in terms of measurement of the construct of social support. Half of the studies reviewed here reported reliability scores for the MOS-SSS; five reported high reliability with coefficients ranging from 0.85 – 0.98 (Corless et al., 2009; Huynh et al., 2013; Lehavot et al., 2011; Turan et al., 2016; Woodward & Pantalone, 2012) and one reporting a moderate Chronbach’s alpha score of 0.64 (Ncama et al., 2008).

CHAPTER 3

Research Methodology

Research Design

Data from two previous HIV medication intervention studies (Enriquez & Cheng, 2016; Enriquez et al., 2015) was used in this secondary analysis to new research questions not previously tested (Doolan & Froelicher, 2009; Polit & Beck, 2008). Through this analysis, the dimensions of functional social support were explored both qualitatively and quantitatively from data in the two parent studies (Enriquez & Cheng, 2016; Enriquez et al., 2015). The purposes were 1) to better understand how adults living with HIV who have experienced repeated challenges with HIV medication adherence describe perceived social support in relationship to medication adherence and 2) to determine whether self-reported total social support or the dimensions of social support described by the MOS-SSS varied by demographic and health variables (i.e. age, gender, race/ethnicity, education, length of time living with HIV, and number of previous HIV medication regimens).

This study used mixed methods convergent design (Bryman, 2006; Creswell, 2013; Morse & Niehaus, 2009), the most well-known approach to mixing research methods (Creswell & Clark, 2007). The purpose of convergent design is “to obtain different but complementary data on the same topic” (Morse & Niehaus, 2009) to best understand the research problem. Convergent design allowed for both qualitative and quantitative data to be analyzed during the same phase of research, which by design, was compulsory in secondary analysis because all data had been previously collected (Clarke & Cossette, 2000; Dunn, Arslanian-Engoren, DeKoekkoek, Jadack, & Scott, 2015).

Morse and Niehaus (2009) described a parallel-databases variant of convergent design in which two parallel strands of data analysis were conducted independently and only brought together during the interpretation phase of data analysis. Merging two sets of results into an overall interpretation fit well with this secondary analysis of existing data (Creswell & Clark, 2007; Dunn et al., 2015; Morse & Niehaus, 2009). The current study merged qualitative data from parent study 1 (Enriquez et al., 2015) and parent study 2 (Enriquez & Cheng, 2016) followed by a separate merger of quantitative data from parent study 1 (Enriquez et al., 2015) and parent study 2 (Enriquez & Cheng, 2016). Each new merged data set was analyzed separately. Per mixed methodology, the qualitative and quantitative data were synthesized and compared in the final analysis (Bryman, 2006; Greene, Caracelli, & Graham, 1989). The study results add to the completeness and expansion of knowledge in the literature of functional social support and medication adherence.

Research Setting

Data for this secondary analysis originally were collected during two parent studies designed as peer-led HIV treatment adherence intervention studies (Enriquez & Cheng, 2016; Enriquez et al., 2015). The first study, a pilot feasibility study was conducted in 2012 and 2013 in an urban clinic in Kansas City, Missouri, serving a large number of vulnerable HIV-infected adults. The clinic, located in a safety-net hospital, predominantly serves low-income adults of color living with HIV disease (Enriquez et al., 2015). The second parent study was conducted in four HIV medical care settings located in Jackson County, Kansas City, Missouri. These settings included an academic

medical center, a community hospital, a safety-net hospital, and a private medical practice (Enriquez & Cheng, 2016).

Participants and Sample

The sample for this secondary analysis originated from two parent studies with a target population of adults living with HIV who had repeated challenges with HIV medication adherence despite having been linked to HIV medical care and having access to ART (Enriquez & Cheng, 2016; Enriquez et al., 2015). Inclusion criteria for the parent studies were: HIV viral load >200 copies, age 18 or older, ability to speak English or Spanish, documented non-adherence to HIV medications by the patient's non-suppressed HIV viral load, community-dwelling individual, beginning treatment with a new regimen of HIV medications or restarting a previous HIV medication regimen that was stopped by the patient. Exclusion criteria for the parent studies was: being naive to HIV medications, being incarcerated or living in a residential care facility where antiretroviral medications are dispensed by a professional caregiver (Enriquez & Cheng, 2016; Enriquez et al., 2015).

Participants in the parent studies were prescribed an average of three previous ART regimens and did not achieve viral load suppression. Parent Study 1 (Enriquez et al., 2015) had a total study sample (n=20) with participants randomized to the peer-led adherence intervention group (n=10) or a time and contact-matched comparison intervention group (n=10). Parent Study 2 (Enriquez & Cheng, 2016) was ongoing in follow up and had a total study sample (n=30) with participants randomized to the active peer-led intervention group (n=20) or a waitlisted control group (n=10). No participants participated in both parent studies (Enriquez & Cheng, 2016; Enriquez et al., 2015).

Procedures

The parent studies from which this dissertation study was conceived tested a tailored peer-led HIV treatment adherence intervention that identified each participant's barriers to adherence in order to focus a series of individualized peer sessions designed to overcome barriers to medication adherence (Enriquez & Cheng, 2016; Enriquez et al., 2015). Participants receiving the intervention (in the parent studies) completed baseline study questionnaires, including the MOS-SSS and the demographic survey, before meeting with a peer interventionist. Peer interventionists trained by the research team provided the tailored, peer-led behavioral HIV medication adherence intervention in the parent studies. Two peers were trained in parent study 1 (one male and one female) and four additional peers were trained in parent study 2. The peers from the first study also worked with participants in the second parent study. The six peers who completed field notes in the parent studies were ethnically diverse (two African American, two Hispanic, and two White) (Enriquez & Cheng, 2016; Enriquez et al., 2015).

A peer interventionist met with patients receiving the study intervention weekly for six weeks with a follow up visit six weeks later. During the visits, peer interventionists recorded field notes. Study investigators had trained interventionists on how to take field notes. Peers used a guide to take the field notes during the sessions (see Appendix C). Participants were informed that field notes would be taken during the peer sessions and all participants were given the opportunity to review his/her own field notes at the end of each study visit.

Discussions with participants related to barriers to and facilitators of HIV medication adherence. Details of the peer intervention from Parent study 1 have been

published. Results demonstrated that participants exposed to the peer intervention had significantly improved medication adherence (Enriquez et al., 2015). Parent study 2 is ongoing (Enriquez & Cheng, 2016). Both parent intervention studies measured social support (Sherbourne & Stewart, 1991) at the baseline visit (pre-intervention) as well as several post-intervention time points (6, 12, and 24-weeks). Analysis of the social support data was not an aim of the original analyses (Enriquez & Cheng, 2016; Enriquez et al., 2015).

Qualitative Data Analysis

For this study, qualitative field notes from both parent studies were analyzed using content analysis (Weber, 1990). Content analysis is a systematic and objective means to examine data in order to describe a phenomenon (Graneheim & Lundman, 2004). It focuses on the characteristics of language with attention to the text's content or contextual meaning (Elo & Kyngas, 2008). The goal of content analysis was "to provide knowledge and understanding of the phenomena under study" (Downe-Wamboldt, 1992). Although there "is no simple *right way* to do content analysis" (Weber, 1990), the procedure utilized in the qualitative data analysis portion of this mixed methodology study involved eight steps (Insch, Moore, & Murphy, 1997; Krippendorff, 2012; Weber, 1990):

1. **Identification of questions to be asked and constructs to be used.** Following discussion with the parent-study investigators, it was determined that the proposed secondary analysis could address research questions related to social support not addressed by the parent studies. Data related to perceived barriers and facilitators of medication adherence were collected through face-to-face

interviews at baseline in both parent studies (Enriquez & Cheng, 2016; Enriquez et al., 2015). The goal of the qualitative research question in this mixed methods study was to analyze the field notes in order to better understand the dimensions of perceived social support relating to HIV medication adherence.

2. **Texts to be examined were chosen.** The transcribed field notes from the parent studies were uploaded into the qualitative software program dedoose (*dedoose*, 2014). Individual field note transcripts were uploaded and organized so that the data could be examined, explored, coded and later integrated with quantitative data (Talanquer, 2014). *Dedoose* (2014) was useful for this study because in addition to allowing for computerized qualitative coding, it provided the ability to combine qualitative data with quantitative demographic data according to *a priori* descriptors (e.g., age category, gender, educational level, or years with HIV). These data were then organized and linked, and chi-square analysis was completed to determine relationships among the demographic data (*dedoose*, 2014; Talanquer, 2014). Phrases were entered into the program to create codes and a coding scheme to facilitate the identification of conceptual themes or patterns. (*dedoose*, 2014; Talanquer, 2014). The choice to use *dedoose* (2014) for this mixed methods study was based on the investigator's experience using it in previous qualitative analyses (Hanna, Mehr, Mercier, Popejoy, & Vogelsmeier, 2015) and the software's unique data analysis features for mixed methodology (*dedoose*, 2014).
3. **Decided on the "unit of analysis".** "Phrase" was the unit of analysis for the qualitative portion of this mixed methods secondary analysis. With the phrase as

the coding unit, expression of an idea within the data was assigned a code by the investigator manually through a process *dedoose* calls “excerpting” (dedoose, 2014). Excerpting used inductive reasoning, by which phrases and categories emerged from data through the investigator’s careful examination and constant comparison of the data (Weber, 1990). The investigator coded phrases was completed “by hand” within *dedoose* (dedoose, 2014).

4. **Determined the categories into which the responses were divided.** This study’s qualitative research question was designed to help better understand the concept of perceived social support. Development of a priori qualitative categories of perceived social support was based on the dimensions of social support as described in the MOS-SSS (Sherbourne & Stewart, 1991). These categories were grounded from the theoretical base in which the MOS-SSS is based (House, 1987; House et al., 1985; House, Landis, et al., 1988; House, Umberson, et al., 1988).
5. **Generated a coding scheme.** To ensure consistency of coding, an electronic version of a coding manual was created in *dedoose* (2014). The manual consisted of category names, definitions or rules for assigning codes, and examples of codes (Denzin & Lincoln, 2011; Weber, 1990). *Dedoose* allowed for writing memos while coding. The coding manual evolved throughout the data analysis process using the constant comparison method and memos completed during the coding process augmented the coding process (Weber, 1990).
6. **Conducted pilot study and revised the categories and coding scheme.** To test the qualitative analysis procedures, a pilot involving the coding of three

participant's field notes was conducted. This pilot involved the coding, testing of procedures, and checking of reliability with a second coder (an investigator from one of the parent studies). Insights from this work were used to modify qualitative procedures to provide additional clarity including the coding scheme (Weber, 1990).

7. **Collected the data.** Once the coding scheme was validated by checking for coding consistency and revising codes and definitions, coding of additional qualitative data continued until reaching data saturation. Data saturation was reached after reviewing and coding field notes for 34 study participants (Enriquez & Cheng, 2016; Enriquez et al., 2015),
8. **Assessed validity and reliability.** To ensure rigor of qualitative data, the following techniques were incorporated into this mixed methodology study: credibility, dependability, confirmability, and transferability (Denzin & Lincoln, 2011).

Qualitative Validity

Credibility

Lincoln and Guba argued that ensuring credibility is key to establishing trustworthiness (Guba & Lincoln, 1994). Credibility of the qualitative inquiry was demonstrated through the strong purpose, aim and qualitative research question of this secondary analysis, and the selection of inclusion and exclusion criteria of participants in the parent studies (Enriquez & Cheng, 2016; Enriquez et al., 2015). Adding to the credibility of this study was the triangulation of data when combining the qualitative and quantitative data to answer research question 4. An additional form of triangulation was

analysis of data collected from a variety of informants who participated in two parent studies at a total of five sites (Enriquez & Cheng, 2016; Enriquez et al., 2015). This study's credibility was further enhanced by the involvement of parent-study principal investigators who were familiar with the data and who mentored the investigator of the current study.

Dependability

Lincoln and Guba stress the need for close ties between credibility and dependability, arguing that demonstration of the former helps ensure the latter (Denzin & Lincoln, 2011; Guba & Lincoln, 1994). Dependability was achieved by using "overlapping methods" or triangulation, such as is the case with a mixed methodology approach (Creswell, 2012, 2013). In order to address the dependability issue more directly, this study's methods were discussed in detail, thereby enabling future researchers to repeat the work, though not necessarily to gain the same results, which is common with mixed methodology design containing qualitative data.

Confirmability

In order to confirm that the result of the experiences and ideas reported in the study findings are that of the informants, rather than the characteristics and preferences of the researcher, parent-study principal investigators reviewed the results of this secondary analysis (Enriquez & Cheng, 2016; Enriquez et al., 2015). This review's purpose was to evaluate the accuracy and evaluate whether the data support the findings, interpretations and conclusions. (Denzin & Lincoln, 2011; Guba & Lincoln, 1994; Shenton, 2004).

Transferability

To facilitate transferability of data from this study's results, a clear description of the setting and participants of the two parent studies were provided, as well as references to the parent studies for additional information on data collection (Enriquez & Cheng, 2016; Enriquez et al., 2015). Because the findings of this secondary analysis were specific to certain treatment settings and individuals, it was impossible to demonstrate that the findings and conclusions applied to other situations and populations. In order to enhance transferability, findings of the qualitative data analysis with appropriate data excerpts (i.e. quotations) along with the merged qualitative and quantitative data are reported for comparison of the phenomenon as described with those seen in practice.

Quantitative Data Analysis Plan

An exploratory quantitative analysis was conducted of the baseline MOS-SSS data to answer research questions that were not part of the planned inquiry of the parent studies (Enriquez & Cheng, 2016; Enriquez et al., 2015). The strengths of this type of analysis were low risk to participants because the data were de-identified and relationships among variables and subgroups (such as the dimensions of social support) not previously analyzed can be examined (Dunn et al., 2015).

Instruments

The MOS-SSS (Sherbourne & Stewart, 1991) was developed by The RAND Corporation and has been extensively tested for reliability and validity across disease states (Appendix B). The parent studies also included a self-report survey to capture demographics and health variables (Appendix C).

The Medical Outcomes Study Social Support Survey (MOS-SSS). The parent studies employed the MOS-SSS (Kelly et al., 2014; Sherbourne & Stewart, 1991) to assess the frequency by which participants perceived the availability of various types of general support (Enriquez & Cheng, 2016; Enriquez et al., 2015). This 19-item, 5-point Likert scale instrument collects data to report a total score for perceived functional social support as well as a score for four sub-domains: emotional support (8 items) tangible support (4 items), affectionate support (3 items), and support through positive social interaction (3 items) plus one additional question which is only used in the calculation of the overall social support score (Sherbourne & Stewart, 1991). The MOS-SSS was developed for patients with chronic conditions and is available for use in the public domain. Scores can range from 0-100, and in a general U.S. population, the mean overall score is 70.1 ($SD= 24.2$), with subscale scores ranging from 69.6 to 73.7. It has high internal reliability (Cronbach's alpha 0.91-0.97) and stability (0.72-0.78) (Sherbourne & Stewart, 1991). The total social support score and the subscale scores were transformed as recommended by the authors of the scale and reported as interval data for analysis (Sherbourne & Stewart, 1991).

Demographic Survey. A demographic survey was developed for use in the parent studies for collecting demographic data. The demographic data collected were age, gender, race/ethnicity, educational status, the number of previous HIV medication regimens and year of HIV diagnosis. The demographic survey did not require testing against any standardized surveys. The survey was used in the parent studies for the sole purpose of collecting factual information (Enriquez & Cheng, 2016; Enriquez et al., 2015). Demographic variables were reported as ordinal (age, education), nominal

(gender, race/ethnicity), and interval (length of time living with HIV, number of previous HIV regimens) data.

Statistical Analyses

Quantitative descriptive analyses were used to address research question 2: How do adults living with HIV who have experienced repeated medication adherence challenges self-report total social support and social support within specific dimensions as measured by the MOS-SSS (emotional/informational, tangible, affectionate, and positive social interaction)? Frequencies and percentages for nominal and ordinal variables as well as means, standard deviations, and ranges for continuous level variables were completed to describe the sample's characteristics.

Correlation analysis and factorial analysis of variance (ANOVA) was conducted to address research question 3: Does the self-reported total social support score and/or the social support score within specific dimensions as measured by the MOS-SSS (emotional/informational, tangible, affectionate, and positive social interaction) vary based on sociodemographic and health variables (i.e. age, gender, race/ethnicity, education, length of time living with HIV, or number of previous HIV medication regimens) in adults living with HIV who have experienced repeated medication adherence challenges? Pearson's product-moment correlation and Spearman's rank correlation coefficients were completed to assess relationships between social support, demographic, and health variables.

Factorial ANOVA's were completed to analyze differences between on the MOS-SSS total social support score between age and education. Age has six groups and education has four discrete groups. Gender and ethnicity/race were also compared on the

total social support score, with three and six groups respectively. Total social support score was compared to the length of time living with HIV, the number of previous HIV regimens and the setting for HIV care through regression analysis.

The ANOVA used the *F* test, which allowed for overall comparison on whether group means differed. The *F* test is the ratio of two independent variance estimates of the same population variance (Field, 2009). The results of the factorial ANOVA are presented in Chapter 4 in the form of main effects of total social support per the MOS-SSS on the demographic and health variables among study variables.

Data analysis triangulation was used as an analysis method to answer research question 4 per mixed methodology: What is the relationship between self-reported total social support, social support within the specific dimensions of the MOS-SSS and the perceptions of social support in relationship to medication adherence in adults living with HIV who have experienced repeated medication adherence challenges?

Quantitative Reliability, Validity, and Generalizability

Reliability refers to the ability of the research findings to be repeated by another researcher as well as to the individual measures within a study (Polit & Beck, 2008). In planning for this study, a mixed methodology design was created with elements of study validity in mind. Planned study procedures for quantitative analysis of the secondary data included a process for ensuring accuracy of the data when extracted from the parent studies in terms of selection of the sample. Additionally, through discussion with parent-study investigators (Enriquez & Cheng, 2016; Enriquez et al., 2015), a strong understanding of how and what data were collected was invaluable in assessing the validity of the measures. These procedures decreased potential bias in measuring

associations between predictors and the outcome variable (internal validity), and the generalizability of their findings to the target population (external validity)(Polit & Beck, 2008).

Protection of Human Subjects

This secondary analysis was completed using de-identified data from two parent studies conducted by members of the current investigator's dissertation committee (Enriquez & Cheng, 2016; Enriquez et al., 2015). The datasets were not publicly available. All data were received for analysis from the original investigators and did not include any identifying information for study participants from either parent study (Enriquez & Cheng, 2016; Enriquez et al., 2015). Data were saved electronically and password protected. This study was reviewed and approved by the MU Institutional Review Board as IRB Project Number 2005952.

CHAPTER 4

Data Analysis and Results

Introduction

The goal of this mixed methods convergent study was to better understand how functional social support relates to medication adherence in adults living with HIV who had experienced repeated challenges with HIV medication adherence as well as to determine if self-reported social support as described by the MOS-SSS varied based on demographic and health variables (i.e. age, gender, race/ethnicity, education, length of time living with HIV, and number of previous HIV medication regimens). The following specific aims were achieved:

- Exploration and description of perceived social support in a sample of adults living with HIV who had experienced repeated challenges adhering to HIV medication regimens;
- Identification of correlates among adults living with HIV who had experienced repeated challenges with HIV medication adherence related to the MOS-SSS dimensions of social support (emotional/informational, tangible, affectionate, and positive social interaction) and demographic and health variables (i.e. age, gender, race/ethnicity, education, length of time living with HIV, and number of previous HIV medication regimens);
- Convergence of results from qualitative and quantitative data analyses to better understand how perceived social support relates to HIV medication adherence.

Research Questions

Research Question 1 (Qualitative): What is the role of perceived social support in adults living with HIV who have experienced repeated challenges with medication adherence?

Research Question 2 (Quantitative): How do adults living with HIV who have experienced repeated medication adherence challenges self-report total social support and social support within specific dimensions as measured by the MOS-SSS (emotional/informational, tangible, affectionate, and positive social interaction)?

Research Question 3 (Quantitative): Does the self-reported total social support score and/or social support score within specific dimensions as measured by the MOS-SSS (emotional/informational, tangible, affectionate, and positive social interaction) vary based on sociodemographic and health variables (i.e. age, gender, race/ethnicity, education, length of time living with HIV, or number of previous HIV medication regimens) in adults living with HIV who have experienced repeated medication adherence challenges?

Research Question 4 (Mixed Methods): What is the relationship between self-reported total social support, social support within the specific dimensions of the MOS-SSS and the perceptions of social support in relationship in adults living with HIV who have experienced repeated medication adherence challenges?

Sample

Field notes and survey data used in this analysis were collected from two Midwestern U.S. studies designed as peer-led HIV treatment adherence intervention studies (Enriquez & Cheng, 2016; Enriquez et al., 2015). Parent study 1, a pilot

feasibility study was conducted in 2012 and 2013 in an urban clinic that serves a large number of vulnerable HIV-infected adults. Healthcare for these patients was completed in a safety-net hospital that predominantly served low-income adults of color living with HIV disease (Enriquez et al., 2015). Parent study 2 was conducted in four HIV medical care settings located in Jackson County, Kansas City, Missouri. The settings included an academic medical center, a community hospital, a safety-net hospital, and a private medical practice (Enriquez & Cheng, 2016).

Qualitative content analysis of data from field notes written by peer interventionists from visits with 34 participants was completed (n=10 from parent study 1; n=24 from parent study 2). Qualitative data were unavailable for analysis from six participants in parent study 2 mainly due to attrition. Five of the six participants were in the wait listed control group and dropped from the study before receiving the intervention. The sixth participant received the intervention, but the field notes were missing from the study notebook(Enriquez & Cheng, 2016; Enriquez et al., 2015). Quantitative data analysis included self-reported baseline MOS-SSS data from 49 participants (n=19 from parent study 1; n=30 from parent study 2). According to the principal investigator of the parent studies, one participant inadvertently did not complete the MOS-SSS at baseline, thus data for that patient were missing (Enriquez & Cheng, 2016; Enriquez et al., 2015).

Self-reported MOS-SSS social support data from participants in both parent studies were interpreted using frequency/descriptive statistics, correlation analysis, and factorial analysis of variance. In order to provide a comprehensive view and overall perspective of social support in this vulnerable population, this study completed data

integration through the mixing of qualitative and quantitative data with resultant analysis and interpretation for convergence and divergence. All data for this secondary analysis were de-identified when received from the parent studies' PI (Enriquez & Cheng, 2016; Enriquez et al., 2015).

Demographic Characteristics of Participants

Data from the parent studies' 49 participants were used to address the research questions in this study. The majority of participants were African American/Black (69.4%), a quarter (24.5%) Caucasian/White and the remainder Latino/Hispanic or mixed race. Nearly 70% (34) were male. Although study participants ranged in age from 18-64 years, more than half were over age 45 (53.1%). Participants' educational backgrounds also varied widely; 16.3% had not completed high school, 38.8% completed high school/GED, 20.6% had completed some college, and only 14.3% had graduated from college.

Most participants received HIV care from a safety net hospital clinic (75.5%, 37). Ten percent of participants received care from a community based clinic and 10% of care was received in a private practice setting. Only 4% (2) of parent study participants received HIV care at an academic medical center. Participants had been living with HIV from one to 32 years. The mean number of years living with HIV was 12. Some participants reported having had only one previous HIV regimen (29%), and many (60%) reported having had far more regimens without achieving viral load suppression. Overall, participants' mean number of previous HIV medication regimens was three (33%), and 13 (27%) reported that they had taken more than four different regimens. All participants had viral loads exceeding 1,000 copies/mL at baseline in the parent studies

because inclusion criteria for the studies was documented non-adherence to HIV medications by the patient's non-suppressed HIV viral load. In the parent studies, a viral load of < 200 copies/mL was the cutoff point for viral load suppression based on the U.S. Department of Health and Human Resources HIV/AIDS Bureau Performance Measures for HIV viral load suppression (Valdiserri et al., 2013).

Table 1. Demographic Characteristics of Participants

Characteristics	Frequency (n)	Percent (%)
Age		
18-24	2	4.1
25-34	10	20.4
35-44	11	22.4
45+	26	53.1
Gender		
Male	34	69.4
Female	13	26.5
Transgender	2	4.1
Race/Ethnicity		
Caucasian/White	12	24.5
African American/Black	34	69.4
Latino/Hispanic	3	6.1
Native American	0	0
Asian/Pacific Islander	0	0
Other	0	0
Education		
Did not finish high school	8	16.3
High school graduate/GED	19	38.8
Some college	15	30.6
College graduate	7	14.3
Type of HIV Care Provider		
Safety net hospital clinic	37	75.5
Private practice	5	10.2
Community-based clinic	5	10.2
Academic medical center	2	4.0

Qualitative Results: Role of Perceived Social Support in Adults with Repeated Challenges with HIV Medication Adherence

This research study sought to answer the qualitative research question: What is the role of perceived social support in adults living with HIV who have experienced repeated challenges with medication adherence? Qualitative data were based on the experiences of adult participants who were non-adherent to HIV medication, whose viral load was not suppressed, and who enrolled in one of two peer-led interventional parent studies (Enriquez & Cheng, 2016; Enriquez et al., 2015).

During the parent study visits, peer interventionists asked participants about past and current barriers and facilitators to HIV medication adherence. Responses to questionnaires about readiness for healthful behavior change, social support (Sherbourne & Stewart, 1991), and self-efficacy for HIV medication adherence were also discussed. The peer interventionists took field notes during the study visits. Peer interventionists' field notes included the setting, people in the room during the visit, and the conversation with the participant. These field notes also included peers' observations as well as quotes from participants (see Appendix C). Details were added to the field notes regarding peers' phone or clinic contacts with participants, as these contacts also reflected participants' social support needs between scheduled study visits. The study team made a consensus decision to use field notes in the parent studies in lieu of tape recording the visits. The parent studies were driven by participatory health research methodology and the community's experience with this population suggested that tape recording could threaten the peer-participant therapeutic relationship (Enriquez & Cheng, 2016; Enriquez et al., 2015). Participants were aware that the peer interventionists were generating

detailed field notes during the visits, and were given the opportunity to read his/her field notes if they so desired. The field notes were coded with a study participant number to ensure confidentiality.

Six peer interventionists recorded field notes by hand during the parent studies. The PI provided the field notes for this study in the form of scanned hand written notes in PDF format. The PI of this secondary analysis transcribed the handwritten field notes into Microsoft Word. The field notes had not been analyzed for social support themes in either parent study (Enriquez & Cheng, 2016; Enriquez et al., 2015). All transcribed field notes were reviewed for accuracy and entered into *dedoose* (*dedoose, 2014*) for qualitative analysis in order to better understand the participants' perspectives on how the dimensions of perceived social support relate to HIV medication adherence.

Content analysis of the field notes was reviewed for a priori social support themes through an excerpting process using inductive reasoning in which phrases and categories emerged from the data through careful examination and constant comparison of the data (Elo & Kyngas, 2008; Weber, 1990). The first round of initial coding used a coding tree with a priori codes and sub-codes based on the MOS-SSS dimensions of social support (Table 2)(Saldaña, 2015).

Table 2. Initial Coding Tree

Affectionate Support	Emotional/Information Support	Positive Social Interaction	Tangible Support
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Love and Affection <input type="checkbox"/> Rejection/Indifference/Hate <input type="checkbox"/> Poor Self Esteem	<input type="checkbox"/> Lack of Understanding <input type="checkbox"/> Lack of Encouragement <input type="checkbox"/> Positive Encouragement <input type="checkbox"/> Giving/Offering Information <input type="checkbox"/> Understanding/Empathy <input type="checkbox"/> Giving of Advice/Guidance	<input type="checkbox"/> Lack of Positive Social Interaction <input type="checkbox"/> Interacting with Others in a Positive Way	<input type="checkbox"/> Behavioral Health Support <input type="checkbox"/> Housing/Food/Transportation <input type="checkbox"/> Medication Assistance Needed <input type="checkbox"/> Unsafe Environment <input type="checkbox"/> Housing Issues <input type="checkbox"/> Abusive Relationship

Content analysis of field notes from three participants was completed and discussed with a second coder (an investigator from one of the parent studies) as a measure of reliability. Following review of the initial round of coding, the coding tree was expanded and modified before completing a second round of coding to develop a sense of categories, concepts or themes. Axial coding was used to extend the analytic work from initial coding and reorganize the data into overarching and subthemes. Redundant codes were removed during axial coding, codes were combined, and the best representative codes were selected (Saldaña, 2015).

Themes began to emerge from the data following axial coding. Excerpts from the field notes described participants' isolation, lack of friends, loneliness, poor support from family/friends/partner, stigma, and rejection/hate from others. Descriptions of unstable life circumstances, abuse/violence, emotional distress, vulnerability, and safety were also common themes during the second round of coding. Upon completion of axial coding, through a process of theming the data (Saldaña, 2015), two overarching themes and

several subthemes emerged (Table 3). The number (%) of participants whose field notes contained excerpts within certain themes or subthemes constituted evidence because this was an indication about whether the point being made (theme or subtheme) was heard frequently or was a rare exception in the data.

Table 3. Overarching Themes and Subthemes

Response Themes	Number of Participants (%)
Extreme Isolation	26 (76%)
Loneliness	15 (44%)
Emotional Distress	23 (68%)
Constant Turmoil	32 (94%)
Structural Vulnerability	22 (65%)

The overarching themes the participants described were 1) the state of disarray in their lives (constant turmoil) and 2) having few people to rely upon for support, spend time with or talk to (extreme isolation). The theme of extreme isolation corresponded with the MOS-SSS dimension of Positive Social Interaction (Sherbourne & Stewart, 1991). Participants who felt isolated frequently described a lack of people in their lives to rely upon, talk to or do things with socially for a variety of reasons. The second overarching theme, constant turmoil, described situations of financial stress, housing/food/transportation needs, medication assistance needs, immigration issues, instability, and feelings of being overwhelmed with life. These situations corresponded with the MOS-SSS dimension of Tangible Support (Sherbourne & Stewart, 1991).

Subthemes of loneliness, structural vulnerability, and emotional distress were prevalent in participants' lives as they struggled to focus on dramatic life circumstances with very little social support.

Theme 1: Extreme Isolation

The majority of study participants described experiences of extreme isolation that peer interventionists captured in the field notes. These included social and emotional isolation from family, friends, and significant others. Extreme isolation is often linked to the subjective concept of loneliness (Turan et al., 2016). At its most basic level, social and emotional isolation has been defined as the lack of meaningful and sustained communication or as having minimal contact with family, friends, or the wider community (Pikhartova, Bowling, & Victor, 2016). More than 80% of the participants whose field notes were analyzed described some form of extreme isolation: poor relationships with family and friends, low levels of participation in social activities and/or the absence of someone to talk with about having HIV.

In their field notes, peers described how participants talked about their HIV status. Participants said that talking about HIV left them feeling isolated and unwilling to engage in relationships or social activities. It seemed the participants viewed their HIV status as a reason for their isolation and experienced what they perceived as “being judged”, “cut off”, or “feeling left out of society”. According to the peers' notes, disclosure of HIV status was a key factor in many participants' lack of relationships. Field notes described situations in which, once participants disclosed their HIV status, family, partners, friends, and others rejected them. This rejection disrupted relationships and caused feelings of social and emotional isolation. One field note captured a participant's remark about

having no close family nearby and therefore having no support system. The peer interventionist wrote that the participant “feels family has not liked her lifestyle and, if anything, she has been used by them for money, services such as watching kids, etc.” Another field note described how, after a participant disclosed her HIV status to her mother, the relationship deteriorated:

When I did tell my mother of my HIV diagnosis she immediately made it about her...how she feels about having a child that is gay and now has HIV... “poor her syndrome”...it makes me not want to tell anyone else. My family hates gay, let alone HIV.

A peer interventionist’s field notes discussed several participants’ the estranged family relationships and subsequent emotional isolation:

He stated he hated his mother at one time and is try to establish something with her now. Mother does not accept that he is gay and likes black men. The last time he saw her it was a fight and he kicked her car.

Another field notes excerpt described a participant’s isolation from family:

His mother raised the children, yet didn’t raise him. Mother will not tell him who his father is and that really bothers him. Says siblings all have different fathers. Raised by grandparents who were abusive and alcoholics. Poor relationships and support from family.

Other field notes discussed participants’ feelings about family and friend relationships.

One participant quotation covered the “emotional trap of conflict among family and friends” and the fact that family issues are “not hopeful for the future”. In a separate field note, a peer noted that the participant said she “missed two doses dealing with my aunt.

She has issues with depression and I am her caretaker since my mom passed in 2008”.

Field notes also described experiences of overt social rejection from people whom participants believed to be friends -- experiences that led to social isolation:

I have no income except food stamps. People are only nice to me to get my stamps. Friends will not let me stay. They sometimes eat my food or take my meds unless I have sex with them. I will not have sex for food or a place to stay and sometimes I just lose my meds.

A peer documented a particularly upset participant who said, “I bought food for someone two days ago then they locked me out, chained the gate and told me I am trespassing. I do not understand. Everyone treats me bad”. A field note described similar rejection and emotional isolation coming from an intimate partner:

I was so afraid to tell my partner [about HIV+ status] because often I have heard her talk about her gay son and how worried it makes her that he is going to end up with “the package”. These are hurtful words... “the package”.

Peer interventionists described participants’ unstable intimate relationships that led to isolation, including domestic issues with obsessive, violent or controlling partners. One male partner was described as having been physically abusive with “rage issues” and “control issues” leading to fear and isolation. A field note vividly described another participant talking about contemplating breaking up with his partner. The peer said the participant was “feeling isolated and lonely despite staying with partner and nine other adults in a town home”. There were graphic details about the participant sometimes having to lock himself in a room to get away from his partner, as well as feeling that “other live-ins cause drama” in his life.

Many field notes told stories of participants being stigmatized due to their HIV status, and mentioned issues with trusting other people, which led to further isolation. One field note stated that the participant's "biggest issue is that he has no one to talk to about HIV stuff" except the parent study peer interventionists. Another field note described a participant discussing feeling stigmatized and further isolated by health care providers. The peer interventionist wrote that the participant no longer uses the drug store nearest his home to fill his HIV medications because it causes stress and anxiety. One participant told his peer interventionist that the pharmacy staff, "treat me bad, always call me out on co-pays, it is embarrassing when I'm unable to pay co-pays". As a result, this participant frequently doesn't fill his medications.

According to an interventionists' field notes, a participant desperately needed someone to talk with about HIV stigma issues and trust-related relationship issues. Another note mentioned that a participant "needed someone who she can trust and talk about self-issues" and that the participant was not feeling understood by anyone other than those in support groups or the peer interventionist. She stated that if she could not be in a safe and understanding environment, she would prefer to be alone. According to her peer interventionist, "she has a friend she can confide in, but she is reluctant to take that step".

One field note stated that a person described herself as "isolated and alone" despite being in a 20-year relationship. This participant discussed the social isolation in a matter of fact way, describing the isolation as "a choice" that she has made based on her personal situation. Participants often described isolation, loneliness, and lack of support as both past and current barriers to HIV medication adherence.

Subtheme: Loneliness

Field notes reflected that participants described themselves being lonely. Half of the participants who peer interventionists' described as feeling socially isolated also spoke of feelings of loneliness. Field notes described participants' loneliness ranging from "feeling extremely lonely and not knowing how to cope" to "attempting to cope with the loneliness by distracting himself with activities". Overall, 44% of the participants whose field notes were reviewed commented at least once to their peer that they were feeling alone in the world or lacking enough human interaction with family or friends. Over half of the field notes described isolation/loneliness/lack of support as a current barrier to HIV medication adherence.

Situational factors seemed to best describe the feelings of isolation and loneliness within the field notes. For example, notes included conversations with participants about having "only one good friend", being new to the community, having no children left at home, dealing with the death of a partner, or other significant family events. Such situations seemed to amplify the participants' feelings of isolation and loneliness. In the absence of someone to spend time with or talk to about day-to-day problems, the situations seemed to overwhelm participants. One participant told a peer interventionist that, "My daughter goes to college. When she leaves, I feel so lonely. I was so used to having a full house...with a child, so many people. Now I feel so lonely". Another participant described a similar situation in which friends once in his life were, but are no longer around, "I now have one good friend. Will sometimes let me bathe and eat there. I plan on going over there. All my other friends are shaky and will stab you in the back sadly."

Some participants talked with peers about trying to increase social activities to combat isolation and loneliness, but many participants told the peers that making friends and socializing was difficult for many participants due to the stigma of HIV and trust issues. One participant was quoted as saying that he “feels like doors are always being closed in his face”. Several peers wrote notes about conversations with participants regarding mistrust of people in general and several participants made goals of trusting people to build friendships. These goals included taking part in social activities and spending time with others simply because they enjoyed their company. The field notes indicated that many participants would like to have more contact with others. In particular, they wanted friends with whom they could take part in leisure activities. A few participants talked with peer interventionists about interacting with others in positive ways such as recent trips out of town with friends or participating in ongoing social events such as “staying social by square dancing with friends”, “acting out a character in a local theater with rehearsals throughout the year”, or “doing community service and attending church every Sunday”. However, the majority of participants indicated to peers that they needed to “find more social activities” and “go out and do more stuff”.

As a further demonstration of their need for social connectedness and increased human interaction, nearly one-third of participants told peer interventionists about the importance of their pets in their lives. The field notes were full of descriptions of pets as companions that filled participants’ time and need for social interaction. One peer wrote about a conversation with a participant who was raising more than 30 chickens as pets. The participant seemed to find the work of tending the chicken yard and caring for the animals to be meaningful because he had few friends or social activities. Pets described

in field notes included many dogs and cats and even a turtle. Peer interventionists said participants were quite willing to talk about their pets and seemed happier when talking about them. One peer commented, “Patient has adopted a stray dog who was hit by a car and is currently taking it to the vet on a regular basis. This keeps the patient busy thinking positively and in an altruistic way”. Another peer commented that a participant “likes to go home after work as cat is company for her. Being in a safe place within self. Has anxiety/trust issues, likes animals”. Based on the comments in the field notes, pets appear to fill a human interaction void for many participants.

Subtheme: Emotional Distress

Over 70% of the participants’ data analyzed in this study had some evidence of emotional distress in the field notes (26 participants of the 34 field notes analyzed). At least half of the field notes mentioned some form of depression or anxiety, though it was difficult to determine from the field notes whether the participants had been formally diagnosed with these mental health conditions or whether the peers made these characterizations. Of the 26 participants who appeared to have some issues with emotional distress, only 30% (7) were documented as being engaged in behavioral health care and/or taking medication for behavioral health by their peer interventionist. In some instances, the field notes mentioned “appointment scheduled with BH (behavioral health) caseworker” suggesting that participants were involved in behavioral health intervention. Descriptions of participants’ emotional distress ranged from vague statements such as, “I’m worried about my health” and “things have been depressing this week” to stories of emotional distress that led to volatile life situations. One peer interventionist described a particularly difficult day with a participant who had a long

history of emotional distress, had been diagnosed with depression and anxiety, but was not then in behavioral health treatment:

Participant came in today and was extremely upset. Had knife hidden in room.

BH (behavioral health) called. Security called. He did give knife to me. He feels I am the only one who cares. Taken to the emergency room where he continued to show aggressive and angry behavior.

Unsafe, violent situations were found to be a part of many participants' lives. The field notes reflected on many of the past events in participants' lives causing emotional distress. Participants told peers about physical/emotional abuse, molestation, rape, sex work, being used for sex by "friends" for food or a place to live, substance abuse, and deaths of and friends/family members/partners. Many participants had these emotional disturbances in the past and they continued into the time field notes were written. A peer recounted one woman's pain about losing the custody of her children. She believed that her legal problems all stemmed from her HIV according to the peer's field note:

She was handcuffed in front of children. States this memory haunts her. She cried during session #1. She continually states, "hates HIV"; it's not fair, she doesn't deserve. Feeling very depressed. She does not want to spiral or lose her kids again.

Several peer interventionists documented that participants' emotional state interfered with their ability to adhere to their HIV medication regimen. "Client stated that he gets depressed and goes into a 'mood'. It starts one day not taking his meds and this starts his downward trend to not being adherent to his meds." Another peer commented that, participant "hasn't kept doctor's appointments and is very depressed today.

Relationship with partner is BAD and getting worse. She is being emotionally and verbally abused.” When discussing another particularly stressful life event, a participant mentioned to his peer that “he is at a turning point in his life and stated that he doesn’t know what it will take to scare him to take his meds”.

At times, hopelessness and helplessness seemed particularly apparent in this vulnerable population at times, due to their emotional distress. One participant told his peer that “if he were to get sick no one would miss him”. Another participant shared with her peer that she “lived for her children and since they are in prison, she feels like she doesn’t have much to live for”. This field note went on to document a discussion between the peer and participant about how the hopelessness was causing lack of motivation to take meds. Emotional distress over the death of a partner or friend/family member also appeared to affect social support systems and medication adherence. In one of the field notes, a peer wrote about a participant:

He felt like he didn’t care much about how bad his health was, but he thought about his partner and family. He stated he hasn’t had a chance to process everything since his partner’s death and is feeling overwhelmed and stressed.

One peer documented, “sometimes he feels like nothing goes his way – feels like life is hard and sometimes wishes his life would end.” Other peers wrote that the participants felt hopeless and helpless and didn’t want to eat or get out of bed. One participant told his peer, “don’t look forward to nothing – if it happens it happens, if it doesn’t it doesn’t”. None of these participants were receiving behavioral health intervention at the time, though most had documentation of referral to behavioral health or case management in the field notes. One field note summed up the emotional state of many

(but not all) participants. A peer spoke with a participant who had recently been diagnosed with AIDS after several decades of a multi-regimen battle with HIV:

Feels his life is dark and hopeless; dealing with diagnosis of AIDS; trying to make it through the day, but his reality is that he may need to be in a nursing home due to not having an immune system. Client became emotional, needed to leave the room; dealing with facing his reality.

Theme 2: Constant Turmoil

Nearly all (94%) of the field notes analyzed in this study evidenced the constant turmoil participants' lives. The field notes were replete with examples and discussions about commotion, confusion, disturbance, and agitation with life circumstances. The peer interventionists described situations in which participants struggled daily with tangible financial problems including housing issues/homelessness, unemployment, lack of transportation, lack of sufficient or healthy food, and unsafe life situations. For nearly all participants, the constant turmoil resulted in a chaotic life. Participants perceived this state of turmoil, compounded by the lack of support from family and friends, as an insurmountable barrier to medication adherence.

Several peer interventionists' field notes described participants' chronic lack of employment, which resulted from a variety of reasons including disability due to HIV and other illnesses. One field note stated, "Patient is on disability and wants to return to work as custodian. That is a goal. Financially needs to work; behind on mortgage payments. Worried about financial and living situation". Another participant told the peer interventionist that although he is employed, he has been sick and has not been paid family medical leave or short term disability and is financially stressed. The peer

interventionist noted that the participant's utilities are in jeopardy and rent isn't being paid. According to the field note, these financial barriers issues were contributing to the participant's ongoing issues with HIV medication adherence. Field notes described the constant turmoil of daily life as overwhelming for participants:

Her spouse is unemployed and looking for work. Food stamps are used as their source of income. She is feeling pressure to get employment, but not sure she is physically capable. Disability has been denied twice and now has been appealed. Today reports being under a lot of stress due to trying to move. Found a new apartment that they would like to move into first of next month. Feels under pressure due to the fact that the housing voucher was already extended and they need to be out of where they are now in two weeks and have not heard back from the new place. Everything is up in limbo. States they will be leaving all belongings except clothes, TV and frying pan. Repeats the fact that they are material things and is having to start all over again. Participant says, "No one to help move. No money to pay any one, so we'll just leave except for what can be carried on the bus. That is if we can get place. If not, don't know what we will do".

Field notes vividly described the constant turmoil in participants' daily lives. For some participants who were homeless, the fixation on finding stable housing appeared to consume their lives. According to the peer interventionist, one participant, "believes homeless is #1 and if he has housing it will "fix everything" "period" according to the participant. The field note quoted the participant, "That is my problem (lack of housing)...I have nowhere to stay. Everything I own is in my car. I must keep all my

meds in car and they get hot or lost. It causes stress, constantly stress”. The following field note further demonstrated the turmoil of day-to-day life and where participants with chaotic lives appeared to prioritize medication adherence (low at times):

Housing will fix everything. Because I’m homeless....

Can’t Bathe

Don’t Eat

No Privacy

Can’t Have Anything

No Refrigerator/No Food

No Sleep

Always Hot or Cold

Always Looking Over My Shoulder

No Feeling of Security

This same participant also commented to the peer interventionist in the field note that having HIV was “the least of his worries”. Such a statement provides further evidence of the profound negative impact that constant turmoil had on this vulnerable population’s ability to adhere to HIV medication.

Field notes well documented that many participants’ chaotic life circumstances were compounded by emotional distress and disturbances. One field note described a participant with a diagnosed mental health condition who had been hospitalized for a physical health condition for two weeks. Following discharge, prescriptions for medications for all conditions, including HIV, were not filled or taken as prescribed due

to the constant turmoil that followed discharge. According to one peer interventionist's field notes,

Patient hospitalized for stroke. When discharged all possessions gone from apartment. Housing and credit issues. Repair in progress. Patient is now reconstructing life. Meds not available for two months. Memory issues. May have bipolar. Trapped in relationship. The participant has domestic issues - male partner; obsessive, distractive with anger issues. Patient has no support system.

Many field notes described lives full of chaos and turmoil lasting many years. One peer interventionist described a participant who, "feels like nothing goes his way – feels like life is hard and sometimes wishes life would end". This participant, had mental health and substance abuse issues, housing and unemployment trouble, and family issues that consumed his every moment. The peer interventionist noted, "He has been homeless. Sleeping in parks. No clothes. Pan handles and begs for food. People just don't know what he is or where he goes". Field notes included a history of time in prison, treatment for substance abuse, a history of physical/verbal abuse, intermittent connection to HIV and behavioral health care, and extremely poor self-reported social support. According to the peer interventionist, this participant was not seeing behavioral health and not taking HIV meds consistently.

Subtheme: Structural Vulnerability

Structural vulnerability refers to a population's or individual's position in a social hierarchy that imposes physical-emotional suffering in patterned ways (Quesada, Hart, & Bourgois, 2011) (Cartwright, 2011; Holmes, 2011). It can be applied to the poor, the sexually stigmatized, the medically uninsured, people of color, the disabled, the formerly

incarcerated, the drug addicted, etc (Quesada et al., 2011). Quesada et al. (2011) introduced the concept of structural vulnerability regarding the plight of Latino migrants in the United States who have been exploited, stigmatized, and criminalized as “illegal aliens” regardless of legal status. The impact of this positioning, or structural vulnerability, has taken a toll on their social and health status. Quesada et al. (2011) suggests that structural vulnerability may also apply to other populations that are vulnerable to economic exploitation and gender/sexual, racialized or other discrimination, such as individuals living with HIV. According to Quesada et al. (2011) an individual’s structural vulnerability is produced by his or her location in a hierarchical social order and is subject to power relationships and their effects.

This study offered clear examples of structural vulnerability among participants. One peer interventionist’s field notes described a participant who worried constantly about immigration issues and felt his partner of eight years controlled their relationship using the fear of deportation. During times the partner was out of town, he caused the participant great stress by making him turn off his computer and cell phone thus isolating him. The partner did not allow the participant to work, and strictly controlled his social activities/movements with others, thus increasing the vulnerability, isolation, lack of support, and emotional distress. One field note was particularly telling, “Wants to work; don’t like the idea of being kept by partner. Feels like a prisoner + being taken care of...”

Despite their vulnerability, participants shared intimate life details with the peer interventionists despite their vulnerability, which was a strong signal of their need for social support. This profound sharing spoke volumes to the peers’ ability to build

trusting relationships with participants. One field note described a participant who had been abandoned at birth, raised by abusive and alcoholic parents, spent his teenage years in foster homes separated from siblings, “experimented with and became experienced at” drugs and sex, lost everything he had in Hurricane Katrina, ended up with HIV, found his way to jail, and wound up homeless and hungry. According to the field note, this participant is “angry about life and feels like he owes children so they run all over him, don’t help out w/ rent, have their friends in & out – a lot of drugs – can’t say no”. Another interventionist described how a participant felt it necessary to carry a copy of his prescriptions in his wallet so that if he was stopped by police (due to his race), he could prove the legality of drugs he was taking.

One example of structural vulnerability participants felt appeared in a field note about a patient who had felt “persecuted” by others all his life. The interventionist wrote that, as a child, the participant had been physically abused by his father because he was gay. Paranoid issues ensued, and sustained substance use was documented. The peer interventionist wrote that the participant wanted to take care of his mother but was shunned, which pitted him against other family members. The participant had moved from shelter to shelter due to feelings of sabotage, and he felt people were talking and scheming behind his back because of his HIV status. The peer documented that the participant’s vulnerability had led to paranoia and feelings of wanting to sue others for defamation.

One participant in particular spoke at nearly every visit with his peer interventionist about feeling used by “friends” for sex in order to get housing, food, or clothing. The interventionist documented that the participant had to use his car as a way

to make money for food, saying “He took people places like a taxi”. During one visit, the interventionist wrote about a situation in which the participant had been locked out of the “place he was staying”. The participant told the interventionist that “a friend called police or threatens to call police if I don’t have money, beer, ciggs, or give out sex then I can’t stay”. The field note indicated that the participant felt very “used by people” socially. Other field notes reported similar incidents in which participants told peer interventionists of circumstances in which others “were nice to get (food) stamps then would not let me stay or would eat my food or take my meds that I paid for unless I had sex with them”. Reports of taking advantage of participants based on their lack of tangible assets, HIV status, mental stability, or past/present social situation were common in the field notes, demonstrates that structural vulnerability was a frequent and contributing occurrence in this population of adults struggling with adherence to HIV medications.

Quantitative Results: Effects of Demographic and Health Variables on Dimensions of Social Support

An exploratory quantitative analysis was conducted of the baseline MOS-SSS data to answer research questions that were not part of the planned inquiry of the parent studies (Enriquez & Cheng, 2016; Enriquez et al., 2015). The raw scores of the participants individual scores on each of the 19 MOS-SSS questions were received in a de-identified format from the parent-study investigators. The MOS-SSS questions contained 19 functional support items designed to measure the four dimensions of social support:

1. **Emotional/Informational Support:** the expression of positive affect, empathetic understanding, the encouragement of expressions of feelings, the offering of advice, information, feedback and guidance;
2. **Tangible Support:** the provision of material aid or behavioral assistance;
3. **Positive Social Interaction:** the availability of other persons to do fun things with you;
4. **Affectionate Support:** involving expressions of love and affection

As a baseline measure, the MOS-SSS measured social support of the parent-study participants at their enrollment visit of the study. The MOS-SSS has been extensively tested for construct validity of its social support measures. Definitions of and internal-consistency reliability of the validity measures have been reported (Sherbourne & Stewart, 1991). The MOS-SSS has been found to be a reliable measure of social support regarding health concepts including mental health, social activity, loneliness, family functioning and physical functioning (Sherbourne & Stewart, 1991). This scale's questions consist of four separate social support subscales and an overall functional social support index. Certain questions correspond to certain subscales and a lower score for an individual scale or for the overall support index indicates that a participant had lower social support in that particular area. To obtain a score for the participants in each subscale, the mean of the scores for each question contained in the subscale was calculated. To obtain an overall social support score, the mean of the scores for all 19 questions was calculated. Finally, to compare the calculated means to published means in the literature, individual subscale scores were transformed to a 0-100 scale using the

following formula, based on recommendations of the development and testing of the scale (Sherbourne & Stewart, 1991):

$$100 \times \frac{(\text{observed score} - \text{minimum possible score})}{(\text{maximum possible score} - \text{minimum possible score})}$$

Table 4. Transformed Total Social Support and Subscale Scores (n=49)

Dimension of Social Support	Questions from MOS-SSS	Minimum	Maximum	Transformed Mean Score	Standard Deviation
Total Social Support	1-19	19	95	62.11	26.28
Emotional/Informational Support	1-8	5	40	64.31	24.38
Tangible Support	9-12	4	20	64.29	32.75
Affectionate Support	13-15	3	15	63.10	33.17
Positive Social Interaction	16-18	3	15	61.05	32.47

Authors of the MOS-SSS recommended scoring and analyzing the social support subscales separately as well as considering tests that predict health outcomes controlling for sociodemographic variables, disease status and disease severity (Sherbourne & Stewart, 1991). In an effort to accomplish this goal, this research study answered two quantitative research questions:

- 1) How do adults living with HIV who have experienced repeated medication adherence challenges self-report total social support and social support within specific dimensions (emotional/informational, tangible, affectionate, and positive social interaction) as measured by the MOS-SSS?

2) Does the self-reported total social support score and/or social support score within specific dimensions (emotional/informational, tangible, affectionate, and positive social interaction) as measured by the MOS-SSS vary based on sociodemographic and health variables (i.e. age, gender, race/ethnicity, education, length of time living with HIV, or number of previous HIV medication regimens) in adults living with HIV who have experienced repeated medication adherence challenges?

A series of Pearson's product-moment correlations were computed to assess the relationships between the social support subscales. Strong correlations existed between all of the social support subscales. The strongest positive correlation was found between Affectionate Support and Positive Social Interaction, $r = .870$, $n=49$, $p < .0001$, indicating that participants who frequently self-reported a lack of persons with whom to do things also may have frequently reported lacking intimacy in relationships. Some of these same individuals also appeared to lack emotional/informational support, as a moderate to strong correlation existed between Affectionate Support and Emotional/Informational Support ($r = .738$, $n=49$, $p < .0001$) and between Emotional/Informational Support and Positive Social Interaction ($r = .734$, $n=49$, $p < .0001$). Tangible Support, on the other hand, appeared to be less connected to Emotional/Informational Support ($r = .496$, $n=49$, $p < .0001$) or Positive Social Interaction ($r = .613$, $n=49$, $p < .0001$) and though it was still statistically significant (Table 5).

Table 5. Pearson's Correlations between Social Support Subscales

		Transformed Emotional Informational Subscale	Transformed Tangible Subscale	Transformed Affectionate Subscale	Transformed Positive Social Interaction Subscale
Transformed Emotional Informational Subscale	Pearson's <i>r</i> Sig. (2- tailed) N		.496 .0001 49	.738 .0001 49	.734 .0001 49
Transformed Tangible Subscale	Pearson's <i>r</i> Sig. (2- tailed) N	.496 .0001 49		.710 .0001 49	.613 .0001 49
Transformed Affectionate Subscale	Pearson's <i>r</i> Sig. (2- tailed) N	.738 .0001 49	.710 .0001 49		.670 .0001 49
Transformed Positive Social Interaction Subscale	Pearson's <i>r</i> Sig. (2- tailed) N	.734 .0001 49	.613 .0001 49	.870 .0001 49	

Pearson's product-moment correlation coefficients were also calculated to assess the relationships between each of the five transformed scores (the total support score and the four transformed subscale scores) as dependent variables and the number of years living with HIV and the number of previous HIV regimens (independent variables). Although both positive and negative correlations were found, none of the correlations between the transformed social support scale scores and the number of years participants had been living with HIV was statistically significant. This indicated that a relationship, albeit a weak one, exists between social support and the number of years the participants have been living with HIV in this vulnerable population. The same conclusion was

reached for the potential correlation between the transformed social support scale scores and the number of previous HIV medication regimens participants self-reported suggesting that changes in social support or the number of HIV medication regimens did not affect one another positively or negatively in a significant way (Table 6).

Table 6. Pearson's Correlations between Social Support Subscales and Health Variables

		Number of Years Living with HIV	Number of Previous HIV Medication Regimens
Transformed Total Support	Pearson's <i>r</i>	.000	-.160
	Sig. (2-tailed)	.998	.278
	N	49	49
Transformed Emotional Informational Support	Pearson's <i>r</i>	.061	-.139
	Sig. (2-tailed)	.678	.345
	N	49	49
Transformed Tangible Support	Pearson's <i>r</i>	-.073	-.022
	Sig. (2-tailed)	.620	.880
	N	49	49
Transformed Affectionate Support	Pearson's <i>r</i>	-.106	-.207
	Sig. (2-tailed)	.467	.159
	N	49	49
Transformed Positive Social Interaction	Pearson's <i>r</i>	.057	-.178
	Sig. (2-tailed)	.697	.227
	N	49	49

A series of Spearman rank-order correlations were conducted to determine whether any relationships existed between each of the five transformed scores (the total support score and the four transformed subscale scores) as dependent variables and the participants' age and gender as independent variables. None of the relationships between total support or the dimensions of social support, age, and gender were found to be statistically significant (Table 7).

Table 7. Spearman's Rank-Order Correlations between Social Support Subscales and Selected Demographics

		Age	Gender
Transformed Total Support	Spearman's <i>rho</i>	.113	.132
	Sig. (2-tailed)	.439	.366
	N	49	49
Transformed Emotional Informational Support	Spearman's <i>rho</i>	.099	.194
	Sig. (2-tailed)	.499	.181
	N	49	49
Transformed Tangible Support	Spearman's <i>rho</i>	.038	.025
	Sig. (2-tailed)	.793	.866
	N	49	49
Transformed Affectionate Support	Spearman's <i>rho</i>	.130	.063
	Sig. (2-tailed)	.374	.667
	N	49	49
Transformed Positive Social Interaction	Spearman's <i>rho</i>	.151	.085
	Sig. (2-tailed)	.300	.559
	N	49	49

Factorial ANOVA testing was completed to analyze differences on the MOS-SSS total social support score between different age and education groups. Age had six groups and education had four discrete groups. Gender and ethnicity/race also were compared to the total social support score, with three and six groups respectively. Total social support score was compared to the length of time living with HIV, the number of previous HIV regimens and the setting for HIV care through regression analysis. A two-way analysis of variance model (Table 8) yielded non-significant main effects of the participants' age on the MOS-SSS total social support score ($F(3,41) = .713, p = .550$) as well education on the MOS-SSS total social support score ($F(3,41) = 1.237, p = .309$). Likewise, the interaction effect between age and education on the MOS-SSS total support score was non-significant ($F(6,35) = 1.510, p = .204$). A second model (Table 9) tested the main effects of gender, ethnicity/race, and setting of HIV care on the MOS-SSS total social support score. The main effects of participants' gender yielded an F ratio of $F(2,41) = .252, p = .778$, indicating that gender was not a significant factor affecting the MOS-SSS total social support score. Non-significant main effects were also found between total social support and ethnicity/race ($F(2,41) = .168, p = .846$) and total social support and setting of HIV care ($F(3,41) = .707, p = .554$). No significant interaction effects between gender, ethnicity/race, or setting of HIV care were found. Finally, a multiple linear regression model was calculated to predict the total social support score based on the length of time living with HIV and the number of previous HIV regimens received. A non-significant regression equation was found ($F(2,45) = .736, p = .485$), with an R^2 of .032. Based on this model, the number of years a participant had lived with

HIV, nor the number of previous HIV regimens received, were significant predictors of self-reported overall support based on the MOS-SSS.

Table 8. Factorial ANOVA – Total Social Support, Age, Education
Dependent Variable: Transformed Overall SS Mean

Source	Type III Sum of Squares	Df	Mean Square	F	Sig.
Model	191489.230 ^a	7	27355.604	38.773	.000
Age	1508.919	3	502.973	.713	.550
Education	2617.909	3	872.636	1.237	.309
Error	28926.884	41	705.534		
Total	220416.114	48			

a. R Squared = .869 (Adjusted R Squared = .846)

Table 9. Factorial ANOVA – Total Social Support, Gender, Ethnicity, HIV Care Setting
Dependent Variable: Transformed Overall SS Mean

Source	Type III Sum of Squares	Df	Mean Square	F	Sig.
Model	191749.315 ^a	8	23968.664	32.284	.000
Gender	374.339	2	187.169	.252	.778
Ethnicity	249.626	2	124.813	.168	.846
Setting	1573.926	3	524.642	.707	.554
Error	30440.051	41	742.440		
Total	222189.366	49			

a. R Squared = .863 (Adjusted R Squared = .836)

Pearson's chi-square testing (chi-square tests for independence) was performed to examine relationships between the demographic and health variables in this vulnerable population independent of the social support scores. To test the relationships in this manner, the number of years living with HIV and the number of previous HIV regimens were grouped as categorical variables to test with age, gender, race/ethnicity, and education and setting of HIV care. No significant relationships were found between the variables through chi-square testing with the exception of a statistically significant relationship between the number of previous HIV medication regimens reported by participants and the number of years that the participants had been living with HIV, $\chi^2(12, n = 48) = 35.32, p = .000$. The chi-square showed a significant relationship existed between these two variables (Table 10). To determine the strength of the relationship, post hoc testing was completed. Cramer's V testing was used to describe the magnitude of the association between categorical variables (nominal) because the contingency table in this case was larger than 2x2 (four categories of number of previous regimens and five categories for number of years living with HIV). The effect size was .495, showing a relatively strong association between the number of years that the participants have been living with HIV and the number of previous HIV regimens that participants self-reported (Table 11).

Table 10. Chi-Square Results – Previous HIV medication regimens and number of years living with HIV

	Value	Df	Asymptotic Significance (2-sided)
Pearson Chi-Square	35.323	12	.000
Likelihood Ratio	39.910	12	.000
Linear-by-Linear Association	10.493	1	.001
N of Valid Cases	48		

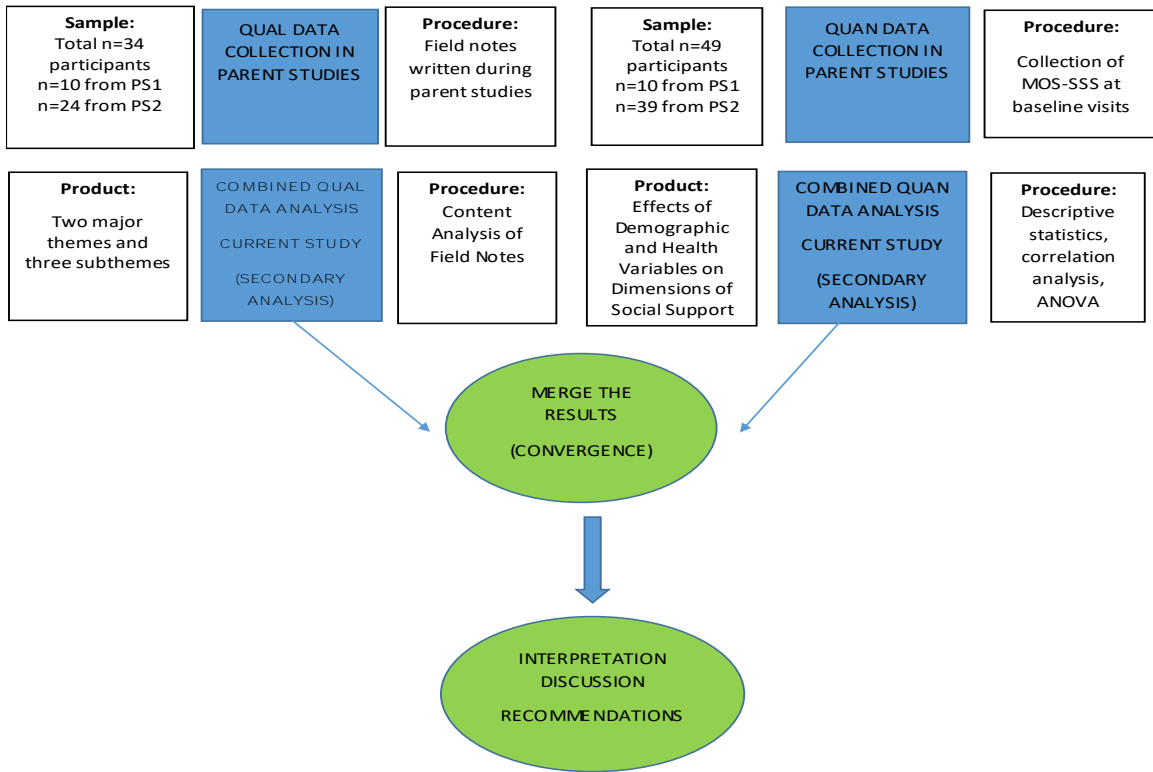
Table 11. Cramer’s V Results – Previous HIV medication regimens and number of years living with HIV

		Value	Approximate Significance
Nominal by Nominal	Phi	.858	.000
	Cramer’s V	.495	.000
N of Valid Cases		48	

Convergence/Divergence of Qualitative and Quantitative Data

By mixing of research methodologies in a convergent design (Figure 3), this research study answered the question, “What is the relationship between self-reported total social support, social support within the specific dimensions of the MOS-SSS and the perceptions of social support in adults living with HIV who have experienced repeated medication adherence challenges?”

Figure 2. Mixed Method Convergent Design



Data Triangulation

This study used a multiple triangulation approach to mixed methodology. When two or more types of triangulation are used in conjunction, greater insight can be achieved into the phenomenon of interest. This study used data triangulation and methodological triangulation. Data triangulation uses multiple data sources with the same focus to provide a broader range of information about the research. Denzin and Lincoln (2011) outline three types of data triangulation: time, space, and person. In this study, data triangulation was accomplished by obtaining data from two parent studies (person) that were conducted at four research settings (space). Methodological triangulation combines multiple methods through study design for data collection and

analysis (Creswell, 2013; Creswell & Clark, 2007). This study was completed using convergent parallel design, analyzing both qualitative and quantitative data in the current study that had been previously collected concurrently in the parent studies. In the current study two parallel strands of data analysis were conducted independently and only brought together during the interpretation phase of data analysis. The current study merged qualitative data from parent study 1 (Enriquez et al., 2015) and parent study 2 (Enriquez & Cheng, 2016) followed by a separate merger of quantitative data from parent study 1 (Enriquez et al., 2015) and parent study 2 (Enriquez & Cheng, 2016). Each new merged data set was analyzed separately. Per mixed methodology, the qualitative and quantitative data were synthesized and compared in the final analysis (Bryman, 2006; Greene et al., 1989).

For continuity, the MOS-SSS dimension definitions are provided here. In the case of low social support in the following dimensions, the definitions would be as follows:

Emotional/Informational Support: lack of expressions of positive affect, empathetic understanding/stigma, encouragement of expressions of feelings; little or no offering of advice, information, feedback or guidance;

Tangible Support: lack of material aid or behavioral assistance;

Positive Social Interaction: lack of availability of persons to do fun things;

Affectionate Support: lack of expressions of love and affection.

The following table provides examples of convergent data combining quantitative data from the MOS-SSS dimensions of social support with qualitative data excerpts within each theme (Table 12).

Table 12. Mixed Methods Triangulation Results			
	QUALITATIVE THEMES WITH SUPPORTIVE QUOTES		
MOS-SSS QUANTITATIVE DATA BY DIMENSION (Transformed Scale 0-100)	EXTREME ISOLATION Loneliness	CONSTANT TURMOIL Structural Vulnerability Emotional Distress	Cross-Cutting Quotes Across Themes and Dimensions
Emotional/Informational Social Support 64.31	“I was so afraid to tell my partner [about HIV+ status] because often I have heard her talk about her gay son and how worried this makes her that he is going to end up with “the package”. These are hurtful words... “the package”.	Everything is up in limbo. States they will be leaving all belongings except clothes, TV and frying pan. Repeats the fact that they are material things and is having to start all over again. Participant says, “No one to help move. No money to pay any one, so we’ll just leave except for what can be carried on the bus. That is if we can get place. If not, don’t know what we will do”.	Further demonstrating the turmoil of day-to-day life and where participants appeared to prioritize medication adherence (low at times) based on such chaotic lives with little to no emotional or affectionate support. A peer interventionist documented the following description from a participant who believed that, housing will fix everything:
Tangible Social Support 64.29	“I have no income except food stamps. People are only nice to me to get my stamps. Friends will not let me stay. They sometimes eat my food or take my meds unless I have sex with them. I will not have sex for food or a place to stay and sometimes I just lose my meds.”	“That is my problem (lack of housing)...I have nowhere to stay. Everything I own is in my car. I must keep all my meds in car and they get hot or lost. It causes stress, constantly stress”.	“Because I’m homeless.... Can’t Bathe Don’t Eat No Privacy
Affectionate Social Support 63.11	“Did four years in Texas jail. Had the best looking MF in there. Liked jail. Was going to let me out six months early...said no and stayed. Got caught with a man in bathroom. Was put in hole three months. Now out and just doing time. Just coasting.”	Patient hospitalized for stroke. When discharged all possessions gone from apartment. Housing and credit issues. Repair in progress. Patient is now reconstructing life. Meds not available for two months. Memory issues. May have bipolar. Trapped in relationship. The participant has unsafe domestic issues - male partner; obsessive, distractive with anger issues. Patient has no support system.	Can’t Have Anything No Refrigerator No Food No Sleep Always Hot or Cold Always Looking Over My Shoulder No Feeling of Security”.

<p>Positive Social Interaction 61.05</p>	<p>One peer wrote about a conversation with a participant who was raising more than 30 chickens as pets. The participant seemed to find the work of tending to the chicken yard and caring for animals to be meaningful because he had few friends or things to do socially.</p>	<p>Participant was locked out of the “place he was staying”. The participant told the interventionist that “a friend called police or threatens to call police if I don’t have money, beer, ciggs, or give out sex then I can’t stay”. The field note indicated that the participant felt very “used by people” socially.</p>	<p>This same participant also commented to the peer interventionist in the field note that having HIV was “the least of his worries”.</p>
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CHAPTER 5

Conclusions and Recommendations

Discussion of Findings

This study employed mixed methodology to examine perceived social support among adults living with HIV who had been prescribed ART medication but did not have a suppressed HIV viral load. Numerous research studies in the HIV literature have documented that social support is a key factor influencing ART medication adherence (Edwards, 2006; Huynh et al., 2013; Mills et al., 2006; Simoni, Frick, et al., 2006; Simoni et al., 2002; Simoni et al., 2007; Vyavaharkar et al., 2012). Although many studies have focused on HIV medication adherence, few have targeted adults who have experienced repeated medication adherence challenges (Conn et al., 2015; Enriquez et al., 2015; Enriquez, Lackey, O'Connor, & McKinsey, 2004). This chapter discusses the present study's research findings, limitations, clinical implications, and recommendations for future research.

Discussion of Qualitative Findings

Study participants were predominantly a sample of adults of color living in poverty. Qualitative data showed that most participants lived chaotic lives and many had poor relationships with family, friends, and domestic partners. Many participants had been victims of abuse/violence, had emotional disturbances, and distrusted others making them vulnerable to society in general and more likely to experience poor health outcomes.

Two distinct, but interconnected themes emerged from the data: extreme isolation and constant turmoil. The overarching themes were associated with a lack of social support in this group of adults living with HIV that had experienced repeated challenges with medication adherence. Several associated subthemes, including loneliness, structural vulnerability, and emotional distress were also commonly described among the participants in this study and contributed to the discussion related to role of perceived social support in this population. The study's results in this population are congruent with Houston et al. (2015) who concluded that for many adults living with HIV, social support of any type is perceived as being scarce or nonexistent.

Extreme Isolation

The majority of study participants described experiences of extreme isolation in the field notes. These experiences included social and emotional isolation from family, friends, and significant others. Extreme isolation has been linked to the subjective concept of loneliness (Turan et al., 2016). At their most basic level, social and emotional isolation have been defined as the lack of meaningful and sustained communication or as having minimal contact with family, friends, or the wider community (Pikhartova et al., 2016). More than 80% of the participants whose field notes were analyzed described some form of extreme isolation: poor relationships with family and friends, low levels of participation in social activities and/or the absence of someone to talk to or with about having HIV. Their disease left them feeling isolated and unwilling to engage in relationships or social activities.

For many participants, disclosure of HIV status was a key factor in the lack of relationships. Field notes recounted stories of participants being stigmatized due to their

HIV status and issues with trusting other people, which led to further isolation. Field notes described numerous situations in which participants had been rejected family, partners, or friends after disclosing their HIV status. Many participants found it difficult to make friends and socialize due to the stigma of HIV and trust issues. This rejection led to the disruption of relationships and subsequent feelings of social and emotional isolation. Participants described experiences of overt social rejection from people whom participants believed to be friends, which led to social isolation. Unstable intimate relationships of participants also led to isolation. Participants appeared to desperately need someone to talk with about HIV stigma and other trust-related issues with relationships. Isolation, loneliness, and lack of support were commonly cited as both past and current barriers to HIV medication adherence. Power relationships and gender-based violence have been documented in the HIV literature in relationship to vulnerabilities and well-being of persons disclosing their HIV status (Dunkle et al., 2004; Shannon et al., 2008). The impact of structural vulnerability took its toll on the social and health status of the participants.

Situational factors seemed to contribute to feelings of isolation and loneliness found in the field notes. For example, peers captured conversations with participants about having “only one good friend”, being new to the community, having no children left at home, dealing with the death of a partner, or other significant family events. These types of situations seemed to amplify the feelings of isolation and loneliness that participants routinely discussed with the peers. Notably, some of these situations, such as having a child leave home, are not unique to this vulnerable population. However, in the absence of a support system, such situations seemed to overwhelm for participants. A large body

of literature dating back to Berkman and Syme (1979) identified that social support offered powerful health benefits and that social isolation was a significant risk factor for mortality. People lacking human contact often feel lonely, though social isolation and loneliness are not always significantly correlated (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015). Loneliness refers to the more subjective state describing feelings of being alone, separated, or apart from others (Cornwell & Waite, 2009). In this study, extreme isolation and loneliness appeared to go hand-in-hand, with greater than half of the field notes analyzed containing written notes indicating that isolation and loneliness were significant barriers to ART medication adherence for participants.

Constant Turmoil

Nearly all the field notes analyzed in this study showed evidence of constant turmoil in the participants' lives. Field notes were replete with examples and discussions of commotion, confusion, disturbance, and agitation with life circumstances. Peer interventionists documented situations in which participants struggled daily with tangible and financial support including housing issues/homelessness, unemployment, lack of transportation, lack of sufficient or healthy food, and unsafe life situations. Many participants perceived the state of turmoil, compounded by the lack of support from family and friends, as an insurmountable barrier to HIV medication adherence.

Evidence of emotional distress was also prevalent in the field notes. This distress included physical/emotional abuse, molestation, rape, sex work, being used for sex by "friends" for food or a place to live, substance abuse, and deaths of and friends/family members/partners. Many participants had experienced these emotional disturbances in the past and they endured into the present. The field notes contained some fatalistic

comments. At times, hopelessness and helplessness seemed particularly apparent in this vulnerable population due to their emotional distress. This study's results are congruent with the literature because in general, studies indicate that access to overall social support promotes adherence to ART in adults living with HIV (Lehavot et al., 2011; Ruanjahn et al., 2010). Huynh et al. (2013) observed that optimal HIV medication adherence was associated both with overall social support and favorable mental health status. This study's qualitative data suggested that participants' emotional state interfered with their ability to adhere to their HIV medication.

This study supports the earlier work by Scheurer et al. (2012) in which unsafe, violent, or unstable life situations involving emotional distress were common in study participants' lives. Of the participants in this study with evidence of emotional distress in field notes, only one in three were documented as being engaged in behavioral health care and/or taking medication for behavioral health. This finding supports an earlier study in a large sample of HIV patients identified as having the unmet need of counseling, significantly reduced odds of being adherent were found (OR 0.32, $p < .01$), and having the unmet need of a support group significantly increased the odds of not taking ART medication (OR 3, $p < .05$) (Scheurer et al., 2012). Current or past alcohol and/or substance use in this study was associated with constant turmoil within life circumstances. Substance abuse, compounded by emotional distress was frequent among this group of adults with repeated challenges to ART medication adherence.

Discussion of Quantitative Findings

Evaluations of the dimensions of social support using the MOS-SSS have been published for several patient populations (AbuRuz, Alaloul, Saifan, Masa'Deh, &

Abusalem, 2016; Evon, Esserman, Ramcharran, Bonner, & Fried, 2011; Faraji et al., 2015; Gallegos-Carrillo, García-Peña, Durán-Muñoz, Flores, & Salmeron, 2009; Kelly et al., 2014; Li, Chen, Chang, Chou, & Chen, 2015; Raggi et al., 2015; Sherbourne & Stewart, 1991; Yu, Lee, Woo, & Hui, 2006). Previous evaluations of the MOS-SSS with other adult populations were used as a basis for comparison to the transformed scores from the current study, which focused on a group of adults who had experienced challenges with HIV medication adherence (Table 13). The authors of the MOS-SSS recommended scoring and analyzing the social support subscales separately as well as considering tests to predict health outcomes while controlling for sociodemographic variables, disease status and disease severity (Sherbourne & Stewart, 1991). To compare the calculated means to published means in the literature, individual subscale scores were transformed to a 0-100 scale, based on recommendations of the development and testing of the scale (Sherbourne & Stewart, 1991).

Using a U.S. general population, Sherbourne and Stewart (1991) reported a mean overall social support score of 70 on the MOS-SSS, with subscale scores ranging from 70 to 74. In comparison, much lower scores were self-reported by the vulnerable participants in the current study who had a mean overall social support score of 62, with subscale scores ranging from 61 to 64. This study's findings reveal that overall social support is low in this vulnerable population, especially when compared to the general population and to adults living with other chronic health conditions.

Table 13. Comparison of MOS-SSS Dimension Data in Different Populations					
Study and Population	Mean Overall Social Support Score	Mean Emotional/ Informational Social Support	Mean Tangible Social Support	Mean Affectionate Social Support	Mean Positive Social Interaction
Studies with Adults Living with HIV					
Current Study Adults living with HIV with repeated challenges to HIV medication adherence in the Midwest United States	62	64	64	63	61
Kelly (2014) Adults newly diagnosed with HIV in the United States	65	60	69	72	65
Faraji, et al (2015) Adults living with HIV in Tehran, Iran	68-85 Data based on demographic variables	Not reported	Not reported	Not reported	Not reported
MOS-SSS Results in United States General Population					
Sherbourne, et al (1991) United States general population	70	Range from 69.6 – 73.7	Range from 69.6 – 73.7	Range from 69.6 – 73.7	Range from 69.6 – 73.7
Studies in Populations of Adults with Other Chronic Diseases					
AbuRuz, et al (2016) Adult patients in Saudi Arabia with CHF	66	61	85	74	64
Evon, et al (2011) Adults living with chronic hepatitis C in the United States	83	84	81	92	83
Gallegos-Carrillo, et al (2009) Older (>55) Mexican adults with diabetes	Dichotomized at score of 50 64% High 36% Low	Dichotomized at score of 50 64% High 36% Low	Dichotomized at score of 50 72% High 28% Low	Dichotomized at score of 50 67% High 33% Low	Dichotomized at score of 50 60% High 40% Low
Li, et al (2014) Adults cervical cancer survivors 5+ years post treatment in Taiwan	81	81	78	83	81
Raggi, et al (2015) Adults with chronic migraines and medication overuse in the United States	78	Not reported	Not reported	Not reported	Not reported
Yu, et al (2006) Elderly adults (>60) in Hong Kong with CHF	57	44	67	63	54

Other researchers have reported social support scores in an adult HIV population that were lower than the general population (Kelly et al., 2014). However, in the Kelly et al. study (2014), it is important to note that scores may have been higher than those found in the current study because those study participants were adults newly diagnosed with HIV. Newly diagnosed individuals likely had not been struggling with ART medication adherence. The current study supports the findings of the Kelly et al. (2014) study that social support should be assessed when trying to problem solve low ART adherence and that strategies to overcome barriers to social support must be addressed. Evon et al. (2011) reported that physical, mental, social, and occupational challenges exist and accompany treatment for hepatitis C, but the investigators found much higher social support existed in her sample of nearly 400 patients who were living with chronic hepatitis C. The mean overall social support score in this sample was 83, with subscale scores ranging from 81 to 92, Evon et al. (2011), suggesting that adults living with and being treated for chronic hepatitis C may not experience similar social support issues as adults living with HIV, especially adults who have experienced repeated challenges with ART medication adherence. Studies in other chronic diseases also reported higher overall and dimensional social support scores, further supporting the theory that baseline social support for the vulnerable population of adults in this study is lower than that of the general U.S. population and that of many with other chronic diseases. Low social support may contribute to participants' difficulty with ART medication adherence and ultimately morbidity and mortality in relation to HIV (Genberg et al., 2016).

In this study, strong correlations existed between the four social support subscales. The strongest positive correlation was found between affectionate support and positive

social interaction, indicating that participants frequently self-reporting a lack of persons to do things with also may have frequently reported a lack of strong positive relationships. This finding is consistent with a study by Raboud et al. (2011) who suggested that promoting positive social interaction might provide the best opportunity for intervention because suboptimal social support in this area strongly predicted medication adherence. The results of this study suggest the importance of exploring interventions with emotional/informational support may also be important to explore because moderate to strong correlations existed between emotional/informational support and affectionate support and also between emotional/ informational support and positive social interaction. Tangible Support, on the other hand, appeared to be less connected to Emotional/Informational Support or Positive Social Interaction. In a longitudinal study by Kelly et al. (2014), baseline tangible support scores were statistically significantly higher ($p = .02$) in adults newly diagnosed with HIV who subsequently had at least 95% adherence to ART. Overall social support scores greater than 50 (OR 2.36, $p = .05$) and tangible support scores greater than 50 (OR 3.01, $p = .02$) predicted adherence equal to or greater than 95% (Kelly et al., 2014). Interestingly, Kelly et al. (2014) reported the assumption that these two specific social support sub-scores (tangible support and positive social interaction) drove the overall significant social support findings related to HIV medication adherence (OR 2.36, $p = .05$). In this study sample, MOS-SSS social support dimension scores were similar to the Kelly et al. (2014) study (all very low), though the dimension scores in this study were slightly lower (ranging from 61-64). This finding may depict differences between Kelly's newly diagnosed HIV population and this study's population, which had been struggling with HIV medication adherence for a

number of years. This study found no significant variation between self-reported overall social support scores or between social support subscale scores based on age or health variables.

Discussion of Convergence/Divergence between Qualitative and Quantitative Data

Convergence – complementary findings from different data sources (qualitative and quantitative) -- strengthens the validity of study results. Divergence, on the other hand, refers to conflicting or contradictory results. Such dissimilar data may help explain more complex relationships between study variables or within study questions. In this study, extreme isolation and constant turmoil were common themes associated with poor overall social support and these data converged with low social support scores within dimensions of social support as measured by the MOS-SSS. Extreme isolation and loneliness corresponded best with affectionate support and positive social interaction in terms of the MOS-SSS dimensions.

Convergent qualitative data excerpts corresponded with low quantitative social support scores in every dimension, confirming that adults living with HIV and struggling with repeated challenges to HIV medication adherence lack social support in many areas of their lives. However, many of the qualitative excerpts in this study corresponded with tangible and emotional/informational support, which was a divergent finding considering that most participants self-scored these two dimensions higher than affectionate support or positive social interaction.

According to the qualitative data, social support affected participants' ability to remain adherent to ART. This relationship needs to be empirically tested in this population. Although positive and negative correlations were found, the quantitative data

lacked statistical significance to support relationships between the dimensions of social support and specific demographic or health variables. Analysis of variance models also yielded non-significant main effects or interaction results for relationships between the variables and the MOS-SSS total social support score. It is conceivable that the non-significant results in this study are due to a lack of power as this was a secondary analysis of data. A larger study with a pre-planned power analysis is warranted to confirm these results.

However, not surprisingly, when the relationship was tested independent of the social support scores, a statistically significant relationship was found between the number of previous HIV medication regimens participants' reported and the number of years that the participants had been living with HIV. A relatively strong association between the number of years participants had been living with HIV and the number of previous HIV regimens participants reported may have indicated that the participants who had lived with HIV the longest also had endured more medication regimen changes. The number of previous regimens and the number of years living with HIV appear to be important factors for this vulnerable population of adults who are struggling with repeated challenges with HIV medication adherence. Most study participants had been living with HIV for a long time and so these individuals had experienced older HIV drug regimens with many side effects and a higher pill burden, which added to the difficulty of tolerating such regimens. These circumstances may have contributed to a lack of confidence in the belief that they would ever be able to adhere to an ART medication regimen.

Limitations

This study has several limitations. First, qualitative data used for this secondary analysis were from field notes written by peer interventionists in the parent studies (Enriquez & Cheng, 2016; Enriquez et al., 2015). Field note data are neither as reliable nor valid as audio- or video-taped data, but they were necessary because of the population's vulnerability and the need to foster the most optimal participant-interventionist relationship for collecting data (Dowell, Beeber, & Schwartz, 2015). The use of field notes as a qualitative methodology has occurred in research with vulnerable populations in the community (Lucero et al., 2016; Sebastian & Bushy, 1999). Peer interventionists took field notes about what participants said during study visits and pertinent information could have been lost in translation from participant to interventionist when writing field notes (Enriquez & Cheng, 2016; Enriquez et al., 2015). Second, quantitative data from the parent studies (MOS-SSS data) were self-reported patient data and thus may have introduced threats to validity (Shadish, Cook, & Campbell, 2002). Third, data from this study may not be generalizable to other populations of adults with HIV medication adherence challenges or to adults with other chronic diseases and repeated medication adherence challenges. Future replication studies could use a more diverse sample of adults who have other chronic diseases and who experience repeated medication adherence challenges or use adults with HIV who are identified as at-risk for adherence challenges due to lack of social support.

Recommendations

In the parent studies, understanding the effect of social support on medication adherence was not a primary endpoint, but rather social support was viewed as a mediator

for the peer intervention in relationship to medication adherence (Enriquez & Cheng, 2016; Enriquez et al., 2015). Further study measuring the direct impact of social support on antiretroviral adherence as a primary endpoint could add to the literature in this vulnerable population. Therefore, a study of the correlation over time between the total social support scores and social support dimension scores in relation to ART medication adherence measures is warranted.

The MOS-SSS is based on *perceived availability of functional support* as recommended by Cohen and Syme, Cohen and Wills, and House and Kahn because of the belief that a person's perceptions of available support are most important (Cohen & Syme, 1985; Cohen & Wills, 1985; House et al., 1985). The fact that a person does not receive support during a given time period does not mean that the person is unsupported. Received support is confounded with need and may not accurately reflect the amount of support that is available to a person. Further study of perceived vs. received social support in this study's vulnerable population would add to the sparse existing literature. A study conducted in San Francisco identified a population with poor adherence and provided them with HIV treatment-specific support (Taylor et al., 2010). The authors found no change in overall social support or adherence to ART. However, research suggested that the need for a paradigm shift in research to consider both perceived and received social support. The optimal match may be found in a better understanding of support *need* (perceived) along with support *provision* (received). A study measuring perceived social support prior to a social support intervention followed by a measurement of received social support would provide for interesting data on this match of perceived need vs. received support and could help in planning future adherence interventions.

Participants in this secondary analysis participated in a peer intervention aimed at improving HIV medication adherence. The peer interventionists recruited for the study were all HIV-positive adults who had been successful in maintaining adherence and had a suppressed viral load over time. A qualitative study of the peers' perceptions about providing social support in the parent studies would provide new information not currently reported in the literature and help in planning future interventions.

Finally, this study's results warrant exploring the combination of social support and behavioral health components in an adherence intervention pilot study. Behavioral health issues were prevalent in participants' lives. These data correlate with published data from Huynh et al. (2013) who suggested that although social support correlated with increased adherence, future adherence interventions should consider adding a mental health treatment component to social support dimensions for best effect.

Conclusions and Implications

Extreme isolation and loneliness resonated as important themes that contributed to the inability to adhere to ART medications for the study participants. To combat the isolation and loneliness, some participants talked with the peer interventionists about trying to increase social activities. Goals included participating in social activities with others and spending time with others simply because they enjoyed their company. Participants shared intimate details of their lives with the peer interventionists despite their vulnerability, which highlighted participants' need for social support in the participants' lives. This profound sharing seemed a testament to the peers' ability to build trusting relationships with the participants. The chaotic nature of participants' lives led to constant turmoil that, when coupled with extreme isolation, overwhelmed

participants in terms of HIV medication adherence over time. Some participants had taken their medication on and off, but in a world of constant turmoil with no support system, remembering to take medication or making medication a priority was not a sustainable behavior.

Numerous research studies in the HIV literature have documented social support as a key factor influencing antiretroviral adherence. Lack of social support has been associated with a lower level of adherence to ART. Numerous studies have suggested that social support may improve quality of life, influence adherence to HIV medication and lead to improved outcomes in adults living with HIV. However, few studies have examined adults living with HIV who have had repeated challenges with medication adherence exists. In response, the present study explored perceived social support in a sample of adults living with HIV who had experienced repeated challenges taking HIV medications. The goal was to understand perceived social support in relationship to HIV medication adherence and to identify correlates among the dimensions of social support (emotional/informational, tangible, affectionate, and positive social interaction) and demographic and health variables (i.e. age, gender, race/ethnicity, education, length of time living with HIV, and number of previous HIV medication regimens).

In this study, two distinct, but interconnected concepts were associated with the lack of social support: extreme isolation and constant turmoil. Associated subthemes, including loneliness, structural vulnerability, and emotional distress were also commonly described by participants and contributed to the discussion regarding the role of perceived social support in this population. Overall social support was low in this vulnerable population, especially when compared to the general population and to adults living with

other chronic health conditions. Strong correlations existed between the four social support subscales with the MOS-SSS. The strongest positive correlation was found between affectionate support and positive social interaction, indicating that participants who frequently self-reported a lack of persons to do things with may also frequently lack strong positive relationships in their lives. This study's results suggest the importance of exploring interventions with an emotional/informational support component because moderate to strong correlations existed between emotional/informational support and affectionate support and also between emotional/ informational support and positive social interaction. This study found no significant variation between self-reported overall social support scores or between social support subscale scores based on age or health variables. Social support, according to the qualitative data, appeared to affect participants' ability to adhere to ART medication regimens. This relationship needs to be empirically tested in this population. In the presence of socioeconomic and psychological stressors, functional social support appears to buffer the stress of health-related behavioral issues such as repeated challenges with medication adherence. This, in turn, has the potential to contribute to HIV disease progression and in turn increase morbidity and mortality. The results of this study suggest that individuals who have experienced repeated challenges with HIV medication adherence lack many dimensions of social support. Hence, no buffer exists for this vulnerable population contributing to an inability to adhere to HIV medications as prescribed.

Appendix A

The MOS Social Support Survey

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you is you need it? **Circle one number on each line.**

Emotional/informational support	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1. Someone you can count on to listen to you when you need to talk.	1	2	3	4	5
2. Someone to give you information to help you understand a situation	1	2	3	4	5
3. Someone to give you good advice about crisis.	1	2	3	4	5
4. Someone to confide in or talk to about yourself or your problems.	1	2	3	4	5
5. Someone whose advice you really want.	1	2	3	4	5
6. Someone to share your most private worries and fears with.	1	2	3	4	5
7. Someone to turn to for suggestions about how to deal with personal problems	1	2	3	4	5
8. Someone who understands your problems	1	2	3	4	5

Tangible support	None of the time	A little of the time	Some of the time	Most of the time	All of the time
9. Someone to help you if you were confined to bed.	1	2	3	4	5
10. Someone to take you to the doctor if you needed it.	1	2	3	4	5
11. Someone to prepare your meals if you were unable to do it yourself.	1	2	3	4	5
12. Someone to help with daily chores if you were sick.	1	2	3	4	5

Affectionate support	None of the time	A little of the time	Some of the time	Most of the time	All of the time
13. Someone who shows you love and affection.	1	2	3	4	5
14. Someone to love you and make you feel wanted.	1	2	3	4	5
15. Someone who hugs you.	1	2	3	4	5

Positive social interaction	None of the time	A little of the time	Some of the time	Most of the time	All of the time
16. Someone to have a good time with	1	2	3	4	5
17. Someone to get together with for relaxation.	1	2	3	4	5
18. Someone to do something enjoyable with.	1	2	3	4	5

Additional Item	None of the time	A little of the time	Some of the time	Most of the time	All of the time
19. Someone to do things with to help you get your mind off things.	1	2	3	4	5

Appendix B

Demographic and Health Data

Age:

____ 18-24 ____ 25-34 ____ 35-44 ____ 45+

Gender:

____ male ____ female ____ transgender

Ethnicity/Race:

____ Caucasian/White

____ African American/Black

____ Latino/Hispanic

____ Native American

____ Asian/Pacific Islander

____ Other

Education:

____ did not finish high school

____ high school graduate/GED

____ some college

____ college graduate

Years living with HIV:

_____ (number of years)

Previous HIV medication regimens:

_____ (number of medication regimens)

Current HIV medication regimen (list names of HIV medications):

Do you take any other medications? ____ Yes ____ No

If yes, how many medications (other than for HIV) do you take? _____

Times per day you take HIV medications:

____ once a day ____ twice a day

Appendix C

Guide for Taking Field Notes

Make note of the following at each study session:

Participant I.D. number: _____

Date of session: _____

During (and after) the session, take notes on the lined notebook paper about what you as the facilitator ask/said and what the participant asked/said during the session.

In addition to taking notes about what was said, please also:

Note the location where session takes place: [where the conversation takes place – examples: conference room, office, exam room, cafeteria, etc.]

Describe location: anyone else present? any interruptions? quiet? Or was there noise from outside the room?

Note your observations about the participant: was the participant calm? shy? nervous? happy? sad? sleepy? alert? bored? attentive?

Comment on the process of the actual session: did you feel it went well, did not go well (if not, why?)

Make some personal notes: how did you (as the facilitator) feel during the session?

Examples: I felt comfortable (why?).....

I felt uncomfortable - why? (give specific example).....

I felt like the participant answered questions openly at first but then shut down when I asked more about his intimate relationship with his partner.

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VITA

Deborah Mercier was born December 17, 1966, in Kansas City, Missouri. She graduated in 1988 from Southwest Missouri State University (now Missouri State University) with a Bachelor of Science degree in Business Management. She quickly returned to school to begin her path towards a nursing career, and earned a diploma in nursing from Missouri Baptist School of Nursing in 1990 and became a registered nurse in 1992. She completed a Baccalaureate degree in Nursing in 2003, followed by her Master's degree in 2005 from Goldfarb School of Nursing at Barnes-Jewish College. She began her doctoral degree in the summer of 2010 at the University of Missouri – St. Louis, where she completed one year of coursework. After transferring to the University of Missouri – Columbia in 2012, she continued her doctoral work and completed the journey in December 2016.

Deborah has been involved in health care since 1992. She has a clinical, teaching, program development and leadership background within the specialty areas of oncology, infectious disease and public health. She has held leadership roles within large public health systems, acute healthcare facilities, multi-hospital systems, outpatient clinics, and educational settings. She has been a nurse educator since 2003, teaching adjunct or full-time in traditional undergraduate programs as well as RN-to-BSN completion and graduate nursing programs. Deborah has been involved in visioning, curriculum planning and development of nursing and public health programs as well as program assessment and accreditation.

Following completion of her terminal degree, Deborah plans to continue to facilitate the growth of nursing, public health and other health sciences while working on research projects that further positive health outcomes for patients. Her research interest area(s) include social support and health outcomes, qualitative research methods, health and social justice, peer interventions, and community-based participatory research.