

The Role of Sense of Belonging and Hope in Medication Adherence in Schizophrenia

By

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Dedication

This dissertation is dedicated to my beloved husband, Ugur Barut, for his support, patience, and incredible love, and also to my father, Jack K. Carter, this is for you.

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CHAPTER 1

Introduction

Overview

The purpose of this dissertation was to explore the associations of sense of belonging and hope with medication adherence in persons with schizophrenia. While the literature on medication non-adherence in persons with schizophrenia is extensive, literature exploring how medication-taking behaviors may be impacted by hope and sense of belonging is limited to non-existent in this population. Exploration of sense of belonging and hope in schizophrenia has potential to provide new understanding of positive factors influencing medication adherence in this population of often chronically ill individuals. The knowledge gleaned from this study may subsequently guide future interventional research to impact the problem of medication non-adherence in schizophrenia that, although well studied, has no consistently effective strategies for improvement in place (Velligan et al., 2009). This dissertation study will provide initial data about relationships between medication adherence and sense of belonging and hope.

Statement of the Problem

Schizophrenia affects approximately 3.5 million people in the United States (Jablensky, 2000; National Institute of Mental Health, 2017; Nose, Barbui, & Tansella, 2003; Schizophrenia and Related Disorders Alliance of America, 2014). At any given time, somewhere between 50-90% of these individuals do not adhere to medications as prescribed (Lacro, Dunn, Dolder, Leckband, & Jeste, 2002; Lieberman et al., 2005; Nose et al., 2003; D. Novick et al., 2010). This lack of adherence ranges from partial adherence to the medication regimen to complete non-adherence. For the purposes of this research, medication adherence is taking 80% or greater of

the medication prescribed as reported by the person. This definition is per recommendations by expert consensus guidelines on medication adherence problems in schizophrenia and other chronic and severe mental illnesses (Velligan et al., 2009). Non-adherence is any deviation from the prescribed medication regimen that results in taking less than 80% of prescribed medications, as reported by the patient, and includes partial and full non-adherence.

Medication adherence challenges are not unique to schizophrenia, but the rates of medication non-adherence are higher in schizophrenia in comparison to other chronic medical illnesses. Medication non-adherence has been identified as an issue in many chronic medical illnesses, including HIV, diabetes, and tuberculosis, and has been studied extensively in various populations. In a quantitative review of 50 years of research, rates of adherence in various chronic medical conditions, including HIV, arthritis, cancer, cardiovascular diseases and others, ranged between 74-88% (Kane, Kishimoto, & Correll, 2013). In this same review, psychotic disorders were reported to have rates of adherence to the medication regimen as low as 61% (Kane et al., 2013).

There are unique challenges for persons with schizophrenia in adhering to their medication regimen including disease-related symptoms such as lack of insight, problematic side effects of medications, and the stigma associated with such a severe mental illness. There are also unique challenges to the study of medication adherence in schizophrenia, including such issues as varying definitions of adherence, symptomology of the disease affecting study participation, and accuracy of measurement tools. These challenges complicate identification of specific factors that influence adherence and that can be consistently targeted to increase adherence rates.

Medication non-adherence in schizophrenia often is problematic at the onset of the disease and continues with increasing prevalence as the illness progresses. Non-adherence rates in the first 12 months of follow-up after experiencing a first psychotic break have been estimated between 53% - 59% (Acosta et al., 2009; Coldham, Addington, & Addington, 2002). Recent literature indicates widely varying non-adherence among persons with schizophrenia with studies reporting non-adherence rates between 12-74% (Garcia et al., 2016; Lacro et al., 2002; Lieberman et al., 2005; D. Novick et al., 2010). One observational study that compared discontinuation rates of different types of antipsychotics over time found that approximately 90% of patients discontinued medication, regardless of type, over a one-year period (Mullins, Obeidat, Cuffel, Naradzay, & Loebel, 2008).

Factors Influencing Adherence Behaviors in Schizophrenia.

Adherence behaviors in schizophrenia have been poorly understood since study was first undertaken on this phenomenon in the 1970s (Lehmann, 1975), almost as long as medications have been in existence for the illness. Researchers from that time drew heavily on the existing knowledge base of factors influencing non-adherence in other chronic illness populations, even though it was estimated that rates of non-adherence in schizophrenia were as much as 20% higher than general medical practice populations (Amdur, 1979). This higher rate of non-adherence suggests that something is different about non-adherence in schizophrenia compared to other chronic illnesses. In the infancy of this research, primary factors that were identified as contributing to noncompliance (referred to in current literature as nonadherence) included complexity of prescription, interference with daily habits, hostile patient attitude, social isolation, poor education, lack of motivation, and even the desire of the patient to remain crazy, among others (Amdur, 1979; Lehmann, 1975; Van Putten, 1976).

Since that preliminary period of inquiry into the phenomenon, medication non-adherence in schizophrenia has been more extensively studied. Additional factors influencing medication non-adherence have been suggested, while some of the factors initially identified continue to be shown to play a role. In a review of the literature in the later part of the 1990s, compliance was found to be associated with multiple factors including illness characteristics, cognition/memory, insight, health beliefs, perceived benefit of medications, alcohol use, substance abuse, medication dosage/route and side effects, family and social support, and relationship with the provider (Fenton, Blyler, & Heinssen, 1997).

In the years since the literature review by Fenton et. al., (1997), there have been little additional findings that have enhanced the body of literature or aided development of strategies proven to decrease non-adherence rates. In a more recent systematic review on medication adherence in schizophrenia, Medic et. al. (2013), identified fourteen factors in the literature as having an association with non-adherence. Of the factors identified, the majority had conflicting findings in the literature (Medic et al., 2013). Throughout the literature, consistent findings with clinical significance are few, and prevalence rates of non-adherence in this population remain largely the same (Amdur, 1979, M. J. Byerly, Nakonezny, & Lescouflair, 2007; Fenton et al., 1997; Medic et al., 2013). This indicates that other approaches are needed to understand the phenomenon and to develop interventions to decrease prevalence rates.

It is noteworthy that medication route, specifically oral medications versus long-acting injectable medications, has been repeatedly identified to be associated with medication adherence. One study found that individuals diagnosed with schizophrenia taking injectable medications were 43 times more likely to be adherent than those taking oral medications (Acosta et al., 2009). This may be related to the individual only passively participating in receipt of

medications because the nurse is responsible for administering the medication to the patient. This indicates a need to specifically study patients who self-manage oral medications to enable a clearer understanding of potential factors influencing adherence behaviors un-confounded by passive medication taking behaviors.

Sense of belonging and hope as potential factors influencing adherence behaviors.

Schizophrenia causes alterations in a person's cognition, perceptions of reality, and social interactions with others, often preventing full participation in work, school and/or family activities even during periods of stable symptoms of the disease (Sergi et al., 2007). These social and relational deficits are further exacerbated when the individual is not adherent to prescribed medication to manage symptomatology of the illness. Additionally, acute symptoms of schizophrenia often produce behaviors and experiences that are outside of social norms and result in stigma and marginalization that further impede social functioning (Wahl, 2012). These behavioral and environmental conditions likely contribute to the social isolation, loneliness, lack of sense of belonging, and hopelessness that are commonly experienced by persons with this disorder.

Loneliness and hopelessness are associated with decreased quality of life (QOL) and identified as roadblocks to recovery (Hayhurst, Drake, & Lewis, 2010; White, McCleery, Gumley, & Mulholland, 2007). Decreased QOL has been linked with medication non-adherence and relapse in schizophrenia (Hayhurst et al., 2010), which may indicate that other interpersonal factors such as a lack of sense of belonging or hopelessness also play a role in medication non-adherence. The obverse of these psychological states, i.e. having a sense of belonging and hope for the future, may result in a more positive psychological state in which patients are more likely to be medication adherent due to feelings of being a part of something and enhanced future

orientation. In a preliminary qualitative study conducted by this researcher, sense of belonging and hope were found to be important in this population, with suggested links to medication adherence that warrant further exploration (Barut, Dietrich, Zanoni & Ridner, 2016).

A factor that may influence a person's sense of belonging and/or adherence to medications is the relationship between the patient and the provider, also referred to as the therapeutic alliance. Therapeutic alliance has been linked to medication adherence (Day et al., 2005; Fenton et al., 1997; Lacro et al., 2002; Leutwyler, Fox, & Wallhagen, 2013; Misdrahi, Petit, Blanc, Bayle, & Llorca, 2012), and it has been suggested that the development of a therapeutic relationship in the first six months of treatment predicts adherence at six months (Frank & Gunderson, 1990). Hagerty and Patusky (2003), who have studied sense of belonging in multiple populations, suggest that a sense of belonging can be engendered within the therapeutic relationship between the nurse and the patient. However, sense of belonging has not been well-studied in schizophrenia, and no literature was identified exploring possible links between sense of belonging and therapeutic alliance.

Exploration of defining attributes of sense of belonging and therapeutic alliance suggests inter-relatedness of these concepts (Hagerty, Lynch-Sauer, Patusky, Bouwsema, & Collier, 1992; Hougaard, 1994; Misdrahi et al., 2012). Therapeutic alliance has been defined as a relationship in which the patient feels understood by the provider (Misdrahi et al., 2009), and feelings of being understood are also described in the experience of having a sense of belonging (Hagerty et al., 1996). A review of the literature on adherence in schizophrenia found that one of the most frequently reported factors influencing adherence behaviors was the relationship with the physician; 41-60% of adherent patients reported experiencing positive aspects of the therapeutic alliance (Day et al., 2005; Medic et al., 2013). This suggests that is likely that the existence of a

strong therapeutic alliance will affect both sense of belonging and adherence behaviors in patients with schizophrenia. Therefore, to examine the relationship between medication adherence and sense of belonging, it will be necessary to control for the influence of the therapeutic relationship to avoid any potential interactive effects.

Statement of Problem Summary

Medication non-adherence is unmistakably an issue of significance in persons diagnosed with schizophrenia. Despite the variability in estimated prevalence of medication non-adherence in schizophrenia, it is clear the incidence is high and exceeds non-adherence rates in other chronic illness populations. While some factors influencing medication adherence in schizophrenia have been well studied in the past several decades, knowledge about other factors that can be targeted to effectively and consistently increase rates of medication adherence is limited. Existing treatment methods based on current models of adherence are insufficient. In order to effectively address this problem, research is needed to increase knowledge of factors that consistently promote medication adherence and thereby improve outcomes in this population. Additionally, new factors need to be explored, since what is currently known about factors that influence adherence in schizophrenia has not impacted the problem of high rates of medication non-adherence.

Significance of the Issue

Significance to Society.

Schizophrenia is a leading cause of disability in the United States and worldwide, with approximately 1.1% of the world population or 51 million people at any given time diagnosed with the disorder (National Institute of Mental Health, 2017). Three and a half million of these individuals are in the United States (Jablensky, 2000; National Institute of Mental Health, 2014;

Nose et al., 2003; Schizophrenia and Related Disorders Alliance of America, 2014). This equates to a little over 7 people per 1,000 or 21,000 people per a city of 3 million in the United States (Nemade & Dombeck, 2006). The impact of untreated disease is greater than the rates of illness, partially due to illness burden, suffering, and elevated comorbidity and mortality rates (Rice, 1999; Schoepf, Uppal, Potluri, & Heun, 2014).

Financial costs of medication non-adherence in schizophrenia. Healthcare costs are disproportionately high for the subset of the population with schizophrenia. It is estimated that overall annual national health expenditures in developed countries related to schizophrenia are approximately 1.1 – 3.5% of total health care expense and comprise 22% of the costs of all mental illnesses (Charrier, Chevreur, & Durand-Zaleski, 2013; Rice, 1999; Thieda, Beard, Richter, & Kane, 2003). In 2002 in the United States, it was estimated that the overall cost of schizophrenia, including direct and non-direct healthcare costs as well as indirect non-healthcare costs, was \$62.7 billion (Wu et al., 2005). In a more recent analysis in 2013, researchers identified the total cost of the illness to be \$155.7 billion and included 24% higher excess direct health care costs compared to individuals without schizophrenia (Cloutier et al., 2016). It has been estimated that 40% of costs associated with treatment for this population are attributed to non-adherence (Olivares, Sermon, Hemels, & Schreiner, 2013; Weiden, Kozma, Grogg, & Locklear, 2004). This expenditure can have only increased in the ensuing years.

Most of the costs of schizophrenia are directly related to treatment delivery, particularly the expense of hospitalization. Costs of medications and outpatient follow-up also share a large portion of the financial burden. Hospitalization often occurs due to illness relapse, and it has been estimated that approximately 75% of relapse occurrences in schizophrenia happen as a direct result of medication non-adherence (Caseiro et al., 2012; Olivares et al., 2013). In the U.S.

in 2005, the overall cost of hospitalization due to medication non-adherence was estimated to range from \$1,392 million to \$1,826 million, not including additional outpatient or pharmaceutical costs (Dilla, Ciudad, & Alvarez, 2013). Schizophrenia has been estimated to be the costliest mental illness to treat, partly due to inflated costs resulting from medication non-adherence (Acosta, Hernandez, Pereira, Herrera, & Rodriguez, 2012; Ascher-Svanum et al., 2010).

Violence and incarceration. While violence is not necessarily common in persons with schizophrenia, individuals experiencing paranoia, delusions, and other psychotic symptoms, which are worsened due to medication non-adherence, may be at elevated risk for violence. This increased likelihood of violence in schizophrenia not only results in increased financial and psychosocial burden to society, but also impacts individual functioning, QOL and has other adverse consequences for the individual and society. Persons who are non-adherent to medications are more than twice as likely to be violent compared to their adherent counterparts and they have a greater probability of being arrested (Ascher-Svanum, Zhu, Faries, Lacro, & Dolder, 2006; Witt, Van Dorn, & Fazel, 2013). Often these arrests are due to behaviors influenced by their untreated or undertreated illness and result in incarcerations that are twice as long as those without an untreated illness (Torrey et al., 2014). In a prospective longitudinal study that followed inmates with schizophrenia after release from prison, it was found that schizophrenia was only associated with an increased risk of violence in the absence of treatment (Keers, Ullrich, DeStavola, & Coid, 2014). These individuals with untreated or undertreated schizophrenia represent approximately 16% of the total jail and inmate population in the United States, or close to 319,000 individuals atment (Torrey et al., 2014).

Risk of suicide. The risks of harm to self are even greater than the risk of violence in schizophrenia, particularly when the illness is not adequately treated. Suicide, a leading cause of death in schizophrenia, is increased as much as seven-fold when the person is even partially non-adherent to medications (Llorca, 2008). Persons with schizophrenia have a greater lifetime risk of suicide than the general population; it has been estimated that approximately 5% of persons with schizophrenia will commit suicide at some point, with higher prevalence closer to illness onset (National Institute of Mental Health, 2017; Palmer et al., 2002). In a systematic review of protective and risk factors for suicide in schizophrenia, it was identified that medication non-adherence was a risk factor for suicide (Hor & Taylor, 2010). Notably, this review found that the only consistently identified protective factor against suicide was adherence to medication (Hor & Taylor, 2010).

Impact on families. There are multiple challenges for family members caring for persons with schizophrenia, including poor understanding of symptoms of the illness (Magliano et al., 2000), as well as the impact on the family economically, socially and psychologically. Objective and subjective burden on family members was found to be higher in family members of patients with schizophrenia compared to family members of patients with other chronic illnesses such as heart diseases, renal diseases or diabetes (Magliano et al., 2000). Some of the top identified consequences of this burden on family members included decreased family leisure activities, increased family conflict, depression among family members, economic difficulties, and compromised ability of family members to attend to work, school and other normal life activities (Awad & Voruganti, 2004). It has also been reported that family members of patients with schizophrenia have lower self-esteem, higher rates of psychological distress, complicated grief

and loss, higher rates of primary care utilization, and increased incidence of chronic medical conditions (Perlick et al., 2006).

Summary of Significance to Society.

A diagnosis of schizophrenia carries a heavy toll for individuals, families and society at large. The burden on society is greater due to the direct impact of medication non-adherence related to the high costs of treatment for relapse, increased risk of violence, higher rates of incarceration, and increased risk of suicide in untreated and undertreated individuals. Medication adherence is the only identified protective factor against suicide. Family members are often primary care-givers for patients with schizophrenia and often experience the heavy burden of medication non-adherence through impaired family dynamics, higher rates of mental and medical illnesses, and economic and social impacts. Overall, the cost of medication non-adherence in schizophrenia to society is high and creates an imperative for solution-finding to decrease this burden.

Significance to Health.

Medication non-adherence impacts human suffering. Non-adherence in schizophrenia has been linked to poorer outcomes, decreased QOL, decreased functioning, increased psychotic symptoms, higher rates of illness relapse, and increased number and length of hospitalizations (Ascher-Svanum et al., 2006; Knapp, Mangalore, & Simon, 2004; Medic et al., 2013; D. Novick et al., 2010; Rittmannsberger, Pachinger, Keppelmuller, & Wancata, 2004). Medication non-adherence results in increased personal and interpersonal suffering resulting directly from the symptoms of the illness. Patients who are non-adherent tend to have greater cognitive impairments, including conceptual disorganization, decreased attention, stereotyped thinking and memory deficits (Acosta et al., 2009). Medication non-adherence also reduces the person's ability to

make significant contributions to society, as persons with the illness may be unable to hold jobs, provide for themselves and/or their family members and are otherwise impeded from having meaningful life experiences that contribute to greater society. This decreased QOL is evidenced by factors that have been shown to be increased in non-adherent patients, such as higher levels of depression and anxiety, cognitive deficits, and acute schizophrenia symptoms, and lower levels of social support (Hayhurst et al., 2010). Overall, patients who are non-adherent have more severe psychopathology and poorer functional outcomes (Acosta et al., 2009).

In a study of Medicaid patients, patients with schizophrenia who were non-adherent to medications had higher rates of psychiatric hospitalization (59% non-adherent vs. 14% adherent) and medical hospitalizations (almost 24% non-adherent vs. 7% adherent) (Gilmer et al., 2004). They also have higher usage rates of emergency psychiatric services, higher rates of substance abuse, higher risk of homelessness, poorer mental functioning, poorer life satisfaction, and poorer health related QOL (Ascher-Svanum et al., 2010; M. J. Byerly et al., 2007; Llorca, 2008).

Medication non-adherence and psychotic relapse. Relapse, or acute psychotic worsening, is highly correlated with medication non-adherence and is of significant overall financial cost to society and to the individual (Ascher-Svanum et. al., 2010). The cost of relapse to the individual is not only financial, but also physical, mental and emotional. Recurrent relapses may lead to increased cognitive decline, exacerbation of comorbid illnesses, discouragement and pessimism about the course of the illness, and increased risk of substance abuse, criminal behavior, and suicide (Dilla et al., 2013). Additionally, the experience of increased psychotic symptoms and being out of touch with reality may cause the individual to experience depression, hopelessness and other evidence of emotional distress that decreases QOL (Hoffman, Varanko, Gilmore, & Mishara, 2008).

Extensive and recurrent relapses have been shown to negatively affect brain integrity in persons with schizophrenia, particularly causing brain tissue loss as shown by MRI comparison studies (Andreasen, Liu, Ziebell, Vora, & Ho, 2013). There is also indication that psychotic relapses may result in decreased capacity for recovery and diminished response to subsequent treatment requiring higher medication dosages (Dilla et al., 2013; Remington et al., 2013). With repeated relapses, especially when behaviors due to symptoms create conflict in the person's life, the person's ability to return to school or work decreases and may result in erosion of social relationships (Kane et al., 2013).

Poor management of comorbid illnesses due to medication non-adherence. The general life expectancy for persons with schizophrenia is 20-25 years less than the general population, largely due to high incidence of medical illnesses such as cardiovascular disease and diabetes (Schoepf et al., 2014; Wildgust, Hodgson, & Beary, 2010). While some of this increased mortality can be attributed to high incidence of smoking and obesity in persons with schizophrenia, it is also related to high rates of non-adherence to smoking cessation and diet/exercise programs designed to mitigate risk (Brown, Barraclough, & INSKIP, 2000; Wildgust et al., 2010). Similarly, non-adherence to medications prescribed for schizophrenia often extends to medications prescribed for comorbid medical illnesses. Compromised medical health due to non-adherence to medications further exacerbates the person's health-related QOL and ability to function as a productive member of society.

Summary of Significance to Health.

Schizophrenia is a serious and debilitating illness that creates a high degree of human suffering, decreases QOL, impairs physical, mental and social health and decreases life expectancy. Non-adherence to medications results in increased symptom burden which may

decrease life satisfaction and ability of the individual to contribute to society and have meaningful life experiences. The risks of illness relapse are higher in non-adherent individuals, resulting in repeated exacerbations of acute illness. Higher rates of relapse increase the likelihood of lasting effects of schizophrenia including permanent cognitive impairment, increased severity of co-morbid medical illnesses and increased risk of suicide. It is estimated that there is an average of 28.5 years of life lost directly attributable to this disease burden (NIMH, 2017). These health impacts of the illness are lessened when individuals are adherent to their medication regimen.

Significance to Nursing.

Role of the staff nurse. Staff nurses, or nurses that provide direct care in psychiatric health care settings, have long been assessing the physical and emotional needs of patients and then planning and implementing individualized care by using interpersonal techniques (Stuart, 2014). Hildegard Peplau, known as the ‘mother’ of psychiatric nursing, identified that the heart of psychiatric nursing is the nurse’s role as a counselor and that the nurse-patient relationship is the bedrock of psychiatric nursing care (Peplau, 1989, 1997). Staff nurses promote mental health through a partnership with the patient whereupon they can help the person to identify personal health and life goals. Through this partnered therapeutic relationship, personal goal setting, and the promotion of medication adherence can occur. The nurse can be an advocate for the patient for resource identification to help them achieve medication adherence, as without adherence, patients will likely have challenges meeting their goals.

The psychiatric staff nurse recognizes the patient as a holistic being who makes healthcare decisions, including decisions about whether or not to take medications. These decisions are often based on individual experiences and interactions with his or her environment

(Stuart, 2014). Recognizing this, the nurse can individualize care to address the person's specific needs regarding adherence to medications and empower the person to be an active participant in his or her healthcare. Psychiatric nurses play a role in monitoring medication use and may be the first healthcare provider to identify signs that the person is not adherent to the medication regime. This monitoring and assessment of the nurse can enable early identification of medication non-adherence and, if the nurse is equipped with effective intervention strategies, may improve medication adherence (Coombs, Deane, Lambert, & Griffiths, 2003).

Patients may fail to take medications due to fear of medication side effects or upon experiencing uncomfortable side effects. Psychiatric nurses have a responsibility to provide education and monitor for side effects of medications. When patient concerns about side effects arise, the nurses can help with patient with strategies to minimize the effects. The psychiatric nurse also provides education about disease process, treatment and medications, and consequences of non-adherence (Happell, Manias, & Pinikahana, 2002). This knowledge and the nurse's monitoring and guidance can help patients to integrate consistent medication-taking behaviors into their lives.

The psychiatric nurse is situated to be a primary contact for the families of persons with schizophrenia. Family support is very important to medication adherence in persons with schizophrenia. However, caregiver burden is high, and caregivers frequently lack education about the disease process of schizophrenia which can strain this vital relationship. The psychiatric nurse is a key point of contact to promote family members' engagement and make sure they receive individualized psycho-education about the illness, symptoms and treatment. This involvement by the nurse can empower family members to support their loved one in adhering to the medication regimen (Cohen et al., 2014).

Role of the advanced practice nurse. The advanced practice nurse fulfills all the aforementioned roles of assessment, education, and advocacy. The advanced practice nurse also fulfills a much-needed role for patients of improving access to psychiatric mental health practitioners with medication prescribing authority (Nolan et al., 2012). Due to enhanced skills in therapeutic relationship development and respect for the patient as an autonomous, holistic being, advanced practice psychiatric nurses have enhanced potential to improve medication adherence in patient populations where adherence is a problem (Nolan et al., 2012). Advanced practice nurses are highly skilled at seeing the perspective of the patient in adherence issues, as well as being effective at educating and garnering support from key support persons to help the patient adhere to the medication regimen as prescribed (Nolan et al., 2012). These nurses also work in healthcare policy and research settings where they serve to advance knowledge and promote policy that support services and environments for patients to be successful in their treatment.

Summary of Significance to Nursing.

Psychiatric staff and advanced practice nurses can play a significant role to improve medication adherence in persons diagnosed with schizophrenia. These nurses are uniquely positioned at multiple intersections of the patient's healthcare experience, in hospitals, outpatient centers and other treatment settings. Knowledge of factors that can impact medication adherence can drive targeted nursing interventions and increase the effectiveness of these nurses' role in decreasing the rates of non-adherence.

Summary of Overall Significance of the Issue

Schizophrenia is a leading cause of disability in the United States and worldwide and significantly impacts society, health, and the profession of nursing. Many of the detrimental

effects of this disease are directly attributable and/or worsened by the high rates of medication non-adherence in this population. Increasing medication adherence in persons diagnosed with schizophrenia has the potential to greatly decrease the societal burden and human suffering caused by the illness. Direct care and advanced practice nurses can play a pivotal role to support medication adherence if they are equipped with the right knowledge and interventions that influence medication taking behaviors in schizophrenia.

Purpose of the Study

The preceding section identifies the magnitude of the problem of medication non-adherence in schizophrenia as well as the significance of the issue to society, health and nursing. Based on this magnitude and significance, research is needed to identify factors that can decrease medication non-adherence. The purpose of this study was to explore the associations of sense of belonging and hope with medication adherence, after controlling for therapeutic alliance, in an outpatient sample of persons diagnosed with schizophrenia. Additionally, demographic and clinical data including the participant's age, gender, marital status, living situation, employment status, and antipsychotic medications were collected for description of the sample.

Research Questions/Hypotheses

Study Aim #1:

Examine the relationship between sense of belonging and medication adherence in persons diagnosed with schizophrenia.

Research Question #1: Controlling for therapeutic alliance, is there an association between sense of belonging and medication adherence in persons diagnosed with schizophrenia?

Hypothesis #1: Persons diagnosed with schizophrenia who have higher levels of sense of belonging will report higher levels of medication adherence than those with lower levels of sense of belonging.

Study Aim #2:

Examine the relationship between hope and medication adherence in persons diagnosed with schizophrenia.

Research Question #2: Controlling for therapeutic alliance, is there an association between hope and medication adherence in persons diagnosed with schizophrenia?

Hypothesis #2: Persons diagnosed with schizophrenia who have higher levels of hope will report higher levels of medication adherence than those with lower levels of hope.

CHAPTER 2

Conceptual Framework and Literature Review

Conceptual Framework

The Theory of Planned Behavior (TPB) guided this study (see Figure 1).

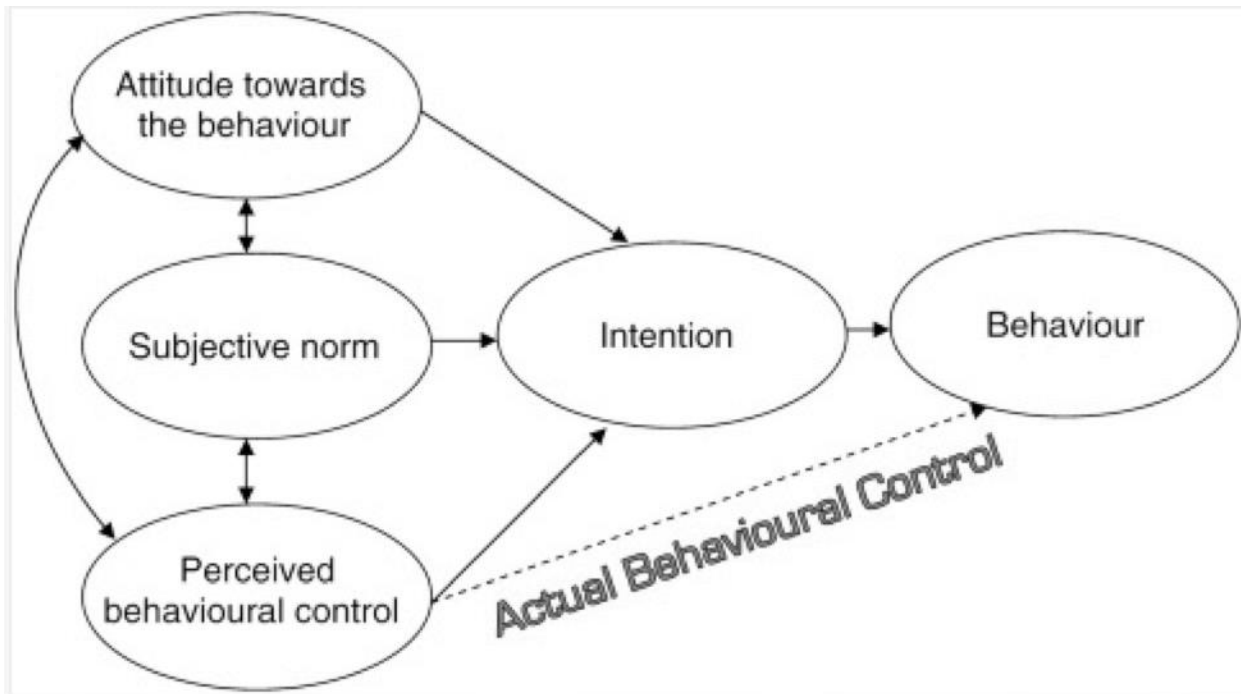


Figure 1. *The Theory of Planned Behavior*

TPB has been successfully used to aid understanding of adherence behaviors in schizophrenia (De las Cuevas & Peñate, 2015; Holmes, Hughes, & Morrison, 2014; Alex Kopelowicz et al., 2007; Lindström & Bingefors, 2000). TPB is a social cognitive model of behavior that states that the likelihood of a person engaging in a particular behavior, such as adherence, is a function, in part, of subjective norm or perceived social pressure and attitude (I. Ajzen, 1991, 2002, 2011; Icek Ajzen & Madden, 1986). Subjective norm is related to the person's belief regarding whether others, particularly loved ones and support persons believe the behavior should be performed (Ajzen, 1991).

Based on TPB and previously identified factors influencing medication adherence in schizophrenia, potential factors influencing medication adherence in schizophrenia were identified (see Figure 2).

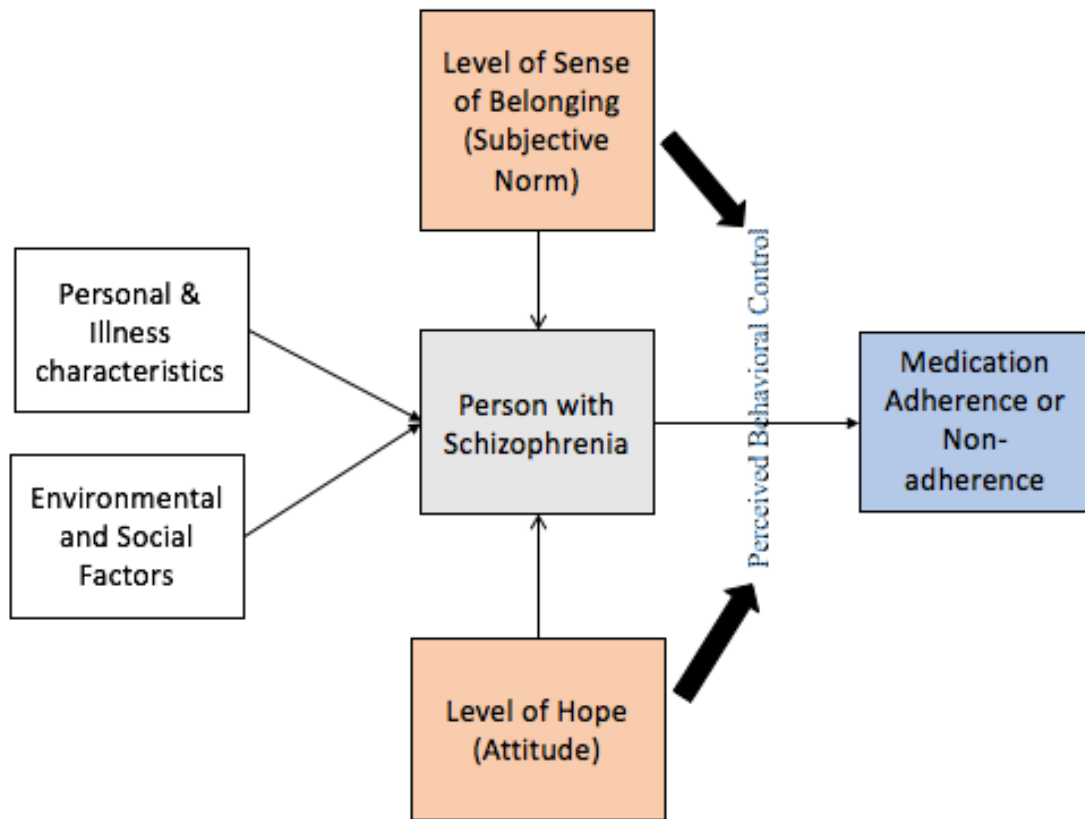


Figure 2. *Potential Factors Influencing Medication Adherence in Schizophrenia*

This conceptual framework, as outlined above, suggests that sense of belonging enhances perception of social pressure and attitude towards taking medications and can be measured as proxy for subjective norm. Persons who have a greater sense of belonging may be more likely to engage in medication adherence due to this subjective norm. Attitude has to do with the person's beliefs about the positive or negative consequences of the behavior (Ajzen, 2002; Ajzen & Madden, 1986). Attitude towards medications has been shown to be related to adherence in

schizophrenia (De las Cuevas & Peñate, 2015). Persons with greater hope have more insight into their illness, may have more positive perceptions of medications and may believe that the medication will improve mental health, all of which could increase adherence behaviors. A key strength of this framework is that it targets attitudes and insight, both factors that may affect hope and have been shown to have some explanatory value related to non-adherence behaviors in schizophrenia. Additionally, TPB's subjective norm construct may account for social contexts, family attitudes or social support that result in a sense of belonging and that may influence adherence in patients with schizophrenia (Mausbach et al., 2013).

Critical Analysis of Relevant Literature

While medication non-adherence in schizophrenia has been identified as a problem since the 1970s, much of the literature has studied the same or similar constructs as factors possibly impacting medication adherence and there has been little in the way of new direction or focus. With the advent of newer second-generation antipsychotics, the climate of medication treatment has changed in the ensuing years. Therefore, to better reflect the current environment of treatment for medication adherence, this literature review has been limited to approximately the last 20 years. Additionally, because this literature review is focused on understanding factors associated with medication adherence in schizophrenia and not the effectiveness of interventions, interventional studies that targeted medication adherence were excluded. Lastly, it is recognized that factors influencing medication adherence may be very different in affective disorders and other mental illnesses compared to psychotic disorders. For this reason, studies that included mental illnesses outside of the schizophrenia spectrum of disorders (e.g. bipolar disorders, depressive disorders, personality disorders) were excluded. Eighteen studies were selected for

inclusion in this integrative review of factors influencing medication non-adherence in schizophrenia.

Literature on Factors Influencing Medication Non-adherence in Schizophrenia

In the schizophrenia research literature, the primary factors identified in the literature review as contributing to medication adherence behaviors can be categorized into three groups: 1). environmental factors, 2). treatment factors, and 3). patient factors (Velligan et al., 2009).

Primary environmental factors included family and/or social support (Agarwal, Sharma, Kumar K. V, & Lowe, 1998; Coldham et al., 2002; Gutierrez-Casares, Canas, Rodriguez-Morales, Hidalgo-Borrajo, & Alonso-Escolano, 2010; Hudson et al., 2004; Leutwyler et al., 2013; D. Novick et al., 2010; Olfson et al., 2000; Quach et al., 2009; Rabinovitch, Cassidy, Schmitz, Joober, & Malla, 2013; Sapra et al., 2013; Tranulis, Goff, Henderson, & Freudenreich, 2011). Social support has been repeatedly found to be associated with medication adherence in schizophrenia (Agarwal et al., 1998; Coldham et al., 2002; Gutierrez-Casares et al., 2010; Hudson et al., 2008; Novick et al., 2010; Olfson et al., 2000; Quach et al., 2009; Rabinovitch et al., 2013; Sapra et al., 2013). Coldham et al. (2002) found that 80% of adherent patients had family support compared to 51% in the completely non-adherent group ($p < .001$); in other words, patients with family support were 1.6 times more likely to be adherent than those without family support. Similarly, Gutierrez-Casares et al. (2010) found that patients with low family support were more than twice as likely to be non-adherent as those with high family support (OR=2.13). Novick et al. (2010) found that patients who were socially active, as the study defined social support, were 1.26 times more likely to be adherent to their medications. Definitions of social support vary widely across studies and it may be that different but similar constructs are actually being measured. Social support may also be a component of the broader

concept, sense of belonging, which captures the feeling of belonging to a group generated by social support. There is no identified research on sense of belonging and medication adherence in schizophrenia; however, sense of belonging is a more comprehensive concept that may prove to have more explanatory value than social support on its own. Therefore, to capture this broader psychological concept, a measure of participants' sense of belonging was collected for this research.

Treatment-related factors impacting medication non-adherence included past non-adherence, medication side effects, medication route (oral vs. injectable), and therapeutic alliance with a provider (Acosta et al., 2012; Agarwal et al., 1998; Ascher-Svanum et al., 2006; Brain et al., 2013; Gutierrez-Casares et al., 2010; Leutwyler et al., 2013; Misdrahi et al., 2012; D. Novick et al., 2010; Olfson et al., 2000; Sapra et al., 2013; Tranulis et al., 2011). Therapeutic alliance, or relationship between the patient and the provider, is a factor identified in the literature as related to medication non-adherence and may share some similarities with sense of belonging that warrant exploration. Misdrahi et. al, (2012) found that in a model with insight and substance abuse, therapeutic alliance accounted for 15% of the variance in adherence ($r=0,663$, $p<0.0001$). Olfson et .al. (2000) measured therapeutic alliance with the Active Engagement Scale and found that patients who scored higher on the optimism subscale were 1.5 times more likely to be medication adherent. Lastly, Rabinovitch et. al. (2013) found that 35% of the variance in adherence was accounted for by therapeutic alliance, and qualitative data suggests that a positive trusting relationship with the provider is important to adherence (Leutwyler et. al., 2013; Tranulis et. al., 2011)

Because of the trusting relationship inherent in a therapeutic alliance, it may share characteristics or evoke similar feelings as having a sense of belonging. Therapeutic alliance may

even promote a sense of belonging in the patient. Because of these potential connections, it was recognized that therapeutic alliance and sense of belonging may have similar and distinct influences on adherence behaviors. Similarly, the therapeutic alliance may influence hope and even hope may be promoted within the context of this relationship. Therefore, when studying adherence in schizophrenia, it will be important to attempt to distinguish between the effects of the therapeutic alliance and the patient's general sense of belonging and hope as well as to assess for the degree of covariance of the concepts in relationship to medication adherence. For this reason, therapeutic alliance was controlled for in this study.

Patient-related factors. Lastly, the patient-related factors included insight, attitudes towards medication, substance abuse, socio-demographic factors, and illness characteristics (Brain et al., 2013; Coldham et al., 2002; Czobor et al., 2015; Gutierrez-Casares et al., 2010; Leutwyler et al., 2013; Meier et al., 2010; Misdrahi et al., 2012; D. Novick et al., 2010; Novick et al., 2015; Olfson et al., 2000; Quach et al., 2009; Rabinovitch et al., 2013; Sapra et al., 2013). One of the most relevant patient factors is substance abuse, which has been repeatedly found to be associated with medication non-adherence (Ascher-Svanum et. al., 2006; Coldham et. al., 2002; Czobor et. al., 2015; Gutierrez-Casares et. al., 2010; Hudson et. al., 2004; Misdrahi et. al., 2012; Novick et. al., 2010; Olfson et. al., 2014; Rabinovitch et. al., 2013). In a large longitudinal study of persons with schizophrenia from multiple states and various treatment settings (community and state settings, university health care settings, and Veteran's Administration facilities), multiple factors were studied, and illicit drug use was found to be the top predictor of medication non-adherence (OR = 1.8, CI = 1.1-3.0 $p = .025$). Czobor et al., (2015) found that individuals who had substance abuse at baseline were twice as likely to be medication non-adherent 6 months later (OR = 1.8, $p < .0001$). The prevalence rates of substance abuse in persons

with schizophrenia are high, with as much as 50% lifetime prevalence (Buckley, Miller, Lehrer, & Castle, 2008; Volkow, 2009). This high prevalence, combined with findings of associations with non-adherence, support a need to report substance use in studies of non-adherence in schizophrenia. For this research, individuals who were identified as having current substance abuse at study enrollment were excluded from the study.

Role of sense of belonging and hope in medication adherence in schizophrenia. Two factors that have only minimal or nonexistent exploration in schizophrenia but that may be related to medication adherence are sense of belonging and hope. While the research on sense of belonging and hope in schizophrenia is scant, there are suggestions of potential linkages. Exploration of sense of belonging and hope has the potential to contribute new knowledge about medication non-adherence in schizophrenia that, if fruitful, could lead to the development of invaluable interventions for this problem.

Loneliness and isolation, the opposite states of sense of belonging, have been identified as themes in the lives of persons with schizophrenia, with related feelings of hopelessness and decreased QOL (Barut et al., 2016; Davidson, 1997). Humans seem to be hard-wired to be with other people; isolation and/or alienation are not only detrimental to overall health but are also perceived as being socially unacceptable or otherwise an unfavorable state of being. Although limited schizophrenia research exists on sense of belonging, the close construct social support, is identified as an area of common deficit in this population (Agarwal et al., 1998; Pyne et al., 2006) and, as previously identified, has been frequently found to be associated with medication adherence. It is important to distinguish that social support and sense of belonging, although related, are separate concepts; a person can have adequate social supports in place yet not feel a sense of belonging (Barut et al., 2016). Belonging and adherence have been linked in other

populations; belonging to a peer support group has been shown to improve adherence in women with breast cancer (Tehrani, Farajzadegan, Rajabi, & Zamani, 2011). The linkages in other populations, combined with the potential for sense of belonging to account for more variance than social support alone, supports the need to study sense of belonging and adherence in schizophrenia.

According to consumers, current literature and health-care policy, hope is central to recovery in schizophrenia (P. E. Deegan, 1997; Frese, 2009b; Kylma, Juvakka, Nikkonen, Korhonen, & Isohanni, 2006). Hope has been identified as a positive coping strategy for dealing with chronic illness (Herth, 1995; Miller, 1989), and is identified as an important value in recovery from schizophrenia and mental illness in general (P. W. Corrigan, McCracken, & Holmes, 2001; Substance Abuse and Mental Health Administration, 2006). Hopelessness, which is compounded by stigma, is a common symptom of schizophrenia and a predictor of suicide (Chien, Leung, Yeung, & Wong, 2013; Schrank, Bird, Rudnick, & Slade, 2012; Wahl, 2012).

Research examining the influence of hope on medication adherence, while limited, suggests a positive connection (Kukla, Salyers, & Lysaker, 2013). This may be because a hopeful attitude supports lifestyle adjustments that promote adherence (Aspeling & van Wyk, 2008), as well as increasing patient activation and engagement in treatment. A recent qualitative inquiry found that hope might be related to treatment adherence (Barut et al., 2016). Hope has been found to be significantly correlated with insight into illness, (Kylma et al., 2006; Lysaker, Campbell, & Johannesen, 2005), a factor which has been repeatedly linked to medication adherence in schizophrenia (E.-M. Beck, M. Cavelti, S. Kvrjic, B. Kleim, & R. Vauth, 2011; Brain et al., 2013; Jónsdóttir et al., 2013). Hope has been linked to adherence in other chronic

illnesses (Berg, Rapoff, Snyder, & Belmont, 2007; Makarem, Smith, Mudambi, & Hunt, 2014), warranting further exploration in persons with schizophrenia.

Summary of Findings

Various environmental, treatment, and patient related factors are identified in the literature as contributing to medication adherence behaviors in schizophrenia. The results of studies on these factors have yielded inconsistent and often conflicting results with no significant impact on the problem. Prevalence rates of medication non-adherence in schizophrenia continue to be high with resulting poor patient outcomes, warranting exploration of new factors, such as sense of belonging and hope, to understand medication adherence behaviors in schizophrenia. Exploration of sense of belonging and hope has potential to provide new understanding of positive factors influencing medication adherence in this population. This research may subsequently guide future interventional research that will decrease rates of medication non-adherence. Interventional research is sorely needed because even though the problem has been widely studied, there are no consistently effective strategies in place that have had any impact on the high prevalence rates (Velligan et. al., 2009).

Definition of Terms

Medication Adherence. The World Health Organization (WHO) defines adherence as “the extent to which a person’s behavior – taking medication, following a diet, and/or executing lifestyle changes – corresponds with agreed recommendations from a health care provider” (Sabaté, 2003 p. 3). This dissertation study uses the common definition of medication adherence defined as the patient’s report of taking equal than or greater than 80% of prescribed medication. This cut-off percentage of adherence is per recommendations by expert consensus guidelines on

medication adherence problems in schizophrenia and other chronic and severe mental illnesses (Velligan et al., 2009).

Medication Non-adherence. Medication non-adherence is when a person inaccurately takes prescribed medications by increasing or decreasing the dosage, taking medications at different times than prescribed and/or failing to take the medication at all (Byerly et. al., 2007; Velligan et. al., 2006). Medication non-adherence then will be defined for this research as any deviation from the prescribed medication regimen that results in taking less than 80% of prescribed medications, as reported by the patient, and includes partial and full non-adherence.

Sense of Belonging. Sense of belonging is a vital mental health concept that is closely correlated with social and psychological functioning (Hagerty et al., 1992; Hagerty & Williams, 1999). For this dissertation, sense of belonging will be defined as ‘the experience of feeling connected or being a part of something (i.e. relationships or involvement with another person[s], group, community, organization, or environment) that makes the person feel as if he or she ‘fits in’ or belongs’.

Hope. Hope is a multidimensional concept that involves looking toward the future with a sense of positive expectation and intentionality. It provides one with a sense that one has a future, enables the person to cope with events in the present and encourages the individual to use crises as opportunities for growth. This research study uses a definition of hope whereas hope is “a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving good, which to the hoping person is realistically possible and personally significant” (Dufault & Martocchio, 1985 p. 380).

Therapeutic Alliance. Therapeutic alliance in the schizophrenia literature has largely been defined in terms of the relationship between the patient and a therapist or counselor (Frank

& Gunderson, 1990) (Horvath & Greenberg, 1989; Hougaard, 1994; Kvrjic, Cavelti, Beck, Rüsç, & Vauth, 2013). This relationship has been described as a 'helping' or 'working' relationship that involves the development of trust and understanding between the patient and the clinician and results in better treatment outcomes (Frank & Gunderson, 1990; Kvrjic et al., 2013). Recent literature suggests that a therapeutic alliance between a prescribing provider and the patient is of equal importance, is defined similarly and involves a positive trusting relationship (Baloush-Kleinman et al., 2011; Canas et al., 2013; Misdrahi et al., 2012) Canas et al., 2013; Misdrahi et al., 2012). For the purposes of this research, a therapeutic alliance includes the patient having a generally positive perception of the relationship with his or her prescribing clinician in which he or she feels understood and includes drug-taking aspects, psycho-education, and the day-to-day relationship with the clinician (Misdrahi et al., 2012).

CHAPTER 3

Methodology

Research Design and Assumptions

This dissertation utilized a descriptive-correlational, cross-sectional research design. Cross-sectional studies are interested in identifying variance in multiple cases at a single point in time and have multiple advantages (Bryman, Becker, & Sempik, 2008). One advantage of the cross-sectional design for dissertation research is that they are typically less expensive than other design types, reduce need to track subjects over time, and enable associations to be made between multiple variables without the need to manipulate the study environment or variables of interest (Bryman, 2008). The disadvantage of using a cross-sectional design is weak internal validity because of inability to identify causal inference or directionality of associations (Bryman, 2008). The cross-sectional design merely provides a picture of one point in time and takes no consideration of influences before or after that time-point. External validity is also restricted, as generalizability is limited to the region and sample characteristics.

Description of Research Settings

The study was conducted in community mental health centers (CMHC) located in Davidson County, Tennessee and included Park Center, the Mental Health Cooperative (MHC) and Centerstone.

Park Center is a not-for-profit organization that provides psychiatric rehabilitation and other supportive services for persons experiencing serious mental illness. Members elect to attend the program and work toward their own recovery through employment training, educational groups and peer support in an environment that provides a safe and compassionate atmosphere to maximize recovery. Park Center primarily serves individuals within Davidson

County and surrounding communities. Park Center provided services to 829 persons in 2016, of which, 37.9% had a schizophrenia spectrum diagnosis.

The Mental Health Cooperative serves individuals with serious mental illnesses, primarily from Middle Tennessee and from the Southeastern region of the United States. At the time of this study, MHC was actively providing care for approximately 10,000 patients, of which approximately 3,150 had a diagnosis of a schizophrenia spectrum disorder. MHC also has a Program for Assertive Community Treatment (PACT) team which is a person-centered mental health service delivery model to promote community living and psychological rehabilitation for individuals with severe and persistent mental illness who have not highly benefited from traditional outpatient services. During the time period that this research was conducted, the MHC PACT team was actively serving approximately 85 patients, of which approximately 60-65 had a schizophrenia spectrum diagnosis.

Centerstone is one of the nation's largest not-for-profit providers of community-based behavioral health care, offering a full range of mental health services in Florida, Illinois, Indiana, Kentucky and Tennessee. As of 2017, Centerstone consisted of more than 50 facilities throughout Middle Tennessee. Participants were recruited from two clinics: The Frank Luton Center and Centerstone Madison. In fiscal year 2016, Centerstone provided services for 56,119 adults and children in Tennessee, of which 3,116 adults were diagnosed with a schizophrenia spectrum disorder. Research conducted at Centerstone required approval from the Centerstone Research Institute (CRI). CRI functions as the research and development arm of Centerstone, committed to developing industry-leading science and supporting the provision of the highest quality of behavioral health care.

Sample and Sampling Plan

Nature and size of sample. Purposive sampling was used to recruit a convenience sample of 65 community-dwelling persons diagnosed with schizophrenia who were between the ages of 18-65 years. This sample size of 65 participants satisfied the minimal requirements for generating stable parameter estimates from the most complex statistical method proposed for study data analysis (10 cases per independent variable in a multiple linear regression with 2 primary independent variables and 1 control variable). A sample size of 65 would achieve 80% statistical power to detect a *beta* coefficient as small as 0.34 which represents 10% shared variance ($\alpha=0.05$). Detectable associations of this magnitude represented meaningful clinical significance for this study.

Inclusion/Exclusion Criteria

Participants were recruited using purposive sampling based on the following inclusion/exclusion criteria:

Inclusion Criteria:

- 1) Primary Diagnosis of Schizophrenia
- 2) 18-65 years of age.
- 3) English-speaking
- 4) Engaged in self-management of oral medications

Exclusion Criteria:

- 1) Current known affective disorder
- 2) Current known or self-reported substance abuse
- 3) History of documented diagnosis of cognitive impairment

- 4) Inability to provide informed consent as demonstrated by positive screen of the Evaluation to Sign Consent (ESC)
- 5) Primary medication for psychosis in a long-acting injectable form.
- 6) Receiving Mandatory Ordered Treatment (MOT) by a court of law.

Rationale for Inclusion/Exclusion Criteria. Participants included individuals with a primary diagnosis of schizophrenia and did not include persons who had a current affective diagnosis or current substance abuse. This exclusion was to avoid the possibility of these conditions influencing the independent variables of sense of belonging and hope.

The age range of 18-65 was chosen to avoid confounding with unique differences in adherence behaviors that may be related to youth or the elderly. Persons who had a history of a documented cognitive impairment were excluded due to the possible effects on memory function and functioning, as well as to ensure ability to provide informed consent. English speaking patients were recruited due to the PI's limitation of only speaking English and the unavailability of the measures in other languages. Patients on long-acting injectable medications for psychosis were excluded, as this is a passive form of medication management in which a nurse is responsible for medication management and may confound the picture of medication adherence.

Recruitment Methods

Community dwelling persons with schizophrenia were recruited for the study with the intent to capture broad socio-economic and ethnic diversity in patients. Recruitment occurred through referral from clinicians at the CMHCs. The study recruitment methods were developed to ideally gain a sample representative of the population in Davidson County, TN, which is roughly 65% Caucasian, 25% African-American, 8% Hispanic, and 2% Asian (US Census Bureau, 2015). Subjects were not excluded based on gender or minority status.

Informational flyers about the study that provided information about how to contact the study team for enrollment screening were made available to potential participants at each of the CMHCs. Referring clinicians at the CMHCs were educated about the study by the PI. Specific processes for each site following the study protocol were developed by the PI and study site liaisons. The study was conducted in private rooms at each of the community health centers respectively.

Referring clinicians screened medical records to determine if the individual met criteria for involvement in the study, and then shared information about the study with identified potential participants. Once an individual agreed to be contacted about the study, if it happened while a member of the research team was on site, the PI or RA (research assistant) met with the potential participant in a private room, provided information about the study, and if indicated, perform informed consent. If the participant was consented and screened into the study, he or she had the option to complete the study at that time or schedule a time at his or her convenience. If the participant expressed interest to the referring clinician at a time when a member of the study team was not on site, the referring clinician emailed the PI via secure file with the name and phone number of the potential participant. The PI or RA contacted the potential participant and shared information about the study. If the person was interested, a time was scheduled to meet for further discussion about the study and informed consent, if indicated, was conducted in person. These meetings were coordinated to be before or after patients' clinic appointments if possible, or at a time of the person's convenience. The participant had the option of completing the study at that time or scheduling another time to complete the study.

Human subjects' protection.

After approval by the dissertation committee, approval was received from the Vanderbilt University IRB prior to recruitment. Additional approvals were obtained from the Centerstone Research Institute and Centerstone administration, from the administration of the Mental Health Cooperative, and from the administration of Park Center. Compliance with the study protocol was assured through regular meetings with the PI's faculty advisor, Dr. Sheila Ridner. This was a non-interventional study, and participants were believed to be at minimal risk. Potential risk for breaches in confidentiality and privacy were mitigated as follows: 1). Patient participation or lack thereof was not shared with the clinical team and patient responses to questionnaires were not shared with the clinical team. 2). Participants were assigned a random number upon study enrollment and all data collection materials were only identified by that number. 3). Electronic data maintained on a secure server in a file accessible only by the research team. 4). Documents which must necessarily contain subject identifiers (i.e. payment forms and informed consents) were stored in a locked filing cabinet accessible only to the PI). Consents and study completion occurred in a private room to ensure privacy.

No direct benefits to participants were anticipated, although some participants did indicate that participation in the study was a positive experience. During the interview, some questions that dealt with personal or emotional matters were identified as somewhat stressful or mildly upsetting to think about for a few study participants. All subjects were given the option to refuse to answer any questions that made them feel uncomfortable. All interviews and surveys were administered by the PI and RA who were trained how to respond to meet the person's needs. In the few instances where participants became upset during an interview, the participants took a break to go to the bathroom or get a beverage and were able to return to the interview

without further distress and completed the study. In two instances, subjects made comments indicating possible threats to self or others. In both instances, the PI/RA followed the standard procedures previously outlined by the respective CMHC for securing subject and staff safety.

Data Collection Methods

Procedures

Potential participants referred by phone or secure email file were contacted by phone, informed about the study, and if interested in continuing, were screened using a PI-developed screening tool to determine whether they met the inclusion/exclusion criteria. For those referred in person at the CMHC, this was done in an interview meeting in a private room. Data was entered directly into REDCap (Research Electronic Data Capture). REDCap is a secure web-based application hosted by Vanderbilt University. REDCap servers are housed in a local data center at Vanderbilt, and all web-based information transmission is encrypted (Harris, 2009).

If the inclusion/exclusion criteria were met, the PI and/or research assistant met with potential subjects in a private room at the CMHC to further provide information about the study, and if indicated, conduct informed consent. After informed consent was completed, a screening tool, the Evaluation to Sign Consent (ESC) (Resnick et al., 2007) was used to determine if the participant continued to fully understand the details and implications of study participation. The ESC is a five-item questionnaire that assesses comprehension of information to provide ethically valid consent and was originally developed for research in psychiatrically ill individuals (DeRenzo, Conley, & Love, 1998; Resnick et al., 2007). (See Appendix A).

The ESC has been assessed to be an acceptable screening tool for comprehension of consent in research of individuals diagnosed with schizophrenia (Beebe & Smith, 2008; Beebe et al., 2010). In testing of this instrument, reliabilities of the scores with persons diagnosed with

psychiatric disorders were moderate (Cronbach's alpha = 0.81, test-retest $r=0.81$) (Resnick et al., 2007). The ESC was used in this study to screen for comprehension of consent prior to enrollment in the study. If subjects were unable to answer the questions in the ESC, they did not continue in the study. If the participants were able to successfully complete the ESC they were assigned a randomized study ID and then were offered the ability to complete the study measures at that time or schedule another time at their convenience.

The data collection interview lasted between 45 minutes to 1 1/2 hours in duration. Participants could self-complete the measures of adherence, sense of belonging, hope, and therapeutic alliance using a computer tablet (See Appendices B, C, D, & E). The PI or RA offered to read any of the items for clarification as needed. Some participants expressed feeling uncomfortable with the computer tablet or expressed difficulty reading the measures on the screen, and the research team member assisted by reading the items, and/or selecting responses on the screen as they were identified by the participant.

The PI or RA collected additional clinical and demographical data using a structured interview tool and the adherence measure. Descriptions of each of these tools follow in the section on instruments.

Data Management. While a random study ID number was assigned to each participant's data record, the PI needed to know each participant's name during the study to coordinate/schedule data collection and random number assignment. A folder was maintained in a locked file cabinet in the PI's office, to which only she had access, with the referral information, appointment schedule and participant list. Upon data collection completion, the list and folder were destroyed. Electronic data outside of the Redcap database is maintained on a

secure server in a file accessible only by the research team. All participant entries into Redcap were triple verified by the PI for accuracy and completeness.

Data Collection Instruments

Brief Adherence Rating Scale (BARS).

The Brief Adherence Rating Scale (BARS) is a three-item tool that enquires about the patient with schizophrenia's knowledge of medication regimen and episodes of missed medications (see Appendix B). It includes a visual analogue scale to assess the proportion of doses taken in the past month (0–100%). The visual analogue scale rating is the final determinant of adherence provided by the BARS. The BARS has been assessed to be comparable to Medication Electronic Monitoring (EM) devices, which are considered to be the gold standard in medication adherence measurement (M. Byerly et al., 2005; M. J. Byerly, Nakonezny, & Rush, 2008). A significant positive relationship has been found between mean BARS and EM adherence ($\beta = 0.98$; $r = 0.59$, $p < 0.001$) as well as high internal reliability (Cronbach's alpha = 0.92) (M. J. Byerly et al., 2008). A moderate-to-strong degree of test–retest reliability was also found for the BARS (β ranged from 0.53 to 0.92 and r 's ranged from 0.46 to 0.86) (M. J. Byerly et al., 2008). For this study, the variable of adherence was dichotomized through use of a greater than or equal to 80% adherence cut-off, where medication taking behaviors that were reported as taking less than 80% of prescribed medications were categorized non-adherent. This 80% cut-off definition of adherence was per recommendations by expert consensus guidelines (Velligan et al., 2009).

Sense of Belonging Instrument-Psychological State.

The Sense of Belonging Instrument-Psychological state (SOBI-P) was used to measure sense of belonging in this study (see Appendix C). The Sense of Belonging Instrument (SOBI) is

a 27-item tool that consists of two separate scales, the 18 item SOBI-P (psychological state) and the 15 item SOBI-A (antecedents) (Hagerty & Patusky, 1995). The SOBI-P evaluates the experience of belonging, including the experience of feeling valued, needed or accepted and the feeling of fitting in with the persons or environment. The SOBI-A is designed to measure antecedents, i.e. motivators and potential for sense of belonging to occur and was not used in this study. In the original psychometric testing with nursing students, nuns and depressed persons, coefficient alphas for the SOBI-P were from .91 to .93 and .63 to .78 for the SOBI-A, with correlation between scales at .45 (Hagerty & Patusky, 1995; Hagerty & Williams, 1999). Items are rated on a 4-point Likert-type scale from 1- 4; higher scores on the SOBI-P indicate that the person experiences a sense of belonging, i.e., that he/she feels valued, needed and accepted (Hagerty & Patusky, 1995).

In the original psychometric testing with nursing students, nuns and depressed persons, coefficient alphas were high for the SOBI-P (ranging from $r = .91$ to $.93$) (Hagerty & Patusky, 1995; Hagerty & Williams, 1999). The SOBI-P exhibited moderate test-retest reliability during initial testing (Hagerty & Patusky, 1995). Other studies have reported similar coefficient alphas for the SOBI-P ranging from .95 to .97 in naval recruits, persons with depression, and traumatic brain injury (Bay, Hagerty, Williams, & Kirsch, 2005; Bay, Hagerty, Williams, Kirsch, & Gillespie, 2002; Choenarom, Williams, & Hagerty, 2005; Sargent, 2002). The measure has limited use in persons with schizophrenia. The full 27-item SOBI was used to test convergent validity of a measure of distal support in schizophrenia (Wieland, Rosenstock, Kelsey, Ganguli, & Wisniewski, 2007).

In preparation for this dissertation research, the PI pilot-tested the SOBI-P in a sample of 20 persons with schizophrenia with a resulting Cronbach's alpha of .93 (Barut et. al., 2016). In

this same study, the SOBI-P exhibited concurrent validity ($r = .86$) with another measure of belonging, the General Belonging Scale (Barut et al., 2016). In this study's sample, the Cronbach's alpha value for the scores was 0.90.

Herth Hope Index (HHI).

The HHI was adapted from the Herth Hope Scale and consists of 12 items that are rated on a 4-point Likert scale with higher scores indicating higher levels of hope (Herth, 1992) (see Appendix D). The author of the HHI defined hope as an inner sense of the future, of positive expectancy and interconnectedness with self and others (Herth, 1992).

The initial testing of the HHI in a sample of acutely ill, chronically ill and terminally ill patients had a Cronbach's alpha of .97, with a range of .94-.98 (Herth, 1992). This measure has been extensively used in persons with chronic mental illnesses (Bergin & Walsh, 2005; Bland & Darlington, 2002; Carretta, Ridner, & Dietrich, 2014; Chimich & Nekolaichuk, 2004; Patrick W Corrigan, Salzer, Ralph, Sangster, & Keck, 2004; Cutcliffe & Barker, 2002; J. R. Cutcliffe & K. A. Herth, 2002; Jones et al., 2012). It has also been extensively used in schizophrenia research (Patrick W Corrigan et al., 2004; Landeen, Pawlick, Woodside, Kirkpatrick, & Byrne, 2000; Littrell, Herth, & Hinte, 1996; Van Gestel-Timmermans, Van Den Bogaard, Brouwers, Herth, & Van Nieuwenhuizen, 2010; Yanos & Moos, 2007). This measure has been translated to multiple different languages, and the Dutch version has a Cronbach's alpha of .84 in a general sample of persons with serious mental illness that included schizophrenia (Van Gestel-Timmermans et al., 2010). Consistent with the prior body of work, the Cronbach's alpha value for the scores in this study was 0.86.

Four Point Ordinal Alliance Scale (4-PAS).

The 4-PAS is a self-rated 11-item questionnaire using a Likert-type rating scale ranging from 1 (“strongly disagree”) to 4 (“strongly agree”) (see Appendix E). The 4-PAS was developed to measure the therapeutic alliance between a prescribing provider and the patient and includes medication-taking aspects as well as relationship with the clinician (Misdrahi et al., 2009). Item scores are totaled with higher scores indicating a more positive therapeutic alliance with the provider. The 4-PAS was developed from an extensive literature review and adapted from the Helping Alliance Questionnaire (Luborsky et al., 1996), which included items specific to psychotherapy that were removed for the 4-PAS (Misdrahi et al., 2009).

Initial testing of the measure was conducted with 92 patients with schizophrenia and schizoaffective disorder. Internal consistency was strong (Cronbach’s alpha = .94) (Misdrahi et al., 2009). Principal factor analysis identified two factors: empathy experienced and psycho-education (Misdrahi et al., 2009). Concurrent validity was assessed with a participant-rated visual analog scale and showed a moderately high association ($r=.62, p<.00001$) (Misdrahi et al., 2009). While it is a newer measure, it has been used in studies beyond the initial testing to assess therapeutic alliance in schizophrenia (Hélène, Hélène, Jean, Jean-Marc, & Antoinette, 2014; Misdrahi et al., 2012). While other measures exist that have been used in schizophrenia, such as the Scale to Assess Therapeutic Relationship – Patient version (Kvrgic et al., 2013), the strengths of the 4-PAS in adherence studies in schizophrenia are fourfold: 1) psychometric testing has been conducted in schizophrenia 2) the tool was developed for persons with schizophrenia and 3) the tool specifically addresses medication-taking and 4) the tool assesses the relationship between the prescribing clinician and the patient instead of a therapist as is the case with other

tools available. The internal consistency of the scores from this instrument in this dissertation sample was consistent with those found previously (Cronbach's alpha = 0.96).

Demographic and Clinical Data Collection

Using a tool created by the PI, information was collected from medical record review and patient interview about the participants' age, diagnosis, gender, marital status, employment status, living situation, and type of antipsychotic medication (see Appendix F).

Data Analysis

Statistical analysis was conducted using IBM SPSS Statistics software (version 24). Only complete responses and measures with randomly missing item responses were used in the analysis. Because of the data collection method described above, missing data values were minimal. There were no systematic patterns of refusal to respond to questions observed in the data collection process.

Descriptive statistical analysis

Descriptive statistical summaries were generated for all the study variables. Frequency distributions were used to summarize the nominal and ordinal variables. Normally distributed data distributions were summarized using mean and standard deviation (SD); skewed distributions were summarized using median and inter-quartile range (IQR). Characteristics of the two adherence groups were compared using Chi-Square Tests of Independence and Mann-Whitney tests. When parametric assumptions were not met, as was the case with the BARS and the 4PAS, the PI worked with the statistician to conduct the appropriate transformations prior to conducting Pearson correlations and linear regression analyses. Both the BARS and the 4PAS data were negatively skewed. These data were reflected to a positive skew and the square root of the data was taken, which was then found to be normally distributed. The distributions were then

reflected back to their original direction for ease of interpretation. Pearson correlations were used to assess the extent of the correlations among the covariate and two independent variables:

4PAS, HHI, and SOBI-P.

Analysis of Specific Aims

Linear and logistic regression models were used to test study hypotheses. The dependent variable was the BARS (adherence) overall score. The continuous scores were used in the linear regression approach; the clinical dichotomies of adherent/non-adherent per percentile cutoff of 80% were used in the logistic regression approach. The independent variables in each type of regression were the SOBI-P (sense of belonging, Aim 1), HHI (hope, Aim 2). Each of those regressions included the 4PAS (therapeutic alliance) as a covariate. A maximum alpha of 0.05 was used for statistical significance.

CHAPTER 4

Results

Screening and Eligibility

Healthcare personnel at the three CMHCs referred a total of 92 individuals to this study. Referrals were either in person while the researcher was at the CMHC or were by sharing name and contact information by email in a secure electronic file. The study team was unable to contact six of the individuals who were referred by email. Per the study protocol, after three unsuccessful attempts at making contact by phone, the individual's contact information was destroyed and he or she was not contacted again for study enrollment. Of the 92 referred, 86 persons were screened for enrollment in the study (See Figure 3). Electronic referrals were preliminary screened over the phone and then a full screen was conducted in person.

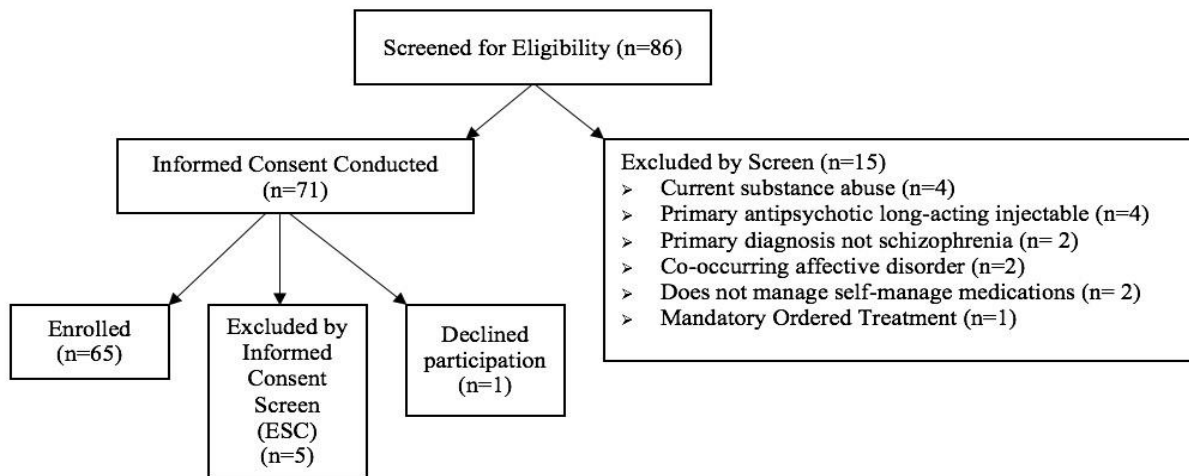


Figure 3. *Study Recruitment and Enrollment*

Of the 86 individuals who were screened for eligibility, 15 were excluded during the screening process for not meeting the inclusion/exclusion criteria. Number of individuals excluded by reason are listed in Figure 3. The informed consent process, which included explanation of the process for screening to confirm informed consent using the ESC, was

conducted with 71 participants. One individual declined participation after reviewing the study and consent document with the PI. Seventy participants agreed to participate after informed consent and comprehension of their consent was evaluated using the ESC. Five people were unable to answer one or more questions of the informed consent screening tool (ESC) after a maximum of two prompts and were excluded from the study. A total of 65 individuals were enrolled and completed the study.

Sample Characteristics

Descriptive statistical summaries of this sample of individuals diagnosed with schizophrenia (N=65) are shown in Table 1. The sample ranged in ages from 19-65 years with a median age of 51. The sample was comprised of 42 (64.2%) males and 23 (35.4%) females. Of these individuals, only 7.7% identified as being married or with a partner, while the majority (92.3%) identified as being single, divorced or widowed. Over half of these lived in a supervised group home (52.3%). The remainder either lived with a family member individuals or friend (29.2%) or alone (18.5%). The sample represented a wide range of educational experiences, with just over 6% achieving a higher education degree while 40% achieved less than a high school education.

Table 1. *Descriptive Statistical Summaries of the Sample Characteristics (N=65)*

Characteristic	n	%
Gender		
Male	42	64.6
Female	23	35.4
Race		
White	33	50.8
Black	30	46.2
Hispanic	1	1.5
Other (Kurdish)	1	1.5
Education		
Grade School	11	16.9
Some High School	15	23.1
High School	7	26.2
Some College	18	27.7
Bachelors	3	4.6
Masters	0	0
Doctorate	1	1.5
Marital Status		
Single/Divorced/Widowed	60	92.3
Married/Partner	5	7.7
Living Arrangement		
Alone	12	18.5
w/Family/Friend	19	29.2
Group Home	34	52.3
Area of Residence		
City/Urban	51	78.5
Country/Rural	6	9.2
Suburb	8	12.3
Employment Status		
Full-time	3	4.6
Part-time	6	9.2
Retired	1	1.5
Disabled	44	67.7
Unemployed	11	16.9
	Median	IQR
Age (years)	51.3	39.5-57.2

Descriptive Summaries of Study Instrument Scores

Scores from each of the study instruments are summarized in Table 2. Fifty percent of the therapeutic alliance (4PAS) scores were between the range of 31.4 and 36.5 within the possible range of 11-44. Adherence ratings per the BARS were high in this study. The interquartile range

of adherence (BARS) ratings for this sample was 76-95%, with a median rating of 90%. Both hope (HHI) and sense of belonging (SOBI-P) were normally distributed. The mean hope (HHI) score on the hope (HHI) measure was 34.6 (SD=5.7) with a total range of 17-45. The scores on the belonging measure (SOBI-P) tended to span the middle range of possible scores (mean=44.5, SD=9.4), where the maximum total score possible was 72.

Table 2. *Descriptive statistical summaries of the study measures (N=65)*

Measure	Median	IQR	Min-Max
Therap Alliance (4PAS)	33.5	31.4-36.5	11-44
Adherence (BARS)	90.0	76.0-95.0	20-100
	Mean	SD	Min-Max
Hope (HHI)	34.6	5.7	17-45
Belonging (SOBI-P)	44.5	9.4	21-69

Of the sample of 65 participants, 45 participants (69.2%) were rated as adherent to medications. Descriptive statistical summaries of adherent and non-adherent participants are shown in Table 3. Adherent and non-adherent participants were very similar across the domains of age, gender, race, education, marital status, living arrangements and employment status. There were no statistically significant relationships between adherence group and any of these variables.

Table 3. *Descriptive statistical summaries of adherent and non-adherent participants (N=65).*

Characteristic	No (N=20) n(%)	Yes (N=45) n(%)	p-value
Gender			0.545
Male	14(70.0)	28(62.2)	
Female	6(30.0)	17(37.8)	
Race			0.395
White	9(45.0)	24(53.3)	
Black	10(50.0)	20(44.4)	
Hispanic	0(0.0)	1(2.2)	
Kurdish	1(5.0)	0(0.0)	
Education			0.904
High School or less	14(70.0)	29(64.4)	
Some College	5(25.0)	13(28.9)	
College Degree	1(5.0)	3(6.7)	
Marital Status			0.140
Single/Divorced/Widowed	17(85.0)	43(95.6)	
Married/Partner	3(15.0)	2(4.4)	
Living Arrangement			0.964
Alone	4(20.0)	8(17.8)	
w/Family/Friend	6(30.0)	13(28.9)	
Group Home	10(50.0)	24(53.3)	
Employment Status			0.857
Full-time/Part-time	3(15.0)	6(13.3)	
Retired/Disabled/ Unemployed	17(85.0)	39(86.7)	
Age	Median(IQR) 49.7(39.7-57.2)	Median (IQR) 52.4(39.1-57.1)	0.804

Note: IQR represents the 25th and 75th percentile values.

Correlations among the covariate (therapeutic alliance) and the two independent variables (hope and belonging) are shown in Table 4. There were no statistically significant correlations between therapeutic alliance and sense of belonging, nor between sense of belonging and hope ($p > 0.05$). However, there was a statistically significant association between therapeutic alliance and hope ($r=0.66$, $p < 0.001$, see Table 4).

Table 4. *Univariate Correlations among independent variables (N=65)*

Measure	4PAS	HHI	SOBI-P
Therapeutic Alliance (4PAS)	-	0.66(< 0.001)	-0.08(0.543)
Hope (HHI)		-	0.08(0.526)
Sense of Belonging (SOBI-P)			-

Note: Values in cells are r (p -value)

Aim 1: Associations of Sense of Belonging with Adherence

Research Question #1: Controlling for therapeutic alliance, is there an association between sense of belonging and medication adherence in persons diagnosed with schizophrenia.

Summaries of the results from both the linear and logistic regressions of the sense of belonging scores with medication adherence are shown in Table 5. The unadjusted correlation of the SOBI-P scores with the BARS continuous scores was not statistically significant ($r=0.12$, $p=0.361$). Neither was the correlation of the combination of the SOBI-P and 4PAS scores with the BARS statistically significant ($R=0.15$, $p=0.492$, adjusted $R^2 < 0.01$). After controlling for the slight correlation of 4PAS with BARS, the unique contribution of the SOBI-P was ~1% shared variance ($beta=0.12$, $p=0.334$, see Table 5).

There were no statistically significant differences between the SOBI-P scores for the two groups created by dichotomizing the BARS score ($p=0.134$, unadjusted findings Table 5). The average SOBI-P score for the adherent group of participants was 45.6 (SD=9.2) while the non-adherent group mean was 41.9 (SD=9.5). Furthermore, consistent with the use of the BARS as a continuous outcome variable, the analysis that included the therapeutic alliance scores with the SOBI-P scores was also not statistically significant ($p = 0.106$, see Table 5).

Table 5. Associations of SOBI-P with BARS controlling for 4PAS (N=65)

Measure	Unadjusted		Adjusted		
	<i>r</i>	<i>p</i> -value	<i>beta</i>		<i>p</i> -value
Therap Alliance (4PAS)	0.09	.487	0.10		.443
Belonging (SOBI-P)	0.12	.361	0.12		.334
	O.R.	<i>p</i> -value	O.R.	95% C.I.	<i>p</i> -value
Therap Alliance (4PAS)	1.05	.205	1.06	0.98 – 1.15	.139
Belonging (SOBI-P)	1.05	.143	1.05	0.99 – 1.12	.100

Linear: Multiple $R = .15$, $p = .492$; $R^2 = .02$; Adjusted $R^2 = < .01$
 Logistic: $X^2_{(df=2)} = 4.48$, $p = 0.106$

Aim 2: Associations of Hope with Adherence

Research Question #2: Controlling for therapeutic alliance, is there an association between hope and medication adherence in persons diagnosed with schizophrenia?

Summaries of the results from both the linear and logistic regressions of hope with medication adherence are shown in Table 6. The unadjusted correlation of the HHI (hope) scores with the BARS (adherence) continuous scores was statistically significant ($r = .26$, $p = .040$). The model that included therapeutic alliance as a covariate was not statistically significant (Multiple $R = 0.28$, $p = .084$, adjusted $R^2 = 0.05$).

The average HHI score for the group of participants classified as adherent on the BARS was 35.8 (SD=4.6) which was statistically significantly higher than that of the group classified as non-adherent which was 32.0 (SD=7.2, $p = .023$). Contrary to the continuous BARS findings, an analysis that included therapeutic alliance as a covariate was statistically significant ($p = 0.039$). There remained a statistically significant increase in the likelihood of being “adherent” using the

clinical category with increasing hope (HHI) values (OR=1.16, 95% CI=1.01-1.34, $p = 0.038$, see Table 6).

Table 6. Associations of HHI with BARS controlling for PAS (N=65)

Measure	Unadjusted		Adjusted		
	<i>r</i>	<i>p</i> -value	<i>beta</i>		<i>p</i> -value
Therap Alliance (4PAS)	0.09	.487	-0.14		.383
Hope (HHI)	0.26	.040	0.35		.035
	O.R.	<i>p</i>-value	O.R.	95% C.I.	<i>p</i>-value
Therap Alliance (4PAS)	1.05	.205	0.97	0.87-1.09	0.603
Hope (HHI)	1.13	.023	1.16	1.01-1.34	0.038

Linear: Multiple $R=.28$, $p=.08$; $R^2=.08$ (Adjusted $R^2=.05$)

Logistic: $X^2_{(df=2)}=6.51$, $p =0.039$

CHAPTER 5

Discussion

Meaning and Significance of Findings

This chapter presents a discussion of the study results. The objective of this research was to study factors influencing medication adherence in persons diagnosed with schizophrenia. Despite decades of research, causative factors that can be positively impacted to consistently improve medication non-adherence are not well-identified. In this quantitative study conducted in community mental health centers, the researcher sought to understand the possible impact of sense of belonging and hope on medication adherence in persons with schizophrenia. It was hypothesized that these factors would prove to be meaningful related to medication adherence and inform future interventional nursing research. Key findings of this study were: (1) sociodemographic variables were not found to be correlated to with medication adherence (2) The majority of participants in this study, (69%), were rated adherent to medications. (3) Individuals with higher sense of belonging scores did not have higher rates of medication adherence. No association or shared variability was found between sense of belonging and therapeutic alliance in relationship to medication adherence. (4) Individuals with higher levels of hope reported higher levels of medication adherence. Hope was found to be significantly associated with therapeutic alliance. When using the clinical categories of “adherent” and “non-adherent”, the relationship between hope and medication adherence continued to be statistically significant after controlling for therapeutic alliance. A detailed discussion of these findings follows.

Sample Characteristics

Sample sociodemographic characteristics varied from the general population of the geographical region included in the study with an underrepresentation of females (35.4% compared 51.8%), underrepresentation of Caucasians (50.8% compared to 65%), overrepresentation of African-Americans (46.1% compared to 25%), and underrepresentation of Hispanics (1.5% compared to 8%) compared to the population in Davidson County, TN (US Census Bureau, 2015). While race was not representative of the region of the study, it may more closely mirror the population of persons diagnosed with schizophrenia in the U.S. (Schwartz & Blankenship, 2014). In a large study of individuals with schizophrenia (n=2327) that recruited participants from six states in the U.S, 52.6% of participants were Caucasian, similar to the 50.8% in this study (Ascher-Svanum et al., 2006). The disparities in race and gender representation may also be related to recruitment occurring in urban location. While schizophrenia diagnosis is largely equally distributed across genders (U.S. Census Bureau, 2015), gender distributions widely vary in the literature. Some studies had a similar percentage of male participants as the 64.6% in this study (Ascher-Svanum et al., 2006; Brain et al., 2013), other studies ranged from 57.4-85% (Haro et al., 2006; Misdrahi, Llorca, Lancon, & Bayle, 2002; Quach et al., 2009; Tranulis et al., 2011).

Participants in this study were slightly older than those of other studies in the literature, with a median age of 51. In the aforementioned study, the mean age of participants was 41.7 % (Ascher-Svanum et al., 2006) In a large European study with close to seven thousand participants, the mean age was 40.2 (Novick, Haro, Suarez, Vieta, & Naber, 2009), and in another medication adherence study, the median age of participants was 45 (Brain et al., 2013). The slightly older median age in this study may have been related to the presence of young adult

programs offered by two of the CMHMCs in this study that were located at different sites from where recruitment activities occurred.

Just over 92% of participants in this study were single, separated or divorced. This mirrors an older study where 94% of participants were single, separated or divorced (Agarwal et al., 1998) and is similar to a more recent study where 85% of participants were single (Tranulis et al., 2011). Other studies had lower rates of single participants with reports of 72.7% (D. Novick et al., 2010) and 71.1% (Misdrahi et al., 2002). This high rate of single persons may be related to the study recruitment sites being in urban areas that are located near low-income housing, which would be more affordable for a single person with easier access to resources such as the CMHCs. Alternatively, this could be representative of this population as the comparative studies listed were conducted across a span of 6-16 years, and with several studies evidencing the higher rate of single individuals. This aligns with and may be related to other research indicating that social support is low in persons with schizophrenia (Agarwal et al., 1998; Davidson, 1997; Pyne et al., 2006).

Additional sociodemographic characteristics of this study were similar to those found in the literature. Slightly more than 52% of persons in this study lived with someone or lived in a group home setting, which was similar to a study in the literature review (Novick et al., 2009). Over 50% of participants were unemployed in this study, which is comparable to another medication adherence study (Brain et al., 2013). Sixty percent of individuals in this study had a high school education or greater, which was similar to several studies (Agarwal et al., 1998; Misdrahi et al., 2012), yet was 20% higher than another study in the literature (Ascher-Svanum et al., 2006). One of the CMHCs had educational programming to assist individuals to take high-school equivalency examinations, which may explain the higher levels of education in this

research sample. For future studies, it may be useful to collect data regarding the types of programming and supportive services available at differing CMHCs to explore the impact of these types of programs on demographics and on key variables of interest.

In summary, this study enrolled a sample of individuals diagnosed with schizophrenia who lived in Davidson County, Tennessee or the surrounding areas. This sample was older and consisted of a higher percentage of males than the general population of persons diagnosed with schizophrenia. These findings may be related to the programming and/or locations of the studied CMHC sites. Because these sample demographics are not widely representative of the general population of Davidson County, Tennessee or of the United States, generalizability of findings are limited to the sites and region studied. To assess the applicability of these findings to the general population of persons with schizophrenia, additional studies would be necessary across geographic regions, to include urban and rural areas in different states.

Discussion of Instrument Scores

BARS (Adherence). Forty-five participants (69.2%) in this study were adherent to medications, rated 80% or greater per the BARS tool. This is higher than the rate of adherence (52.5%) found by research using the BARS with a similar number of participants (M. J. Byerly et al., 2008). The higher rate found in this study could be related to adherence and supportive programs at the CMHC sites or regional differences in the sample. The rate of adherence in this study is similar to some other studies that used tools other than the BARS to measure objective and subjective indicators of adherence with rates of adherence between 71-73% (Brain et al., 2013; Diego Novick et al., 2010). It is also possible that the findings do not accurately portray the participants' actual adherence level, particularly considering that rates of non-adherence in many studies identify lower rates of adherence (Acosta et al., 2009; Coldham et al., 2002; Garcia

et al., 2016; Lacro et al., 2002). While the BARS tool has been shown to be significantly associated with the gold standard in adherence measurement (electronic monitoring devices), with high internal reliability, this is the result of one study (M. J. Byerly et al., 2008), and replication of these results are needed. Because the tool relies on self-report of medication taking behaviors of the individual and the final adherence core is based on the subjective decision-making of the rater, additional psychometric testing may be needed to determine if the tool reliably measures adherence in schizophrenia.

SOBI-P (Sense of Belonging). The SOBI-P was developed to measure the level of perceived sense of belonging, with initial testing in nuns, students, and depressed individuals (Hagerty & Patusky, 1995). Sense of belonging has not been widely studied in schizophrenia, and no studies were found using the SOBI-P in schizophrenia beyond the initial testing by this researcher (Barut et al., 2016). The range of possible scores for the SOBI-P are 18-72, with higher scores indicating higher levels of sense of belonging. In this sample, the scores were predominantly centered in the lower-middle of the range, with an IQR of 31.5-36.5. This indicates that these participants had some degree of sense of belonging, but not strongly so. In a study of persons with depression, the SOBI-P mean score was 49.14, while a comparison group had a mean of 64.5 (Choenarom et al., 2005). The lower scores for this group, are perhaps not unusual, as related concepts, such as experiences of loneliness, isolation and a lack of social support, are reported to be commonly experienced in this population (Agarwal et al., 1998; Davidson, 1997; Pyne et al., 2006). In this study, the lower scores may be related to the high percentage of single individuals, who may not have the social support or sufficient interactions to experience a higher sense of belonging. It may also be that sense of belonging is deficit in this

population because of impaired social cognition and other symptoms of schizophrenia (Shean & Meyer, 2009).

It is notable that in the preliminary qualitative study by this researcher, most subjects spoke of the importance of sense of belonging in their lives, suggesting that this is an important construct in this population (jbarut et al., 2016). A common symptom of schizophrenia is concrete thinking, and in the aforementioned study, participants were asked directly about their sense of belonging, whereas this instrument never directly asks about sense of belonging or uses the word belonging in any of the items. It may be that the construct measured by the SOBI-P is too vague and abstract for persons diagnosed with schizophrenia. Additionally, individuals with schizophrenia may not experience sense of belonging in the broad context of society and in the world. These individuals often have few relationships, little in the way of social support, and often experience stigma from friends, family and society at large. Notably the SOBI-P has multiple questions that specifically target societal acceptance, fitting in with friends, family and mainstream society, and having a place in the world. This may not capture the experience of sense of belonging in persons with schizophrenia because of the stigmatizing nature of the illness and challenges these individuals face socially. In order to understand this construct and the lived experiences of belonging identified in the previous study more fully, psychometric testing, including factor and component analysis, would be beneficial to determine if the SOBI-P effectively measures sense of belonging in persons with schizophrenia.

HHI (Hope). The HHI has been widely used in studies with persons diagnosed with schizophrenia. The range of scores for the HHI is 12-48. The mean hope score for this sample was 34.6, with a standard deviation of 5.7. This is higher than scores noted in other studies in the literature that reported these scores with a mean of 22.5 (Littrell et al., 1996) (Littrell, Petty,

Hilligoss, Peabody, & Johnson, 2001). This indicates that this sample of older individuals with schizophrenia may be more hopeful than the general population of persons with this disorder. Again, this could be related to regional differences or programming at the CMHC sites that could enhance hope. The higher hope scores may also be related to life-experiences and resilience in managing the disorder for individuals who are older and may have had the disorder for a longer span of time. This cannot be validated however, as it was not within the scope of this study to collect information about site programming and attendance nor was length of time since initial schizophrenia diagnosis measured. This would be useful to explore for future studies.

4PAS (Therapeutic Alliance). The 4PAS is an 11-item tool with scores ranging from 11-44. The instrument was developed specifically to measure the relationship between prescribing clinicians and persons with schizophrenia and includes interpersonal and medication-related aspects of the therapeutic alliance. The interquartile range of scores in this sample fell on the higher end of the range of scores, indicating that this group had moderate to strong therapeutic alliance with their prescribing clinician. Both physicians and nurse practitioners employed at the respective CMHC sites referred patients to this study, but data specific to type of provider was not collected. Future studies may seek to understand these relationships by exploring if any differences exist in the relationship of physicians or nurse practitioners and their therapeutic alliance with patients diagnosed with schizophrenia.

Discussion of Research Questions

Research Question #1: Controlling for therapeutic alliance, is there an association between sense of belonging and medication adherence in persons diagnosed with schizophrenia.

Sense of belonging was not found to be related to either therapeutic alliance or medication adherence. It was an unexpected finding that sense of belonging did not have any

relationship to medication adherence, particularly since the related concept of social support has been found to be strongly associated with medication adherence in several studies (Agarwal et al., 1998; Coldham et al., 2002; Gutierrez-Casares et al., 2010; Hudson et al., 2004; D. Novick et al., 2010; Olfson et al., 2000; Quach et al., 2009; Sapra et al., 2013). It may be that this sample of predominantly single individuals did not have high levels of social support and that may have impacted the findings across the sample. Concurrent measurement of sense of belonging and social support would be beneficial for future studies to determine the relatedness of these concepts as well as any impact on medication adherence. As previously mentioned in discussion section on study instruments, it may also be that the SOBI-P is not accurately measuring sense of belonging in this particular population. In a previous qualitative study, participants expressed that sense of belonging was a valuable component of the human experience and suggested linkages to medication adherence (Barut et. al., 2016). Further research on sense of belonging is needed in schizophrenia to better understand what, if any, impact sense of belonging has on the illness and outcomes related to treatment.

Another unexpected finding of this study was a lack of correlation between sense of belonging and therapeutic alliance. Hagerty et al (1996) suggested that therapeutic alliance may impact sense of belonging. Defining attributes of sense of belonging and therapeutic alliance, such as interconnectedness and interpersonal relatedness, suggested possible interrelatedness of these two constructs. This was not borne out by this study using the SOBI-P to measure sense of belonging. While attributes of therapeutic alliance and sense of belonging may be similar across the two concepts, based on the findings of this study, it appears that sense of belonging and therapeutic alliance are distinct phenomenon that may be completely independent of each other. There was no indication that having a strong therapeutic alliance affected sense of belonging in

persons with schizophrenia. It does not necessarily follow that having a therapeutic alliance or positive relationship with a healthcare would create a sense of belonging in the world. It would be of interest to study this further to identify if therapeutic alliance and sense of belonging retain distinct properties with other mental illness populations and other health groups or if there are characteristics of how persons with schizophrenia relate to others that create this distinction.

This study theorized sense of belonging as a proxy for subjective norm, or the experience of wanting to engage in behaviors because significant other persons in the individual's life desire that he or she do so, and therefore as driving motivating behaviors which would yield medication adherence, in accordance with the Theory of Planned Behavior (TPB). However, this was not supported in this study, and it may be that subjective norm and/or sense of belonging are expressed differently in persons with schizophrenia related to the cognitive, perceptual and relational impacts of the illness. While there is some research using the TPB in schizophrenia (Kopelowicz et al., 2007; Kopelowicz et al., 2012), research using the model in this population related to adherence is limited. It is possible that the assumptions of TPB concerning subjective norm do not operate in the same way in this population and different assumptions and/or models are needed. It raises the question of whether there are effects of the disease that create unique interactions with the world such that feeling a sense of belonging has a different level of impact on the behavior of persons with schizophrenia compared to the general population. Further exploration of variables that would impact behavior planning and motivating factors influencing medication-taking behaviors in this population are needed to provide further understanding.

The current study alone does not provide a basis to rule out the potential experiential and clinical relevance of sense of belonging for persons diagnosed with schizophrenia. It is possible that individuals with schizophrenia characteristically do not have high levels of sense of

belonging and that sense of belonging is not related to medication adherence, despite the previous study's indication that sense of belonging is important in this population (Barut et al., 2016). It may be that the symptomology of schizophrenia, including the impact of the disease on cognitive, interpersonal and social functioning impacts how the person experiences sense of belonging. Further phenomenological and experiential exploration of the concept of sense of belonging in schizophrenia is needed to better understand the role of sense of belonging in the lives of these individuals.

Research Question #2: Controlling for therapeutic alliance, is there an association between hope and medication adherence in persons diagnosed with schizophrenia?

Hope is identified in both clinical and research literature as being an extremely relevant factor in the health of persons with mental illness, and in schizophrenia specifically (Chien et al., 2013; Corrigan, 2006; P. Deegan, 1994; Frese, 2009a; Kylma et al., 2006; Substance Abuse and Mental Health Administration, 2006; Wahl, 2012). This was mirrored in this study; hope was found to be significantly associated with both medication adherence and therapeutic alliance in persons with schizophrenia.

After controlling for the significant contribution of therapeutic alliance, hope no longer had significant explanatory value on medication adherence using the continuous variable of percent of adherence. It is notable that this overall group had a high range of therapeutic alliance, and that while most participants were adherent, the range of adherence was from 20% to 100%. The high levels of therapeutic alliance combined with a wide range of adherence scores could have influenced this finding. For the purpose of this study, and per expert consensus guidelines (Velligan et al., 2009) the clinical categories of adherence, where taking 80% or greater of medications prescribed equals adherence, have more clinical relevance to practice. When

comparing adherent versus non-adherent groups per this definition of adherence, those identified as adherent tended to have more hope than those who were non-adherent to medications. Using the clinical categories, after controlling for therapeutic alliance, participants with higher hope values were increasingly likely to be adherent to medications ($p=0.039$). Intrinsic and/or extrinsic factors may be present in the more hopeful individuals that resulted in higher rates of adherence to medications. It is also possible that there are other factors that are influencing the medication-taking behaviors that then results in medication stabilization and decreased symptoms of schizophrenia, thereby causing the individuals to experience more hope. Longitudinal studies of hope and adherence over time may yield more explanatory information about these differences.

The Theory of Planned Behavior model was chosen for this study because of its strength in targeting attitudes, such as hope, to influence desired behavior. Attitudes have been shown to impact medication adherence in persons with schizophrenia (E. M. Beck, M. Cavelti, S. Kvrjic, B. Kleim, & R. Vauth, 2011; Brain et al., 2013; De las Cuevas & Peñate, 2015). There is a moderate amount of literature on hopelessness, but the literature on hope in schizophrenia is limited, particularly literature exploring hope and medication adherence. Because hopelessness is a common symptom of schizophrenia, hope may be more meaningful to these individuals when it is experienced. Hope may result in positive experiences and support personal choices that enhance engagement and adherence to treatment. Additional understanding is needed to understand how individuals with schizophrenia experience hope, as well as how hope influences their adherence to medications and other treatment. This will aid development of interventional research to help to determine how clinicians can positively affect hope specifically with the aim of increasing medication adherence.

In the univariate correlations, therapeutic alliance was strongly correlated with medication adherence ($p < 0.001$) and with hope. The multivariate correlation showed that hope was no longer statistically significant after controlling for therapeutic alliance, indicating that hope and therapeutic alliance may have shared aspects that influence medication adherence. There are multiple characteristics of the therapeutic alliance to consider that may be impacting these relationships. These include having a trusting relationship, effective communication, consistency and reliability of the relationship to name a few (Haddad, Brain, & Scott, 2014). Any and/or all of these factors combined may be important factors in improving hope and/or medication adherence. Further study is needed to evaluate how to leverage the therapeutic relationship to increase hope and medication adherence in this population.

Strengths and Limitations of the Study

This research is the only known quantitative study exploring the role of hope and sense of belonging on medication adherence in persons with schizophrenia. As such, the study contributes invaluable information to the extensive body of research on this ongoing dilemma of medication non-adherence in this population. A strength of this study is the conceptualization of these existential factors as potential factors influencing medication within the framework of the Theory of Planned Behavior, particularly related to hope and attitudes. This research targets insights and attitudes, both of which have consistently been shown to impact medication adherence in schizophrenia. The findings of this study advance the body of literature on medication adherence in schizophrenia in a way that has not been previously conducted and illustrates that having an attitude of hope is, in fact, related to medication adherence in persons diagnosed with schizophrenia. Additionally, it identifies that persons who are not adherent to medications have lower levels of hope compared to individuals who are adherent to medications.

Another strength of this study is related to specific aspects of the study instruments. Both the measure for therapeutic alliance (4PAS) and for medication adherence (BARS) were specifically developed for use in persons with schizophrenia. The hope instrument (HHI) was initially tested with persons with depression but has been used extensively in various mental illness and health states. Additionally, the HHI was developed over two decades ago, and has been in use since that time (Herth, 1992).

A third strength of this study is the referral and screening process. Participants were initially screened by their clinician at the CMHC using the inclusion/exclusion criteria. Clinicians were provided education on the screening and referral process by the PI, and only referred individuals who were identified as meeting the inclusion/exclusion criteria. To preserve anonymity of the individual, clinician information was not recorded, and the study team did not have access to the medical record of those referred to the study. The study team then conducted a thorough screen. If conditions were met, the individual was further screened for comprehension of informed consent before enrollment in the study occurred. This is of particular importance, as cognitive impairment, which can include comprehension and decision-making ability, is a common occurrence in persons with schizophrenia. This screening process provided an additional human subjects protection for this vulnerable population.

A weakness of this study was the use of two instruments (SOBI-P and HHI) with limited validity and reliability testing in persons with schizophrenia. The SOBI-P has evidence of good reliability and validity in other studies, and preliminary data suggested similar high reliability in persons with schizophrenia; however extensive psychometric testing with this instrument in schizophrenia has not been conducted. While the HHI has extensive history, has been widely used in schizophrenia, and has high reliability in other mental illness populations, no

psychometric testing data is available specifically in schizophrenia beyond the reliability findings in this study.

Other potential areas for concern include bias, issues of self-report of key variables, and lack of use of objective measures. The subjects completed the study measures, and if an individual had challenges reading the measures, the PI offered to read the questions aloud and either obtained verbal responses or the subject chose his or her response on the tablet screen. This introduced a risk of administration bias. There was also a risk of social responsiveness bias. Since the researcher was present as the subject completed the instruments, it is possible that some participants could have responded in what he/she believed was the expected response. The following steps were taken to minimize these risks and the impact on the findings: (1) the researcher was diligent in informing the subjects of the study purpose and objectives and to ask the questions in a neutral tone and manner, (2) participants were encouraged to make the item selections on the tablet themselves whenever possible and (3) the RA was also thoroughly trained to administer measures in the same manner as the PI.

Other limitations of this study include the small sample size and the restriction to community mental health centers in one region of a metropolitan area. This limits generalizability of the findings, as rural areas and regions outside of the Nashville Metro area were not included in this study. Moreover, it is possible that non-adherent participants declined to participate upon hearing of the study from the community mental health clinic and therefore were never referred to the study. The participants were also not stratified by research site. Knowing the research site may have provided key insights into the high degree of adherence of this sample. The different community mental health centers had different programs available, such as Psychiatric Assertive Community Treatment teams, group therapy and other programs

that may have influenced the high rate of adherence, which is not representative of the general population of persons with schizophrenia based on the current literature. However, due to the small sample size, stratifying the sample by site had the potential to increase risk of loss of confidentiality and the sample was not large enough to control for possible variances by services offered at each CMHC. Lastly, data was not collected about length of diagnosis or treatment specifics such as duration of treatment or type of medication (typical/atypical antipsychotic). This information might have yielded important additional insights into the rates of high hope and medication adherence in this study.

Implications for Nursing

The significant findings of this research hold meaningful new knowledge that can benefit the practice of mental health nursing for both the bedside and the advance practice nurse. First, the study clearly illustrates that the therapeutic alliance between clinician and patient can significantly impact the medication adherence of patients diagnosed with schizophrenia. The most effective intervention in the psychiatric nurses' toolbox is the ability to quickly and effectively build a therapeutic relationship that builds trust and is a reliable and consistent force in the lives of their patients (Dziopa & Ahern, 2009; Peplau, 1997). Secondly, this study identified a significant positive relationship between hope and medication adherence. Nurses can improve hope in the lives of the individuals diagnosed with schizophrenia by providing nursing care that embraces the totality of the person's human experience within the context of the therapeutic relationship (J. Cutcliffe & K. Herth, 2002). This relationship can enable the nurse to provide a reflective mirroring for individuals that validates their worthiness as a person and inspire hope for a meaningful future. Additionally, within this relationship of trust the nurse can provide the patient with education about strategies to manage their illness, including information

targeting medication-taking behaviors and benefits of medications. These nurse-led interventions can inspire hope that symptom management is possible and that patients can lead productive and purposeful lives. This inspiration of hope within the specific and individual context of the person's life and the therapeutic alliance with the nurse may increase medication adherence and improve outcomes.

Medication non-adherence is a very significant problem for individuals diagnosed with schizophrenia and impacts human suffering for these patients and their families. Not only does medication non-adherence decrease quality of life for these individuals, it also increases the risk of relapse and serious short and long-term impacts on health for individuals and families. Medication adherence leads to improved outcomes and is the only consistently identified protective factor for suicide. Nurses have a responsibility to improve these outcomes, and specifically to focus on strategies that will improve the therapeutic alliance with the patient while inspiring hope within the patient such that medication adherence can be improved for these individuals.

Recommendations for Future Research

This study presents new findings relevant to the body of literature on medication adherence in persons diagnosed with schizophrenia. The literature to date has identified many factors that may influence non-adherence, such as substance abuse, poor social support, lack of insight, among others. Despite decades of research on the subject, factors that can be influenced to consistently improve medication adherence has not been identified. This is the first known study to examine the relationship between hope and medication adherence, and the results are promising for the potential ability to influence this existential factor and thereby improve medication adherence. Additional studies are needed to validate these findings across a wider

geographic region and with a larger number of participants. If the findings within this study regarding hope are replicated, additional research will be needed to develop and trial interventions that nurses and other clinicians can employ to improve hope within these individuals. Hope has been anecdotally supported as being profoundly important to mental health in individuals experiencing acute mental illness by experts, mental health agencies and the literature (P. E. Deegan, 1997; Kylma et al., 2006; Substance Abuse and Mental Health Administration, 2006). Linking hope to outcomes in schizophrenia offers the opportunity to create a new avenue for exploratory and interventional research across other chronic mental illnesses.

Therapeutic alliance, which has been studied related to medication adherence with evidence of positive effect. This study is unique in that therapeutic alliance was identified as potentially influencing both relationships of hope and sense of belonging with medication adherence. While therapeutic alliance was not significantly correlated with sense of belonging, it was significantly correlated with both hope and medication adherence using. Using the clinical categories of adherence, after controlling for therapeutic alliance, hope continued to contribute unique significance to whether or not a person adhered to his or her medications. Additional research is needed to explore the relationship between hope and therapeutic alliance to determine how to best leverage the clinician in the lives of these mentally ill individuals in such a way that will consistently improve their lived experience and positively impact outcomes. It may also be useful to conduct research exploring similar variables to hope, such as optimism, inspiration, motivation, agency, sense of purpose and/or perceived control to help identify strategies that may be useful to aid clinicians in improving hope.

While the findings in this study did not discover significant relationships between sense

of belonging and medication adherence in persons diagnosed with schizophrenia, it clearly identifies the need to further study the phenomenon of sense of belonging in this population. One previous qualitative study indicated that the SOBI-P had face validity in persons diagnosed with schizophrenia, with indications that it holds clinical relevance for this population (Barut et. al., 2016). Additional qualitative studies are needed to explore the societal context and personal experience of sense of belonging in the lives of persons diagnosed with schizophrenia. In the 1950's Abraham Maslow identified a hierarchy of basic human needs that included love and belonging needs as central to human health and happiness secondary after physiological and safety needs (Maslow, 1954). Self-determination theory proposes a similar basic psychological need, relatedness, or the need to feel connected to others, as a requisite to health and quality of life (Ryan & Deci, 2000). Social inclusion, being a part of something, and feeling as if one belongs, are identified as important to health, particularly mental health (Anant, 1967; Hagerty et al., 1992) (M. Lambert et al., 2004). Feeling as if one belongs enhances meaning in life, another vital construct to health and well-being (M. Lambert et al., 2004). The terms 'sense of belonging', 'need to belong', and 'belongingness' are used interchangeably in the literature to describe this favorable state, but while the construct is widely deemed to be important to mental health, it lacks definitiveness both in conceptualization and in measurement.

The SOBI-P needs further psychometric testing and factor analysis in individuals with schizophrenia to determine if it is a valid tool for use in this population. Lastly, it would be beneficial to conduct research in schizophrenia explore constructs that may be related to sense of belonging such as social support, relatedness, and interconnectedness, for example. In the original testing of hope instrument used in this study, the factor analysis revealed a third factor of hope as "interconnectedness with self and others" (Herth, 1992 p. 1256). Considering the

significance of hope found in this study using the HHI, it may also be useful to explore factors within the concept of hope as potentially aiding understanding of the concept of sense of belonging in this population.

This study used the Theory of Planned Behavior as a conceptual model to support understanding of attitudes and subjective norm influences on medication adherence behaviors. Kopelowicz et al (2007) used the model in a study of medication adherence in Mexican American adults with schizophrenia, but other studies using the model are limited in this population. Future studies may benefit from model testing of the Theory of Planned Behavior to determine if it is useful in helping to explain behaviors in schizophrenia. Qualitative studies would also aid understanding of the experience of subjective norm in this population.

This study used a screening tool to confirm participants' understanding of informed consent. Persons with schizophrenia may have a higher degree of impaired decisional capacity compared to other well individuals, indicating a need for evaluation of informed consent in research (Appelbaum & Redlich, 2006). The ESC was used in this study to protect these subjects who may be vulnerable due to the neuropsychological effects of their illness. Future studies, not only on medication adherence, but other research with individuals diagnosed with schizophrenia should consider use of the ESC screening tool, or a similar tool tested in schizophrenia, to protect this population.

In conclusion, this study identifies multiple areas whereupon further exploration is needed related to improve understanding of how hope and therapeutic alliance can improve medication adherence. Research is needed to develop nurse-driven interventions that instill hope and potentially increase adherence. Further inquiry is also needed regarding the role of the therapeutic alliance in increasing hope and improving medication adherence in persons with

schizophrenia. Research that expands on the findings of this study can hopefully lead to improvements in medication adherence and, as a result, improve quality of life and meaningful lived experiences for this population of chronically mentally ill individuals.

Lastly, additional research is needed to understand sense of belonging in persons with schizophrenia. Sense of belonging is acknowledged as a psychological need and motivator of social behavior and is a crucial factor of healthy psychological and social functioning (Anant, 1967; Hagerty et al., 1992; N. M. Lambert et al., 2013; Maslow, 1954). Further exploration of this concept may yield a more refined definition and measurement that will allow future research to improve psychological and social functioning in the population of persons diagnosed with schizophrenia.

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APPENDIX A: Evaluation to Sign Consent

Confidential

Schizophrenia Med Adherence Study Screening Database
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Evaluation to Sign Consent

Record ID _____

Instructions: Make a subjective judgment regarding the first question below, then ask the patient questions 2 through 5. You may select the language to use in asking the questions in order to help the patient understand them.

1. Is the patient alert and able to communicate with the examiner? Yes No

2. Ask the patient to name at least two potential risks incurred as a result of participating in the study.
Was the person able to identify two potential risks? Yes No

3. Ask the patient to name at least two things that will be expected of him/her in terms of patient cooperation during the study.
Was the patient able to name at least two expectations of the study? Yes No

4. Ask the patient to explain what (he/she) would do if (he/she) decides that they no longer wish to participate in the study.
Was the patient able to explain what to do if they no longer wish to participate? Yes No

5. Ask the patient to explain what (he/she) would do if (he/she) is experiencing distress or discomfort.
Was the patient able to explain what he or she should do if experiencing distress or discomfort? Yes No

Was the potential participant alert, able to communicate and give acceptable answers to items 2,3,4, & 5? Yes No

If the previous question was yes, the screen is negative, assign study ID and proceed with next steps of study.

If the previous question was no, the screen is positive, DO NOT assign a study ID. Thank the person for his/her time and inform that he/she is not eligible for the study at this time.

STUDY ID:

Evaluator _____

Date _____

Date of Approval: 2/22/2016



APPENDIX C: Sense of Belonging – Psychological State

Confidential

Page 1 of 2

Sense of Belonging - Psychological State

SENSE OF BELONGING INSTRUMENT

Psychological Experience

SOBI-P

Instructions: Here are some statements with which you may or may not agree. Please choose the response that most closely reflects your feelings about each statement.

	Strongly Agree	Agree	Disagree	Strongly Disagree
1. I often wonder if there is any place on earth where I really fit in.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I am just not sure if I fit in with my friends.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I would describe myself as a misfit in most social situations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I generally feel that people accept me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I feel like a piece of a jig-saw puzzle that doesn't fit into the puzzle.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I would like to make a difference to people or things around me, but I don't feel that what I have to offer is valued.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I feel like an outsider in most situations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I am troubled by feeling like I have no place in this world.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I could disappear for days and it wouldn't matter to my family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. In general, I don't feel a part of the mainstream of society.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I feel like I observe life rather than participate in it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. If I died tomorrow, very few people would come to my funeral.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. I feel like a square peg trying to fit into a round hole.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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APPENDIX D: Herth Hope Index

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Herth Hope Index

HERTH HOPE INDEX

Listed below are a number of statements. Read each statement and choose the option that best describes how much you agree with that statement right now.

	Strongly Disagree	Disagree	Agree	Strongly Agree
1. I have a positive outlook toward life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I have short and/or long range goals.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I feel all alone.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I can see possibilities in the midst of difficulties.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I have a faith that gives me comfort.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I feel scared about my future.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I can recall happy/joyful times.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I have deep inner strength.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I am able to give and receive caring/love.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. I have a sense of direction.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I believe that each day has potential.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. I feel my life has value and worth.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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APPENDIX E: Four Point Ordinal Alliance Scale

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Four Point Ordinal Alliance Self-Report (4-PAS)

Four Point-Ordinal Alliance Self-Report (4-PAS)

Listed below are a number of statements. Read each statement and choose the response that best describes how much you agree with that statement.

	Strongly Disagree	Disagree	Agree	Strongly Agree
1. I believe my doctor is helping me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I am comfortable with the relationship I have with my doctor.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I have a better understanding of the symptoms of my illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I've been feeling better since my doctor has been treating me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I feel I can count on my doctor.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I feel I understand my doctor.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I feel my doctor really understands me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I think my doctor gives clear explanations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I feel my doctor wants me to get better.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. I feel that my doctor and I work together as a team.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I think we understand my problems in the same way.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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APPENDIX F: Demographics and Clinical Data Collection Form

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Demographics and Clinical Data Collection Form

Information on this form is to be collected from the participant interview.

What is your birthdate?

(Month/Day/Year)

What is your Gender?

Male Female

What is your race?

White Black Hispanic
 Other

If you chose other, what is your race?

What is the highest level of education you have completed?

Grade school
 Some high school
 High school
 Some college
 Bachelor's degree
 Master's degree
 Doctoral degree
 Post-doctoral

What is your marital status?

Single Married Partner Widowed Other

If you chose other, what is your marital status?

What is your employment status?

Employed full-time Employed part-time Retired Disabled Homemaker
 Unemployed

What are your living arrangements?

Live alone Live with a friend(s)
 Live with parent(s) Live with family
(spouse/partner, children, other family member)
 Live in a supervised residential home/group home

What best describes your area of residence?

City/Urban Country/Rural/Small town Suburb

Demographics and Clinical Continued: Medications

Please complete the survey below.

Thank you!

Date _____

This form is the continuation of the Demographics and Clinical Data Collection form and is to be completed by the PI/RA through direct questioning of the participant. After data entry, verify responses with the participant.

List the medications the patient is currently taking, including name of medication, dosage and frequency (if known).

What type of antipsychotic medications is the patient taking?

- _____
- First Generation (Typical)
 - Second Generation (Atypical)
 - Both First and Second Generation

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