

THE INFLUENCE OF DECISION-MAKING PREFERENCES ON MEDICATION
ADHERENCE FOR PERSONS WITH SEVERE MENTAL ILLNESS IN PRIMARY
HEALTH CARE

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Jennifer Wright-Berryman

The Influence of Decision-making Preferences on Medication Adherence for Persons
with Severe Mental Illness in Primary Health Care.

People with severe mental illness (SMI) often suffer from comorbid physical conditions that result in chronic morbidity and early mortality. Physical health decision-making is one area that has been largely unexplored with the SMI population. This study aimed to identify what factors contribute to the physical healthcare decision-making autonomy preferences of persons with SMI, and to identify the impact of these autonomy preferences on medication adherence.

Ninety-five adults with SMI were recruited from an integrated care clinic located in a community mental health center. Fifty-six completed a three-month follow-up. Multiple linear regression for hypothesis 1 (n=95) and hierarchical regression for hypothesis 2 (n=56) were used to analyze data on personal characteristics, physical health decision-making autonomy preferences and medication adherence. For the open-ended questions, thematic analysis was used to uncover facilitators and barriers to medication adherence.

With this sample, being male predicted greater desired autonomy, and having less social support predicted less desired autonomy. When background characteristics were held constant, autonomy preferences and perceived autonomy support from the physician only contributed an additional 1% of the variance in medication adherence. Lastly, participants reported behavioral factors and having family/personal support to take

medications as facilitators to medication adherence for physical health care, while citing financial and other resource limitations as barriers.

Hea-Won Kim, Ph.D., Chair

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Chapter 1: INTRODUCTION

Prevalence and Definitions

Mental health disorders account for four of the ten leading causes of disability in the U.S. (NIMH, 2001), and severe mental illnesses such as schizophrenia, bipolar disorder, and major depression are found in approximately 5% of the U.S. population (McGrath, Saha, Chant, & Welham, 2008). Severe mental illness (SMI) is defined by the United States Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA) as:

- A mental, behavioral or emotional disorder (excluding developmental and substance abuse disorders)
- Diagnosable currently or within the last year
- Of sufficient duration to meet diagnostic criteria specified within the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*
- Resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities (SAMHSA, 2008B)

Various terms are used to describe a person in mental health treatment, including “patient,” “client,” and “consumer”. This list of terms is not exhaustive, but representative of language used in medical/treatment settings. For this study, the term “patient” will be used when referring to a medical setting, and the term “consumer” will be used when referring to a mental health treatment setting. In all other cases, “person(s)” or “people” with mental illness will be used.

The Morbidity and Mortality Crisis

People with severe mental illnesses often have comorbid physical conditions that contribute to morbidity and mortality rates that are higher than the general population. In

2006, the National Association of State Mental Health Program Directors (NASMHPD) published a technical report providing a comprehensive look at the morbidity and mortality crisis for people with SMI (NASMHPD, 2006). This report contained a sixteen-state study on mental health performance measures, including mortality data from eight states (Lutterman, 2003), plus morbidity and mortality studies from Maine, Ohio, and Massachusetts. Overall, people with SMI died approximately 25 years earlier than the general population, and approximately 10 years earlier than those with non-severe mental illnesses, such as milder forms of depression and anxiety (Lutterman, 2003). In Massachusetts, persons between the ages of 25-44 served by the state public mental health system were 6.6 times more likely to die younger from cardiovascular disease than those in the general population (Freeman, 2006). In Ohio, heart disease was the leading cause of death for the SMI sample, with an average age of death at 51 years, amounting to 27 years of potential life lost (B. J. Miller, Paschall, & Svendsen, 2006).

Numerous studies provide further insight into the nature of the morbidity crisis. In general, a majority of persons with SMI are found to have one or more physical health comorbidities, and half of those persons have two or more concurrent physical health diagnoses (Jones et al., 2004). Sokal et al. (2004) compared physical health data of a group with schizophrenia and a group with depression and matched controls from the general population. They found that compared to the matched controls, the group with schizophrenia was more than twice as likely to suffer from asthma, more than three times as likely to have chronic bronchitis, and were nine times more likely to have emphysema. The group with depression was also twice as likely to have asthma, and four times more likely to have chronic bronchitis and emphysema than the control group. Additionally,

the group with depression also had increased odds of rheumatoid arthritis and stroke. Both groups had increased rates of diabetes, but the group with depressive disorders had a higher rate than the group with schizophrenia.

Researchers have identified several contributing factors to this morbidity and mortality crisis. Many of these factors are associated with a metabolic syndrome that occurs from taking atypical antipsychotic medications for long periods of time. Deakin et al. (2010) describe the metabolic syndrome as a group of risk factors (such as weight gain, hypertension and insulin resistance) that occur together to increase the risk for cardiovascular disease, type II diabetes, and stroke. Although metabolic syndrome has been attributed to weight gain and subsequent insulin resistance as a result of taking atypical antipsychotics, the exact causes of the syndrome are not fully understood (De Hert, Schreurs, Vancampfort, & Van Winkel, 2009). Casey et al. (2004) reported that people with schizophrenia using antipsychotics such as olanzapine and clozapine were six times as likely to have insulin resistance compared to the group using conventional antipsychotics. In another study by Cohn et al. (2004), men with schizophrenia were at greater risk than women with schizophrenia for coronary heart disease, but both groups were twice as likely to have metabolic syndrome when compared to the general population. Additionally, metabolic syndrome occurs at a younger age in the population with schizophrenia and seems to occur in older age versus the general population. In the reference group, the rate increased more linearly with age (Cohn, 2004). Therefore, increased risk starts earlier and lasts longer in the schizophrenia group.

Obesity in this population, another risk factor associated with metabolic syndrome, is related to both psychotropic medications and sedentary lifestyle. A study comparing a

group with SMI with a geographically-matched group in the general population found that significantly more of the SMI group was obese: 50% of females and 40% of males, versus 27% of the females and 20% of males in the matched comparison group (Dickerson et al., 2006). Research has uncovered that people with SMI eat a diet that is higher in fat, lower in fiber and nutritional foods, and get less exercise than those in the general population (S. Brown, Birtwistle, Roe, & Thompson, 1999). Poor choice in self-care is only one explanation for these habits. Another explanation is that living in poverty restricts the ability for those with SMI to obtain nutritional foods and exercise opportunities (Newcomer, 2007). Obesity has become a national healthcare agenda, not just for people with mental health issues, but for the general population. Recently, the Center for Medicaid and Medicare Services announced a plan to provide Medicare coverage for intensive obesity counseling, and it is expected that over 30% of Medicare recipients will be eligible for the benefit (CMS, 2011).

Another major concern about the lifestyle of people with SMI is the high rate of smoking, which is more than twice that of the general population (Lasser et al., 2000), as approximately three-quarters of people with SMI smoke cigarettes. Smoking has been shown to improve the neurocognitive processes in schizophrenia, including recognition and attention (Quisenbert et al., 2013). The rate is even higher among those who have a comorbid substance abuse disorder, almost five times that of the general population (Ferron et al., 2011). The relationship between smoking and disease has been widely studied in the medical and epidemiological literature, and it has been concluded that smoking leads to a higher risk for cardiovascular disease (Bowden, Miller, & Hiller, 2011) and cancer (Howard et al., 2010). Cardiovascular disease remains the leading

cause of death in the United States, and is also the leading cause of death among the SMI population (Newcomer & Hennekens, 2007). Cancer seems to be less of a problem, but this may be because the life expectancy of people with SMI is often too short to be able to adequately determine cancer prevalence and incidence (Howard et al., 2010).

According to Lambert, Velakoulis, and Pantelis (2003), limited access to adequate physical healthcare, poor treatment adherence, and general neglect of physical needs are also reasons why people with SMI have more comorbid illnesses. One explanation could be the lack of resources that people have to afford care (DiNitto, 2012). Additionally, some patients with SMI have difficulty expressing or describing their physical symptoms, and understanding the treatment directions given by the physician to make lifestyle or other changes at home. People with SMI may encounter system barriers that complicate taking care of their physical health needs. Dickerson et al. (2003) highlighted some of these various factors in a study looking at healthcare utilization for persons with SMI. Problems included trouble getting through via telephone to the doctor, having to wait too long to see the doctor, no transportation, an office/clinic being closed, and not being able to afford care. More than one of these barriers was experienced by 60% of the SMI population in this study, whereas in the comparison group- persons without SMI, only 19% experienced more than one of these barriers. Traditional physician office environments can also be a deterrent in seeking care. In a qualitative study, those with SMI reported that their symptoms were exacerbated by long waits in the noisy and crowded waiting rooms at their primary care clinics, and therefore swift access upon entry was important to them (Lester, Tritter, & Sorohan, 2005). This study inferred that

if these issues were improved, people with SMI would feel more comfortable in seeking regular care.

Attitudes and behaviors of the physicians can also prevent ongoing, comprehensive, quality care for persons with SMI. Negative attitudes toward people with mental illness could make a person with SMI feel stigmatized, and less motivated to seek care (Borba et al., 2012). Lambert and colleagues (2003) cite several primary care physician-related factors that become barriers to treatment. For example, primary care doctors often become preoccupied with the mental illness and do not pay close attention to the physical health aspects of persons with SMI. Some doctors simply resist treating patients with SMI because of the complications of their mental illness, viewing their physical healthcare problems as psychosomatic complaints. The authors also highlight that doctors report not having the time or resources to treat the complex physical healthcare problems of persons with SMI, as these appointments can take longer and be more intensive. The recovery philosophy - the idea that people with SMI can recover from their mental illness - of the primary care physician (PCP) is also important to consumers with SMI. In focus groups, people with SMI emphasized the need for the PCP to have a focus on their mental health recovery journey, stating that this would provide optimism in their physical healthcare treatment (Lester et al., 2005).

People with SMI may also not be receiving high quality primary care. Miller, Druss, Drombowski, and Rosenheck (2003) found that although 80% of those surveyed with SMI had access to primary healthcare, a majority expressed that the care offered did not meet their needs, and was not considered to be high quality care. Of those surveyed

that had regular care, 14% said they still preferred to use the emergency room for their medical services because they did not feel their doctor provided good care.

A Response to the Crisis: Integrated Care

Historically, persons with comorbid mental health and medical issues would have to visit several sites to manage their illnesses. This presented a barrier to comprehensive care, as challenges such as transportation, time management and financial resources would prevent someone from accessing needed providers (Druss & Bornemann, 2010). As awareness grew about the morbidity and mortality crisis of persons with SMI, so did advocacy of reducing these barriers by developing models of care that used a more collaborative partnership between mental health and medical providers, often referred to as “integrated care” (Butler, 2008).

Integrated care has been conceived as medical and psychiatric providers working collaboratively and deliberately in their communications and actions to address the individual needs of the person with comorbid disorders within the context of a primary treatment setting (IOM, 2006). Integrated care has evolved from the concept of “medical home”, where a person’s whole healthcare is addressed through a team of people working collaboratively (Mauer, 2008). Integrated care for people with SMI is comprised of several tenets, such as streamlined communication between physical and psychiatric providers (Goff, 2007), co-location of services (Druss, 2007), expanding the care paradigm of both psychiatric and general medical providers (Weiss, Haber, Horowitz, Stuart, & Wolfe, 2009), organizational and cultural changes that foster the holistic approach to providing services (Druss, 2007), and using a chronic care model to inform

disease management approaches (Horvitz-Lennon, Kilbourne, & Pincus, 2006).

However, several different designs of integrated care exist. Some integrated care models consist of primary care and psychiatric doctors who communicate and work collaboratively from their separate offices, while others use co-location and attend treatment team meetings together, and share medical and support staff. There are also models where mental health staff are located in the primary care office, but the doctors remain separate (Butler, 2008).

The use of technology has enhanced the ability for physicians to coordinate efforts. Center for Medicaid and Medicare Services Innovation has recently funded projects that look at the meaningful use of electronic medical records, where “meaningful use” is defined as using technology to prescribe, communicate with patients, and keep records (Buntin, Burke, Hoaglin, & Blumenthal, 2011). Specific to integrated care services, an electronic medical record can contain both primary and behavioral care data, allowing the providers to see the most updated changes made in their patient’s care (Tai, 2012). The use of a combined medical chart has the potential to further improve health outcomes, as accuracy and efficiency of the medical record available to providers at the time of appointment can facilitate the comprehensive and time-sensitive care of persons with comorbid conditions (Tai, 2012).

The Substance Abuse and Mental Health Services Administration (SAMHSA) funded numerous integrated care programs across the country in the last several years (www.samhsa.gov/Grants/2010/awards/sm-09-011.aspx), which is in line with their 10x10 initiative to increase the longevity of people with SMI by ten years within the next ten years (SAMHSA, 2008). Because costs associated with co-location, electronic

medical record/information technology enhancements and hiring staff for an integrated clinic could be prohibitive in initiating these programs, the government commitment has helped to overcome the potential financial barriers in implementing these programs. Additionally, elements of the Patient Protection and Affordable Care Act could enhance the sustainability of these integrated care programs. Medicaid expansion, increases in benefits to essential healthcare packages, and increased reimbursement for primary care (Croft, 2012) could further bridge the funding and service gap for people with SMI who would previously not be able to access or afford care.

Integrating care might not be sufficient to address the complex physical healthcare needs of persons with SMI (Kathol, Butler, McAlpine, & Kane, 2010). Integrated care models have shown to improve access to care, thereby increasing initial visits and screenings, but several patient and physician elements have yet to be studied, such as patient health behaviors and treatment outcomes (Scharf, 2013). This study proposes that understanding consumers' physical healthcare decision-making autonomy preferences could inform primary care providers in creating a person-centered care atmosphere, which could enhance the treatment relationship and influence adherence recommended treatments, such as taking medication. Improved adherence could ameliorate exacerbation of physical illness and could increase quality of life and longevity.

Study Purpose

People with SMI are dying approximately ten to twenty-five years before persons without SMI, and the focus on what could help is lacking in the literature. It is critical

that this problem be studied and addressed, in order to develop interventions that could lead to longevity and improved quality of life for persons with SMI. There are several areas that need to be better understood about the physical healthcare of people with SMI. A review by Street, Elwyn, and Epstein (2012) suggests that a relationship exists between treatment adherence and physicians' accommodation of patient preferences. The authors conceptualize preferences as what patients want from their healthcare, and that these preferences, when germane to the problem at hand, should be honored in the spirit of providing high-quality and ethical care, and that the physical healthcare encounter should be studied from the perspective of the patient: the person who will ultimately be deciding on whether or not to follow through with treatment decisions.

Honoring patient preferences can positively impact treatment adherence. A study that measured desired decision-making style and decisional conflict for persons with HIV/AIDS considering anti-retroviral therapy reported a decrease in decisional conflict about the therapy when their preferences were accommodated (Kremer, Ironson, Schneiderman, & Hautzinger, 2007). Similarly, Katz et al. (2005) suggested that acclimating decisional preferences for women with breast cancer was directly related to having a mastectomy, being more satisfied with treatment (Lantz et al., 2005), and being less depressed (Vogel, Leonhart, & Helmes, 2009). Also, evidence in primary care reported that when patients had more involvement in their decision-making, they reported fewer illness concerns, a stronger sense of control, and better symptom management (Brody, Miller, Lerman, Smith, & Caputo, 1989).

The majority of studies about decisional preference and health outcomes focus on the general population, which highlights the lack of literature regarding the relationship

between decision-making autonomy preferences and adherence outcomes. Additionally, there is limited literature that specifically addresses this relationship in the SMI population. The few studies done with the SMI population (which will be presented in chapter 2) have shown that their involvement in medical decisions has a positive effect on treatment acceptance and adherence (Loh et al., 2007; Simon, Loh, Wills, & Härter, 2007); however, the literature also suggests that persons with SMI perceive their roles in decision-making as less participatory with their primary care providers than with their mental healthcare providers (Daumit, 2002).

Mental healthcare literature provides substantial evidence that people with SMI desire a shared decision role in their psychiatric encounter (J. R. Adams, Drake, & Wolford, 2007; Deegan & Drake, 2006; Hamann et al., 2006a; Hamann et al., 2009). However, because of the lack of literature regarding decision-making autonomy preferences for persons with SMI in the primary care setting, it remains largely unknown what these preferences might be in an primary care setting and whether or not they are related to improved outcomes. Therefore, the primary goal of this study is to better understand the physical healthcare decision-making autonomy preferences of persons with SMI, and how those preferences affect treatment adherence, specifically, their physical healthcare medication.

Chapter 2: LITERATURE REVIEW

This review will begin by presenting a theoretical model adapted from the conceptual framework of Street, Elwyn, and Epstein (2012). This will be followed by an in-depth look at the literature on decision-making for people with SMI in both mental health and primary care literature. Finally, literature will be presented that supports the variables under study, leading to hypothesis formulation.

Theoretical Framework

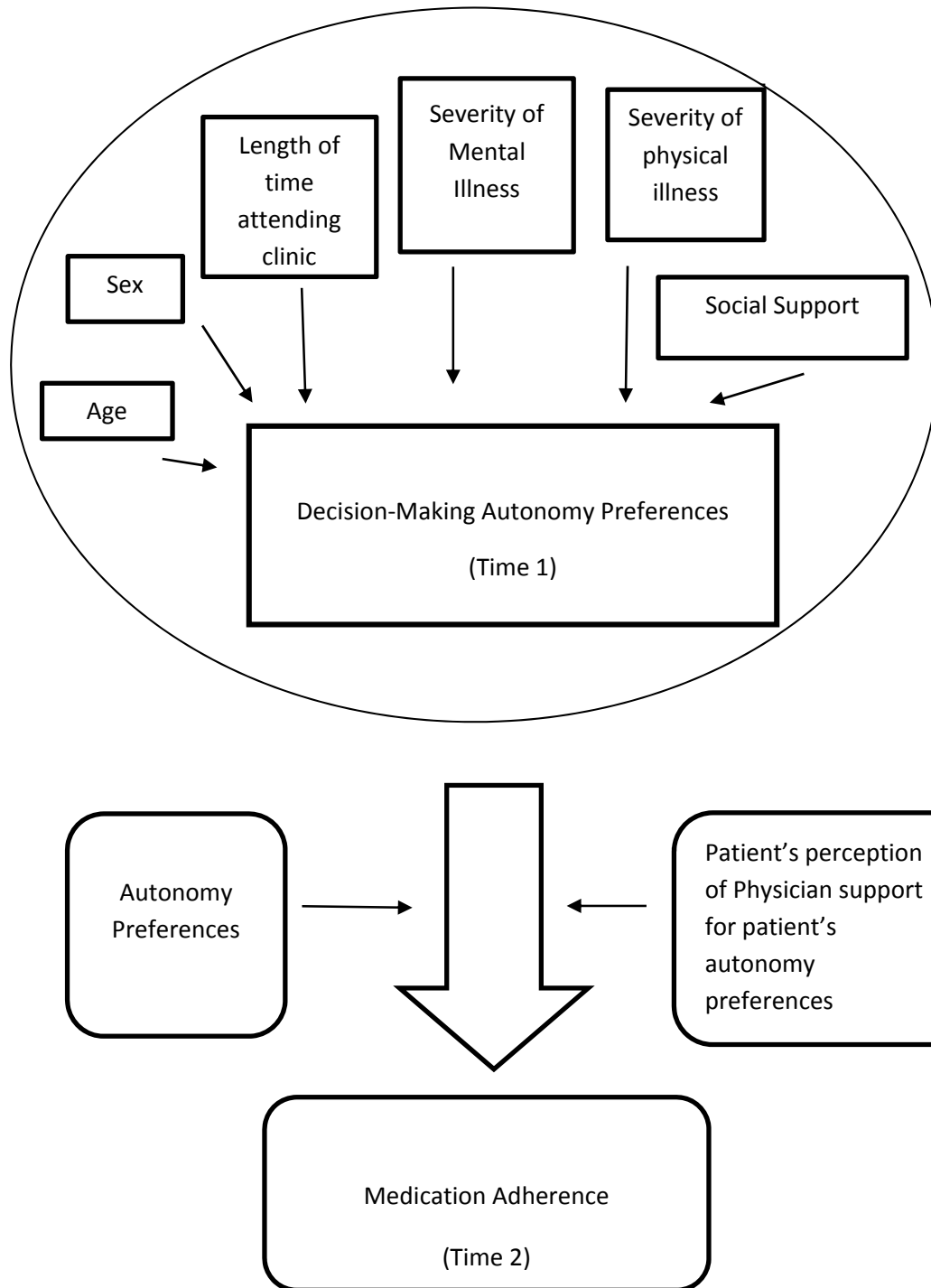
Figure 1 represents a theoretical model adapted from the conceptual framework of Street, Elwyn, and Epstein (2012), who use an ecological perspective to understand a patient's healthcare experience. It should be noted that the theory by Street, Elwyn, and Epstein is not specific to the SMI population, but is designed for the general population.

From an ecological perspective, the factors that create a patient's experience could be related to culture and/or illness experience, as well as individual characteristics (Payne, 2005) - it is these factors that interact in complex ways, and which could inform how strongly a person feels about their decision-making in a primary care encounter. The strength of these preferences could then potentially influence whether or not a patient chooses to adhere to, or follow-up with, treatment.

Another important factor of this ecological perspective is the patient's perception of physician support of their decision-making autonomy preferences. A great deal of literature addresses the relationship between perceived autonomy support and health outcomes. Autonomy support is defined as a patient's feeling that their wishes and preferences are being heard and honored by their physician, and research suggests that

physician autonomy support leads to improved health outcomes (G. C. Williams, Freedman, & Deci, 1998; G.C. Williams, Rodin, Ryan, Grolnick, & Deci, 1998).

Figure 1: Conceptual Model



Models of Decision-Making

According to current literature, there are three presiding forms of treatment decision-making. The first is paternalistic decision-making - where the practitioner makes the decision and the patient consents to that decision, the second is shared decision-making – where the patient is provided with detailed information regarding the illness and treatment options, and the practitioner and patient come to an agreement together, and, lastly, informed decision-making - where the patient has the information and the patient makes the decision completely separated from direct influence of the practitioner (Puschner et al., 2010).

Entwistle and Watt (2006) further detail these models by comparing them side-by-side (Table 1). They suggest that there are three components which inherently separate each model: information transfer, deliberation, and decision about implementing treatment. The paternalistic model of decision-making has a one-way method of communicating: from doctor to patient, with minimum information provided to obtain informed consent. The doctor deliberates alone, and the doctor makes the final decision about treatment options and implementation strategy. In the shared decision-making model, the communication is two-way: the doctor provides all the treatment option information, and the patient provides personal insights and preferences. The doctor and patient make the decision together, and may bring others in, such as family and social supports, as well. In the informed model, the communication is again one-way: the doctor provides all the medical information necessary for the patient to make a decision on her/his own. The patient then makes a decision (with possible discussion outside the

doctor's office, with family or others) and the patient comes to her/his own conclusion and lets the doctor know how to proceed.

Table 1.

Models of Decision-Making

	Paternalistic Model	Shared Decision-Making	Informed Model
Information transfer	One way (doctor to patient)- minimum information provided for informed consent	Two way (doctor to patient and patient to doctor)	One way (doctor to patient) all relevant information provided for patient to make decision
Deliberation	Doctor alone, or with other doctors	Doctor and patient (possibly with support from others)	Patient (possibly with support from others)
Decision about implementing treatment	Doctor	Doctor and patient	Patient

Paternalistic Decision-Making

Paternalism in healthcare has been a concern of medical professionals and researchers for several decades, and was addressed in the 1950s by Balint (1957), who compared person-centered and illness-centered care. He challenged paternalism by moving patients to the center of the decision-making process instead of leaving them in the periphery. Paternalism encompasses the compliance model, which places expectations of following doctor's orders precisely and without question. This does not allow for the flexibility of a person's life experiences or preferences, and often results in a person's drifting from the physician's recommendations for treatment.

Shared Decision-Making

Shared decision-making (SDM) suggests that there are two experts in the healthcare decision-making process, the patient and the practitioner. SDM has three distinct elements: *active participation* of both patient and physician, *information sharing*, and *agreement* between patient and physician (Sandman & Munthe, 2010). This approach has been touted as a necessary movement in medical care for several reasons.

First, patients could become more responsible for their health and wellness, and physicians could hold patients more accountable to the agreement made between them (Hoving, Visser, Mullen, & van den Borne, 2010). Second, patients and physicians could become more engaged and form a therapeutic relationship and trust, which is an essential component of effective communication (McCabe, Heath, Burns, Priebe, & Skelton, 2002). Finally, patients who are more involved in their treatment decisions are more likely to be satisfied with their care, and therefore more invested in treatment (Scheibler, 2003).

SDM holds to several social work values, such as a person's right-to-choice and self-determination, person-centered care and empowerment of the client (Drake, 2010), while also strengthening the informed consent process. As previously mentioned, informed consent is often obtained with inadequate information provided by the physician under the paternalistic model. With the SDM model, information exchange is such that a patient is well-informed of their treatment alternatives, risks, and benefits and possible outcomes. The patient therefore has a better opportunity to make an informed decision (King, Eckman, & Moulton, 2011). Informed consent is a core tenet of the

social work code of ethics (NASW, 2008), and is also an imperative in all medical treatment and most research protocol, which could make the use of SDM a useful tool in a variety of settings.

Informed Decision-making

Informed choice/decision-making is a method where the patient makes the decision on her/his own after having been given all the relevant information about treatment alternatives (Puschner et al., 2010). The patient might consult with family, friends, or significant others outside of the doctor's visit, but in the end present the decision to the doctor as her/his own. This model of decision-making has some underlying assumptions: that the patient does indeed have enough information to make an informed decision, that the patient has asked all the questions that she/he needs to ask, and that the patient is highly knowledgeable about the illness and how the different treatment options will impact his or her life. This also assumes, to some extent, that the patient knows how to access information outside of the doctor's expertise (e.g. other experts, research studies, the internet; (Puschner et al., 2010).

Another assumption, similar to shared decision-making, is that the person is capable of making a rational choice, and that all the alternatives have been presented to the patient. In many ways, the physician can continue to assert paternalism in both SDM and IDM, because they have control over what options are presented. The patient may not be aware that certain options might be found undesirable by the physician, or that they might have negative outcomes, and so therefore will not be offered (Sandman & Munthe, 2010). Therefore, a flaw with informed decision-making is that the doctor,

without a therapeutic bond to the patient, might continue to embody paternalism, while the patient is left in the dark. Unless the patient chooses to do nothing, she/he is, in some respects, at the mercy of the treatment options available, unless more information is gathered outside the doctor's office.

Each of these models could have a place in the decision-making process. Consider the paternalistic style in the wake of a crisis: if someone has been in a car accident and is unable to make decisions for reasons of trauma or injury, and family are not accessible, paternalism could certainly be warranted and necessary. In the case of someone who has a severe mental illness, the illness may be a barrier to comprehending that treatment is imminently necessary, given the risk of life or self-injury. Another reason for using the paternalism approach is if the patient does not wish to be involved in making the decision. A patient might defer the decision to the physician, even after attempts by the physician to engage and offer information and choices to the patient.

Shared decision-making might fit where the above circumstances are not present. SDM also insinuates that there are options available, and that a decision needs to be made. In some cases, no decision needs to be made because there are no treatments available, or there is only one treatment available, and the patient's goal is wellness. SDM and the informed choice model might be ultimately appropriate when the treatment options come with high risk, or low benefit, or are controversial in nature (Puschner et al., 2010).

Decision-Making Autonomy Preferences in Mental and Physical Healthcare

Healthcare decision-making autonomy preferences for persons with mental illness is a fairly new topic in the literature. Prior to the 1990s, most healthcare decisions were made by the doctors in keeping with the paternalistic model (Sandman & Munthe, 2010). Since the 1990s, literature has begun to address healthcare decision-making for the general population, and even more recently, for the SMI population. The literature about persons with SMI making physical healthcare decisions is still immature, and most of the studies to date look specifically at mental healthcare treatment decisions, not physical healthcare decisions.

A great deal of literature in mental health supports the consumer's desire for a shared decision-making approach, but less is known about persons with SMI and primary care decision-making. There are three studies that specifically compare the mental and physical healthcare preferences of persons with SMI. Adams et al. (2007) and O'Neal (2008) both found that persons with SMI preferred more autonomy in their mental health decision-making during their psychiatric encounters, but preferred a more passive role when it came to primary care. Hamann and colleagues (2005) found that persons with SMI had a greater desire for autonomy in psychiatric care decisions than primary care patients for their general medical decisions.

There are several studies that look at preferences strictly in mental healthcare, but no studies exist that strictly look at decision-making autonomy preferences for SMI in a primary care setting. Some studies look at decision-making itself, finding that many doctors in primary care do not practice shared-decision making (Young, Bell, Epstein,

Feldman, & Kravitz, 2008); however, when SDM is practiced in primary care, patient satisfaction is higher (Loh et al., 2007).

Perceived Autonomy Support and Treatment Adherence

Treatment adherence is viewed as the key moderator between treatment recommendations and positive patient outcomes (Bosworth, Oddone, & Weinberger, 2008). Therefore, finding ways to increase adherence could, in theory, decrease morbidity and mortality for persons with SMI. The relationship between autonomy support and physical healthcare treatment adherence in the general population has highlighted the need for physician awareness of patient preferences (Street et al., 2012) and studies have shown that honoring autonomy preferences has a positive impact on treatment adherence (G. C. Williams, Freedman, & Deci, 1998; G.C. Williams, Rodin, Ryan, Grolnick, & Deci, 1998). Specifically, patients' perceptions of physicians' support for their autonomy has shown to improve long-term medication adherence (G.C. Williams et al., 1998), adherence to glucose control strategies related to persistent type II diabetes (G. C. Williams et al., 1998), adherence to weight loss and control activities (Silva et al., 2008), adherence to a smoking cessation regime (Geoffrey C. Williams et al., 2006), and adherence to injury rehabilitation pathways (Chan, Hagger, & Spray, 2011). However, this phenomenon has not been studied with persons with SMI in primary care.

Physical Healthcare Decision-Making Autonomy Preferences and Treatment Adherence

As previously reported, people with SMI can have multiple comorbidities, and therefore managing their illnesses can be overwhelming. Additionally, studies on these comorbidities have demonstrated that the medications used to treat mental illness can create serious physical health complications. Therefore, persons with SMI need healthcare partners - providers who are person-centered and mindful of the specialized needs and circumstances for persons with SMI regarding their physical healthcare.

Person-centered care is central to honoring a person's self-determination and autonomy. Person-centeredness, born of Carl Rogers' client-centered theory (C. R. Rogers, 1977), has become a core tenet of social work theory and practice (Rowe, 1996). The values of person-centeredness in a medical setting would include the physician believing in the inherent worth and dignity of the person, and the physician holding a fundamental respect for the person's freedom to decide, and also understanding that the person's decisions are self-driven and goal-directed, even if the physician is unaware of the person's goal (C. R. Rogers, 1977). If a physician or care-giver is person-centered, this could increase the person's feelings of being heard and valued. Person-centeredness is therefore an essential component of the patient-physician dynamic, if it is to lead toward empowerment and self-determination on the part of the patient. A physician who is person-centered will attempt to uncover and honor a patient's preferences for his or her treatment decisions.

The consumer is the person who not only will play a role in the decision-making process, but will also be the one who does or does not execute the decision being made. Therefore, it is of the utmost importance to understand how much autonomy and control is desired in the decision-making process. It has been shown that honoring decision-making autonomy preferences has resulted in better engagement and treatment adherence (Loh et al., 2007; Raue, Schulberg, Heo, Klimstra, & Bruce, 2009; Stacey et al., 2008). This study looks specifically at medication as a form of treatment. It has been suggested in the literature that when patients make the decision of what psychiatric medications to take, they are more likely to adhere to that medication (Wilder, Elbogen, Moser, Swanson, & Swartz, 2010).

Honoring a person's decisional preferences has shown positive outcomes in both mental health and primary care settings. In a study by Hunot et al. (2007), patient preference for a different treatment decision than the one that was made (i.e. psychotherapy versus medication) was a predictor of non-use or discontinued use of antidepressants. Similarly, Raue and colleagues (2009) found that preference strength for persons with depression in primary care was significantly associated with initiation of treatment and adherence rates at 12 weeks. Unfortunately, the relationship between a person's decisional preferences and adherence in physical healthcare making is nearly non-existent for persons with SMI, and so turning to the literature focused on the general population could shed some light, and assist in providing a comparison for this study's focus on the SMI population. However, the literature in physical healthcare linking patients' decision-making autonomy preferences with treatment adherence is also limited.

The few studies that exist are newer in the literature, possibly revealing that this topic is currently gaining interest in the research community.

A cross-sectional study of 4198 patients with diabetes who worked with physicians on self-management and follow-up care explored the possible relationship between patients' decisional style preferences and diabetes treatment adherence (Heisler et al., 2009). This study reported that patients who preferred shared decision-making over a physician-dominated style were more likely to adhere to the routine of three month A1C tests, which is an evaluation of glycemic control. Participants who reported preferring completely autonomous decisions were more likely to adhere to their routine lipid test regime. Overall, they found that patients who were more participatory in treatment decisions adhered to the scripted treatment regimens for diabetes care.

A prospective cohort study of patients with depression explored the relationship of perceived decision involvement with treatment adherence and depression outcomes. Analyses showed that the more involvement they perceived to have in their treatment decisions, the more treatment adherent they were, and the more reduction in depression symptoms they experienced at six and twelve months (Clever et al., 2006). The authors suggest that increasing patient involvement is key to improving treatment adherence and outcomes.

These studies with the general population support the hypothesis that there is a positive relationship between a physician honoring patient's decision-making autonomy preferences and improved treatment adherence. Furthermore, there appears to be a more

specific association between the preference for shared decision-making, higher desired autonomy, and improved adherence and outcomes.

Literature Support of Background Characteristics

As previously presented in the preference-health outcome theoretical framework, there are several factors that could impact both the individual decisional preferences and treatment adherence choices of persons with SMI. The ecological perspective asserts that a complex interaction can occur between these factors (Payne, 2005), which could influence the strength of preferences as well as the adherence to those treatment decisions (Street et al., 2012). This study specifically investigates the relationship between patient factors, decision-making autonomy preferences and medication adherence, however, there is inadequate literature exploring medication as a specific treatment. Therefore, studies were reviewed that looked at treatment adherence, which includes medications in several studies.

Influence of Age on Decision-Making Autonomy Preferences and Treatment Adherence.

O'Neal and colleagues (2008) reported that both older and younger adults wanted shared decision-making related to psychiatric medications, but that older adults desired a more passive role regarding general medical decisions. This finding was similar to that of Arora and McHorney (2000), who reported that younger patients (between 35 and 44 years) preferred more control in medical decision making, claiming that older patients report having more trust in their physicians, therefore feeling comfortable leaving the decision to them.

Raue et al. (2009) found that among midlife and elderly patients with depression, three month treatment adherence rates were significantly related to patients' treatment decision preferences being honored by their physicians. Additionally, in a case study by Raue and colleagues (2010), it was highlighted that older patients with depression were more engaged in decision-making when presented with options. Finally, in a meta-analysis (Say, Murtagh, & Thomson, 2006), seventeen studies found that younger persons wanted more control of medical decisions than those who were older.

Medical literature reports that older patients tend to be "good adherers" to medication versus younger patients (Hinkin et al., 2004). However, Carney et al. reported that older persons with depression are significantly less adherent to physical healthcare medications than their non-depressed counterparts. They found that depressed patients were only adherent 45% of the days measured versus 69% of the days for the non-depressed comparison group.

Influence of Sex on Decision-Making Autonomy Preferences and Treatment Adherence.

Studies that explore the differences between men and women regarding desired autonomy and control in medical decision-making report that women are more likely than men to want autonomy and an active role (Arora & McHorney, 2000; Dwight-Johnson, Sherbourne, Liao, & Wells, 2000; Levinson, Kao, Kuby, & Thisted, 2005). Similar findings were reported by Dwight-Johnson et al. (2000), who found that women with affective disorders not only preferred more autonomy and control in treatment decisions than men, they also expressed that they had specific treatment preferences, where men

did not express a preference for one treatment over another. Women were found to have more help-seeking behaviors, and to prefer a collaborative form of decision-making (Levinson et al., 2005). Women also preferred to receive more information about their illness, and wanted to have pre-prepared questions answered (Arora & McHorney, 2000).

Studies that investigate the relationship between sex and mental health treatment adherence for persons with SMI consistently report that women with SMI are more adherent to treatment follow-up than men with SMI. Women engage in mental health services more readily than men (C. H. Brown, Bennett, Li, & Bellack, 2011) and in terms of medical interventions, women with SMI have sought out more preventative and diagnostic services (Xiong, Iosif, Bermudes, McCarron, & Hales, 2010). Regarding ongoing, long-term medical intervention, women with depression who were HIV-positive were found to be more adherent to retroviral therapy than their male counterparts (Turner, Laine, Cosler, & Hauck, 2003). Other studies suggest that the natural care-taking role of women could result in a desire for an active participatory role in their own healthcare decision-making (Arora & McHorney, 2000; Levinson et al., 2005). There are no studies that specifically address the relationship between sex and medical decision-making autonomy preferences for persons with SMI; therefore, this study will explore this as new ground.

Length of Time Attending Clinic, Decision-Making Autonomy Preferences and Adherence

No studies were found specifically referring to the relationship of length of time attending an outpatient primary care clinic and decision-making autonomy preferences

and adherence for people with severe mental illness. Three studies were found in general population literature and all three showed positive results. Clayton et al. (2011) found that persons with longer time attending the clinic, most were able to achieve their preferred decision-making role. Of those who reported not achieving their desired decision-making role, 16% were brand new patients, 16% were patients who had been attending less than a year, and 68% had been with the clinic multiple years. A study exploring doctor advice on smoking cessation showed that length of time at clinic had a positive impact on patients quitting smoking (Hymowitz et al., 1997), and a prospective cohort study on diabetic patients showed that in a short time (14 months) at an integrated renal clinic (located in a general medical hospital), patients had improved hemoglobin A1c results (Patel, Shilliday, & McKay, 2009).

The Influence of Severity of Mental Illness and Physical Disease on Decision-Making Autonomy Preferences and Treatment Adherence.

Decision-making capacity for persons with SMI is generally measured against the person's functional level as it relates to the demands of a particular decision-making task (Wong, Clare, Holland, Watson, & Gunn, 2000). The functions of competence include the ability to 1) understand the relevant information, 2) appreciate its implications for one's situation, 3) reason with the information, and 4) express a treatment choice (Appelbaum, 2007).

Frequently, people with severe psychiatric disorders have competence questioned. For example, people with schizophrenia could have fluctuation in severity of psychiatric illness which could change level of functioning, and their capacity to make decisions

when acutely ill (Appelbaum, 2007). Tan et al. (2009) also suggest that the seriousness of the healthcare decision determines the threshold for competence. Therefore, the nature of the mental illness and the complexity of the physical healthcare decision to be made could confound capacity to make a treatment decision, and could be used as the clinical factors to determine if someone is able to make his own treatment decisions.

There are studies, however, that look at how persons with severe mental illness are able to make their healthcare decisions when their illness is well-managed. Wong et al. (2000) found that people with SMI, when their symptoms were well managed, were not more impaired than the general population in decision-making when compared to two other groups: those who had learning disabilities, and those who had dementia. A meta-analysis (Okai et al., 2007) of 27 studies that looked at capacity of persons with SMI to make treatment decisions while on an acute inpatient psychiatric hospital found that 71% of those assessed were able to make treatment decisions. Those that were deemed incapable (29%) suffered from severe psychosis. These studies indicate that those with acute psychotic illness that require hospitalization tend to have capacity problems, and would require more assistance with decision-making.

Perception of how serious the physical disease is can also impact the person's desired level of decision-making involvement. Levinson et al. (2005) found that healthier people were more likely to desire stronger involvement than those who were sicker. Similarly, Arora and McHorney (2000) found in their large study (n=2197) that patients with diabetes or heart disease were more likely desire a passive role than those with non-serious hypertension. It has also been found that disease trajectory (progression) can affect decision-making autonomy preferences. As patients become more familiar with

their diagnosis and disease, learn better how to manage it and begin to feel better, they become more empowered to be more involved in their care decisions (Say et al., 2006).

Much of the literature about treatment adherence for people with SMI focuses on compliance with psychiatric treatment. Those studies that do explore physical healthcare adherence compare groups with and without SMI, and the consensus is that people with SMI are usually less adherent to treatment than those without (Kreyenbuhl et al., 2011). However, no difference in adherence was found across SMI diagnoses of schizophrenia, bipolar disorder, and major depression (Xiong et al., 2010). The literature suggests that the cognitive impairment that can accompany severe mental illness can cause disorganization and loss of functioning, which could complicate adhering to a medication regime (Thames et al., 2011). Perception of physical disease severity and its relation to treatment adherence has not been studied among the SMI population; however, a recent meta-analysis of studies on the general population reported a negative relationship between patient adherence and illness severity perception (DiMatteo, Haskard, & Williams, 2007) - people who self-reported more serious diseases were less adherent to treatment than those who reported perceiving their disease as less serious.

The Influence of Social Support on Decision-Making Autonomy Preferences and Treatment Adherence.

In the seminal article by Cohen and Wills (1985), social support is defined in two ways: interpersonal resources (e.g. friends, family) and the larger social network (community embeddedness). In an extensive systematic review, they report that having interpersonal support has a buffering effect on stress that occurs during critical events. In

the mental health literature, social support is also defined in two specific ways: informal, as in support from families, friends, and others in the interpersonal network, and formal, as in professional mental health or other staff who are paid to participate in the care of the individual (Clark, 2001; Cummings, 2009). Cummings and Kropf (2009) studied the differences where formal and informal supports are observed in the lives of people with SMI. They found that formal support (from professionals, such as mental health workers) was most often in the form of assistance with psychiatric symptom coping, physical health, information, and dangerous behavior. Informal support (family, friends) was most often in the form of assistance with self-care activities, symptom coping, and money management.

Literature shows that people with SMI report lower amounts of informal social support than those without mental illness (Kilbourne, McCarthy, Post, Welsh, & Blow, 2007). This could be the result of caregiver burden or burnout due to behaviors resulting from poorly managed illness (Loukissa, 1995), or because of loved one's self-stigma (Hasson-Ohayon, Levy, Kravetz, Vollanski-Narkis, & Roe, 2011). This is an unfortunate situation, because the benefits of informal support for people with SMI are clear in the literature. It has been reported that informal social support has had a positive impact on symptoms (S. E. Rogers, Anthony, & Lyass, 2004; Travis, Lyness, Shields, King, & Cox, 2004) and can help reduce or eliminate the abuse of substances (Clark, 2001). Additionally, informal social support has shown positive outcomes in general healthcare. In a meta-analysis of 122 studies over nearly fifty years in the general population, DiMatteo (2004) reported a significant relationship between several aspects of informal social support, including practical and emotional support, and medical treatment

adherence. It was found that practical support (e.g., assistance with transportation and money) had the greatest impact on treatment adherence. However, this review excluded healthcare visits that were psychiatric in nature, and does not flesh out the types of adherence, so, although the DiMatteo review provides a basis for conjecture about how social support affects treatment adherence, it is not specific to medication adherence for those with SMI.

A great deal of literature addresses the impact of professional support on client outcomes in mental health treatment. Several models of case management have been evaluated and have shown positive impact on hospitalization rates (Bond, McGrew, & Fekete, 1995; Burns, Fioritti, Holloway, Malm, & Rossler, 2001) as well as homelessness and employment (Bond, Salyers, Rollins, Rapp, & Zippel, 2004; Mueser, Bond, Drake, & Resnick, 1998). However, no studies have been done that highlight the influence of formal support on physical healthcare outcomes for the SMI population. An apparent gap in the literature exists regarding the impact of formal and informal support on physical healthcare treatment adherence. However, the mental health literature shows that such an impact exists, which would support a hypothesis that the more support (formal and/or informal) a patient has, the more adherent they are to treatment.

Barriers and Facilitators of Medication Adherence

Much of the literature dedicated to exploring the reasons why people with SMI do not take their medications as prescribed is specifically limited to 1) their psychotropic medications (medications taken for their mental illness) and 2) non-adherence risk factors associated with mental illness. No studies were found that specifically gleaned

facilitators and barriers to medication adherence in primary care for persons with SMI *from their perspective*. With integrated care and medical home initiatives, more and more primary care providers will be addressing physical, and even some mental, healthcare issues for persons with SMI, which makes this information critical and useful in navigating the future of attending to the comorbid needs of this population.

Several studies cite severity of mental illness and poor insight as the primary reason among people with SMI to stop taking their psychiatric medications and more than 50% of people with SMI are found to go off of their medications within a year of a hospitalization (Zygmunt, Olfson, Boyer, & Mechanic, 2002). However, what do people with mental illness say about the reasons they do not stay on their medications? A focus group of persons with depression and anxiety explored the things they perceived would be helpful for their illness. The group members cited psychotherapy treatments and medications, however, they *all* preferred the former to the latter as a primary treatment method (Prins, Verhaak, Bensing, & van der Meer, 2008). The authors suggested that perceived need for type of treatment could influence whether someone is adherent to prescribed treatment. Therefore, perception of not needing a form of treatment (and therefore not following doctor's orders) might be labeled in the literature as "no insight" or "non-compliance" when, in fact, the reasons could be further explored qualitatively, adding to the potential intervention implications for the field. A study by Wilder et al. (2010) elaborates on this idea: when consumers pre-state their desired medications, they are more likely to adhere to those medications. They found that consumers who stated their medication preferences ahead of time were 1) more likely to have those prescribed and 2) were more adherent at 12 months. This could imply that preferred decision-

making autonomy of the person was honored, which facilitated adherence. Because the literature in this area is limited, this study will explore new ground in uncovering the reasons why people with SMI adhere or do not adhere to their prescribed physical healthcare medications.

Summary, Study Aims, and Hypotheses

This review highlights the current glaring gap in the literature: physical healthcare decision-making autonomy preferences have not been adequately studied for persons with SMI in the primary care setting, nor has the relationship been explored between their physical healthcare decision-making autonomy preferences and treatment adherence. Some of the current studies in the mental health/psychiatric field are plagued with problems common to research in the social sciences: low samples size and power, non-random sampling, reliability and validity challenges of measures, and qualitative methods without triangulation, peer and member checking. The literature guiding this study is presented to support the conceptual model and theory underpinning this study. However, much more evidence resulting from rigorous studies is needed to further inform the social work, psychology, and medical fields on how best to create a decision-making environment that will support the physical wellness goals of each individual with SMI.

Based on the theory and research related to this topic, two major considerations have emerged. First, preferences for decision styles could vary, based on age, gender, race/ethnicity, severity of illness, perceived severity of physical disease, and perceived external support. Second, supporting decision-making autonomy preferences related to treatment adherence are present for the general population (Street et al., 2012), but this

same phenomenon has not been studied among the SMI population. From these considerations, the following aims and hypotheses are proposed:

Specific Aim 1. To identify what factors contribute to the physical healthcare decision-making autonomy preferences of persons with SMI.

Hypothesis 1. Physical health decision-making autonomy preferences can be predicted by patient characteristics of age, sex, length of time at clinic, mental illness severity, physical health severity, and perceived social support. It is hypothesized that patients who are younger, female, have less severe mental illness, have less severe physical health issues, and higher levels of perceived social support, desire more autonomy.

Specific Aim 2. To identify the impact of physical healthcare decision-making autonomy preferences on medication adherence.

Hypothesis 2. When controlling for patient characteristic variables (listed above), higher levels of desired autonomy in decision-making and perceived autonomy support from physician will predict higher levels of (primary-care prescribed) medication adherence.

Chapter 3: METHODS

Study Design

The purposes of this three-month longitudinal study were to explore the complex relationship between the characteristics of people with SMI and their decision-making autonomy preferences in a primary care context, and to identify how these preferences are related to medication adherence. A convenience sample of adults (age 18 years and older) with SMI was used, and the participants were either new or returning patients to the integrated care clinic. Three researchers were involved in data collection, the primary investigator (PI) of the study, from the University School of Social Work and two research assistants affiliated with the University Psychology Department. The research assistants had been involved with a previous study that was similarly designed, and therefore had experience with the measures and procedures involved in this study. The members of the research team completed all the University required IRB and study-related training. The research assistants were monitored by the PI, who provided training to ensure accurate data collection. All three research staff stayed in close communication and used a spreadsheet to organize recruitment. The PI performed all the data entry for all the measures. The follow-up (Time 2) phone contacts were made by the PI and a research assistant. The calls were scripted and the script was followed closely.

Study Participants and Setting

This study was conducted at an integrated primary care clinic located onsite at a CMHC in Indianapolis, Indiana. All consumers of the CMHC are offered participation in the clinic, with over 400 of a potential 700 currently participating after two years in

operation. At the time of data collection, the clinic was actively recruiting new referrals, so that numbers were consistently increasing during this study recruitment. Thirty to forty patient appointments were scheduled per week. The goal was to recruit at least 15 participants a week for ten weeks, spread out over a four month period. However, the recruitment faced several issues, which will be outlined in the results section.

This clinic was staffed by one primary care physician, one registered nurse, and one licensed practical nurse. The clinic was started through a service grant provided by SAMHSA, and is among several others similarly funded programs around the country. The primary care team met with the CMHC teams weekly to review cases and address any concerns about mental and/or physical health treatment. A database was kept by an administrative assistant to identify which consumers from what mental health teams are seen in the primary care clinic. The purpose of the cross-communication between the primary care staff and the mental health staff was to provide an integrated approach to care in addition to co-location.

Study Procedures

Approval for this study was granted by the Indiana University Purdue University Indianapolis (IUPUI) Institutional Review Board. Participants were approached at the integrated care clinic waiting area after they finished an appointment with their physician. They received a brief explanation of the study, and were asked if they were interested in participating. If they agreed, the informed consent process took place. After informed consent was read to the participant, a short quiz about the nature of the study was given to assess their ability to understand to what they were consenting. If the participant

answered all five questions correctly, the participant continued in the study. If they were unable, they could retake the quiz up two more times. If the participant did not pass the quiz in three tries, they were considered ineligible. This method of consent comprehension has shown to have some effectiveness in increasing understanding and ability to consent for research (Hochhauser, 2008). Of the participants initially recruited for the study, only two were unable to pass the consent quiz in three attempts, and they were therefore excluded from completing the measures.

After completing the informed consent process, participants were asked for contact information including telephone numbers (home and cell), and for an email address, if applicable, in order to contact them for collecting three month measures. Upon consent, Time 1 measures were administered by one of the research staff. After completion of surveys, participants were given a gift bag with several small hygiene items, such as toothbrush and toothpaste, soap, shampoo, and deodorant. They were also made aware that after they complete the three month measures, their names will be entered into a drawing for one of five \$50 gift cards to a retail outlet. At the completion of the study, five participants who completed the study were randomly selected and were given a gift card.

At Time 2 (three months from Time 1), participants were called by one of the research staff and asked if they would be willing to complete the short, follow-up questions, which consisted of the four medication adherence yes/no questions and the two medication adherence facilitators and barriers open-ended questions. Multiple attempts were made to reach the participant within a one-month window following the three-

month mark. If they could not be reached during that time, or if their phone was disconnected, a note was made in a log and no more attempts were made.

Measures and Instruments

Background characteristics such as sex, age, perceived social support, severity of mental and physical health, and length of time attending the clinic were used to predict autonomy preferences in physical healthcare decision-making for the first hypothesis. These background variables were controlled for in the second hypothesis. Then, the variables of perceived autonomy support and autonomy preferences were added to the model to observe the impact on medication adherence at Time 2. Table 2 displays a list of variables and measurement scales.

Table 2.

Variables and Measurement Scales

Variable	Measure	Description
Age	Self-Report	Age in years
Sex	Self-Report	1= male 0= female
Ethnicity	Self-Report	1= American Indian/Alaskan Native 2= African American 3= Asian 4= Caucasian 5= Other
Race	Self-Report	1= Hispanic/Latino 2= Not Hispanic/Latino
Length of Time at Clinic (months)	Medical Record	Number of months attending clinic
Mental Illness Symptom Severity	Colorado Symptom Inventory (Shern, Lee, & Cohen, 1996)	-16 items -Self-administered -Good internal consistency and test-retest reliability - $\alpha=.86$
Perceived physical illness severity	Short Form-12 (Ware, Kosinski, & Keller, 1996)	-6 items (physical health domain) -Self-administered -Good correlation with previous larger version -Good test-retest reliability - $\alpha=.82$
Perceived social support	Interpersonal Support Evaluation List (ISEL) - Appraisal - Assist - Belonging	-30 items - 3 subscales -Self-administered -Good test-retest reliability and internal consistency - $\alpha=.82$ (appraisal) - $\alpha=.80$ (assistance) - $\alpha=.87$ (belonging)
Who is providing social support?	Single Question Researcher Developed	-Self-administered
Autonomy Preferences	The Autonomy Preference Index, Decision-Making Scale (Ende, Kazis, Ash, & Moskowitz, 1989)	-15 total questions -6 general questions (4 for analysis) -9 vignette questions, three for each of three vignettes -Self-administered

		-Good reliability - α =.81 (total scale)
Perceived Autonomy Support	The Health Climate Questionnaire (G.C. Williams, Grow, Freedman, Ryan, & Deci, 1996)	-6 questions -Self-administered -Good internal consistency - α =.97
Medication Adherence	Morisky Medication Adherence Scale (Morisky, Green, & Levine, 1986)	-4 questions -Self-administered -Good internal consistency and sensitivity - α =.51 (Time 1) - α =.48 (Time 2)
Barriers and Facilitators to Treatment Adherence	Open ended question at 3 months (Time 2)	-Interviewer-administered -Participants were asked what, if any, barriers and facilitators they experienced regarding treatment adherence

Background Characteristics

Background variables such as sex, age, ethnicity, and race were all collected at Time 1 using data sheet developed by the researcher. Number of months attending the clinic as well as mental and physical health diagnoses was all obtained from the participants' medical chart.

Severity of Mental Illness Symptoms

Severity of mental illness was assessed by the Colorado Symptom Inventory (Shern et al., 1996). The Colorado Symptom Inventory (CSI) is a self-report measure of psychiatric symptoms, in which respondents report on the frequency of the various symptoms they have experienced in the last 30 days. A five-point Likert scale was used for the 16 questions (no subscales), with 1= not at all, 2= once during the month, 3= several times during the month, 4= several times a week and 5= at least every day.

Examples of questions are “In the past month, how often have you told others you acted ‘paranoid’ or ‘suspicious’?” and “In the past month, how often did you hear voices, or hear or see things that other people didn’t think were there?” In a study on the psychometric properties of the CSI with the homeless population with SMI, Conrad et al. (2001) found that the CSI had excellent internal consistency ($\alpha = .90$) and a good test-retest reliability ($r = .79$). Boothroyd and Chen (2008), in a follow-up study on the psychometrics of the CSI using a sample of 3,784 adult Medicaid respondents, also found that it had excellent internal consistency (.92) and good test-retest reliability (.71). Regarding validity, Conrad and colleagues also tested the CSI against the Brief Symptom Inventory and all the hypothesized relationships were in the predicted direction and were statistically significant. The CSI’s internal consistency reliability was analyzed for this current study and for comparison to previous literature. For this sample, internal consistency was good ($\alpha = .86$), but was slightly lower than previous findings with similar samples. A single summary score was used for analysis, with a higher score indicating a higher perceived severity of mental illness.

Severity of Physical Illness

The Short-Form Health Survey 12 (SF-12) was used to measure severity of physical illness. The SF-12 is a self-report tool developed from the SF-36 (Ware & Sherbourne, 1992) with two specific domains: mental health (referred as MCS- Mental Component Summary) and physical health (PCS- Physical Component Summary), with six questions for each domain. Only the physical health domain (six questions) was used for this study. Respondents were asked to rate a question about their general health, using a five-point Likert scale, with a score of 1 indicating “excellent” and a 5 indicating

“poor”. The next three questions ask the impact of physical health on activities, using a three-point scale, with a 1 indicating “limited a lot” and a 3 indicating “not limited at all.” The final two questions ask about impact of physical health on daily activities, impact of pain on daily life, and impact of physical health on social activities, again using a 5-point Likert scale with 1= “all of the time” and 5= “none of the time”. Ware et al. (1992) found the components of the SF-12 to be correlated with the related components of the SF-36, with stability over a two- week period of .89 (PCS). In a study using the SF-12 with a large sample of persons with SMI (n=946), Salyers et al. (2000) found that the instrument distinguished the respondents with SMI from the general population, had a good test-retest reliability (PCS= .73) over one week, a two-factor distinction was confirmed and the scale was related to other similar indexes as expected. Internal consistency for this study sample was good ($\alpha=.82$). A summary score was created using oblique confirmatory factor analysis (Fleishman, Selim, & Kazis, 2010) for the physical health components of the scale. Higher scores indicated more severe physical health problems.

Social Support

Social support was measured using the Interpersonal Support Evaluation List (S. Cohen & Wills, 1985). The ISEL measures perceived support using four different domains: perceived ability of someone to do things with (belonging), the perceived availability of someone to talk about problems with (appraisal help), perceived availability of practical aid (assistance), and perceived availability of a positive comparison when comparing one’s life to someone else’s (self-esteem support). Rogers et al. (2004) tested the reliability and validity of the ISEL with people with SMI. They

found evidence to support a three-factor structure by combining self-esteem and belonging. Coefficient alphas for the three subscales ranged from .82 to .88 with a total scale coefficient of .92. The authors found that the reliability and validity testing with the SMI population approximated the general population (S. Cohen & Wills, 1985). The scale has 30 items, with three subscales, and 10 items in each subscale. Respondents were asked to indicate how much support they perceived receiving. Examples of items from the three subscales include: “There are several people I trust to help solve my problems” (appraisal), “If I needed help fixing an appliance or repairing my car, there is someone who would help me” (assistance), and “I often meet or talk with family or friends” (belonging). Internal consistency reliability for this study was strong: total scale ($\alpha=.92$), appraisal ($\alpha=.82$), assistance ($\alpha=.80$), and belonging ($\alpha=.87$).

After recoding several reverse-worded questions, summary scores were created for each of the three subscales for analysis, with higher scores indicating higher perceived support. To further identify specific support networks, a single question asking the participant to name their primary support person(s) was added by the primary investigator to the end of the ISEL. Several participants provided two or more people who provided support, however, when this occurred, respondents were asked to clarify *who* provided *more* support. The person named by the participant as providing more support was placed in a “primary support” category. Other supports were put in “secondary support” and in the case of one participant who listed three different supports a third; “tertiary support” category was used. The responses were then coded into specific relationship categories (e.g. sibling, parents, spouse/partner/significant other, mental health professional, other professional) and then condensed into smaller categories of formal

(professional, i.e. mental health case manager) and informal support (family, friends, neighbors, roommates).

Autonomy Preferences in Medical Decision-Making

The Autonomy Preference Index (API), decision-making scale (Ende et al., 1989) was used to measure patients' preferences for taking an active role in their own care and how these preferences are affected by varying disease severity. The API has two subscales: information preferences and decision-making autonomy preferences. The decision-making preference subscale was used for this study, to keep the focus on the decision-making dimension. The API decision-making preference subscale consists of 15 items, divided into two sections. The first section contains six general questions about decision-making, and nine items related to three clinical vignettes. The six general questions ask when the participant feels they should make the decision, or when they should allow the doctor to make the decision for them. For example, the first question asks the participant to rate the statement, "The important medical decisions should be made by your doctor, not by you" and the second statement is "You should go along with your doctor's advice even if you disagree with it." The six general questions ask the respondents to rate the extent to which they agree with each statement on a five-point Likert scale with 1= "strongly disagree" to 5= "strongly agree". After appropriate recoding, item analysis revealed two items with poor item to total scale correlation ($\alpha=.42$). Once these two items were eliminated, reliability improved toward acceptable ($\alpha=.70$). These four items were then used to create a summary score. The higher the score, the more autonomy the participant preferred.

In the vignette section, each vignette describes an illness and the severity of illness increases with each vignette. The first vignette represents an upper respiratory tract illness, the second vignette describes high blood pressure, and the third describes myocardial infarction (heart attack). The three questions that follow each of the three vignettes are unique to that vignette. The questions following the first vignette about upper respiratory illness are “Who should decide”... 1) Whether you should be seen by a doctor, 2) Whether you should have a chest x-ray, and 3) Whether you should try taking some cough syrup. The questions following the second vignette about high blood pressure are “Who should decide”... 1) When your next visit to check your blood pressure should be” 2) Whether you should take some time off work to relax, and 3) Whether you should be treated with medication or diet. The questions following the third vignette about a heart attack are: “Who should decide... 1) how often nurses should wake you up to check your temperature and blood pressure, 2) Whether you can have visitors outside of your immediate family, and 3) whether a cardiologist should be consulted. The response choices are the same for each question following each vignette scenario: 1= “you alone”, 2= “mostly you”, 3= “the doctor and you equally”, 4= “mostly the doctor,” and 5= “the doctor alone”.

In a previous study, test-retest reliability for the entire scale with a sample in a two-week interval was .84, and Chronbach’s alpha coefficient was .82. This scale has been used in several mental health studies with the SMI population (J. R. Adams et al., 2007; Hamann et al., 2005; Hamann et al., 2006b; O’Neal et al., 2008); however, none of the studies reported psychometrics for the scale when used with persons with SMI. With this study sample, the vignette section had somewhat better internal consistency ($\alpha=.78$)

than the general scale ($\alpha=.70$) and the general (with the reduced 4-item scale) and vignette scales taken together had good reliability ($\alpha=.81$). For analysis, after recoding negatively-worded items so that higher scored items indicated more autonomy, a summary score was created for the total scale (both general scale and vignette scales together). For the total scale, higher scores indicated more desired autonomy.

Perceived Autonomy Support

The level of autonomy support from the physician as perceived by the patient was measured by the Modified Health Care Climate Questionnaire (HCCQ). This measured how much the patient perceived the support from the physician for their desired decision-making autonomy. The HCCQ is a six-item scale modified from an original 15-item scale designed to assess the perceived autonomy of persons seeking care for obesity and weight loss (G.C. Williams et al., 1996). The modified version consists of questions that are most representative of the concept of autonomy support (G.C. Williams et al., 1998). It has been successfully used with diabetic patients regarding glucose control methods (G. C. Williams, Lynch, M., Glasgow, R.E., 2007) as well as in an adherence study for patients with various chronic conditions that require long-term medication treatment (G.C. Williams et al., 1998). The questions explore how the patients feel about their encounters with their doctors, specifically regarding whether their autonomy desires were honored. The scale asks the responder to rate questions like “I feel that my physician has provided me with choices and options” and “My physician encourages me to ask questions”. Perceived autonomy support questions are rated on a five-point Likert scale, with 1= “not true at all” to 5= “very true”. The modified scale has a Chronbach’s alpha of .80 and is highly correlated with the original scale ($r=.91$). A factor analysis with a

sample of 1,183 participants yielded an one-factor solution, with all factors loading at or above 0.74 (G.C. Williams et al., 1996). This scale has been used in one study of Chinese persons with SMI (Chiu, Ho, Lo, & Yiu, 2010), but psychometrics were not reported. For this study, internal consistency was strong ($\alpha=.97$). A summary score was used for analysis, with a higher score indicating a stronger feeling that autonomy was supported.

Medication Adherence

Several methods exist to collect data on medication treatment adherence, including pill counts, chemical tests, pharmacy data, and self-report. For feasibility, this study used the self-report method. The Morisky Medication Adherence Scale (Morisky et al., 1986) is widely used as a measure of medication-taking behavior. The theory undergirding the MMAS is that medication non-adherence can happen in several ways, such as forgetting, carelessness, stopping the drug when patient feels better, or starting the drug because patient feels worse. Patients tend to want to give their providers a positive response about taking medication, but by using questions that reverse the wording of the non-adherence areas, a measure of non-adherence can be achieved by the sum of the answers “yes” to the four questions. This self-report scale asks questions such as “Do you ever forget to take your medicine?” and “Are you careless at times about taking your medicine?” with simple “yes” or “no” responses. The scale was administered at Time 1 and repeated at Time 2. Responses of “no” was coded as “0” and responses of “yes” was coded as “1”, and a summary score for the four items was used for analysis, with a higher score indicating higher non-adherence to physical health medication.

Although reliability from a longitudinal study using the scale was not quite adequate (Chronbach's $\alpha = .61$), each item on the scale significantly contributed to the overall reliability coefficient, and the alpha decreased if any one of the items was deleted. Additionally, the scale was identified as one-dimensional through a principal components analysis (Morisky et al., 1986). The scale was also found to have good sensitivity (.81) and specificity (.44) and was able to predict adherence in both high and low index score categories of controlled blood pressure patients (Morisky et al., 1986). The scale has been used in a recent study (Bates, Whitehead, Bolge, & Kim, 2010) with a large group of people with bipolar disorder ($n=1,810$) and was found to correlate strongly with a medication satisfaction scale, however, specific psychometrics for the MMAS were not reported. Internal consistency for this study was also inadequate ($\alpha = .51$) at Time 1, and ($\alpha = .48$) at Time 2.

Barriers and Facilitators to Medication Adherence

At three month follow-up, two open-ended questions were asked to solicit participants' perspectives on barriers and facilitators to physical health medication adherence. The responses were recorded verbatim in a data collection sheet. The specific open-ended questions were: "What barriers, if any, do you experience following the medication orders given to you by [insert primary care doctor's name]?" and "What helps, if anything, successfully following the medication orders given to you by [insert primary care doctor's name]?"

Data Analysis

Preliminary analyses

IBM Statistical Package for the Social Sciences (SPSS) version 20.0 was used for all analyses. Means and standard deviations were calculated for all continuous variables. Data were inspected for normality, assessing for skewness and kurtosis. Data were initially screened visually for normality using histograms (Field, 2009). All data were normally distributed except for months attending the clinic, which were positively skewed. There were more people who were new to the clinic, which accounted for the non-normal distribution. Residual plots were then inspected for regression variables and found to be homoscedastic, as the data on the plots appeared linear when a line was applied (Field, 2009). All scores from surveys were transformed into summary scores unless otherwise indicated. Data analysis was organized around each hypothesis. The level of significance for statistical tests was set at .05.

Hypothesis 1: Physical health decision-making autonomy preferences can be predicted by patient characteristic variables of age, sex, length of time at clinic, mental illness severity, physical health severity, and perceived social support. It is hypothesized that patients who are younger, female, have less severe mental and physical health problems, and higher levels of perceived social support, will prefer higher level of desired autonomy.

As there were several independent variables in this model, chances of multicollinearity, or shared variance, between the independent variables, were higher than models with fewer independent variables (IVs) (Pedhazur, 1997). Therefore,

methods were used to check multicollinearity such as observing the correlations, as well as the values for the tolerance and the variance inflation factor (VIF). Pearson's r correlations were used to determine the magnitude and direction of the bivariate linear relationship between each independent variable and the dependent variable (DV) and to observe which independent variables, if any, were highly correlated (Nathans, Oswald, & Nimon, 2012). According to Field (2009), multicollinearity exists when variables are correlated at .70 or higher. The highest significant correlations between predictors were the three subscales for social support, and this relationship would be expected as they are three dimensions of a single scale. The highest correlation between the subscales was the belonging factor and the assist factor of the ISEL ($r = .72$). The two subscales with the smallest effect sizes with the dependent variable were dropped from the model (belonging and assistance), while appraisal of social support was kept for the regression analysis. All other significant correlations between independent variables were low to moderate ($r = .21-.62$).

Multiple linear regression was used to predict desired autonomy preferences for physical healthcare. The dependent variable of desired autonomy preferences for physical healthcare was analyzed using the summary score from the Autonomy Preference Index total scale (combining the general scale and the vignette scale). The predictor variables for analysis were age, sex, months attending the clinic, severity of psychiatric symptoms (a summary score from the Colorado Symptom Inventory [CSI]), perceived severity of physical illness (a summary score from SF-12 physical health subscale), perceived social support (three summary scores from the subscales of Interpersonal Support Evaluation List).

Hypothesis 2: When controlling for characteristic variables (listed above), it is predicted that the higher the preferred autonomy for physical healthcare decision-making and perceived autonomy support from the physician, the more adherent the person will be to medication.

Hierarchical multiple regression (HMR) was used to analyze the second hypothesis (J. Cohen, Cohen, West, & Aiken, 2003). HMR evaluates the relationship between a set of independent variables, controlling for the impact of a different set of independent variables on the dependent variable. Variables are loaded in a sequence of blocks that may contain one or more variables. The order of variable block entry is predetermined by the author, and is related to the theory driving the model (Schafer, 1991). The conceptual model (Figure 1) in this study asserts that there is a hypothetical relationship between autonomy preferences and medication adherence. The first block of predictors was entered as control variables, and then the second block, which contained the autonomy preferences and autonomy support variables, was entered, in order to identify how much variance in medication adherence is uniquely contributed by the second block. This is done by observing the change in the variance (r^2) between the two models. In block 1, the continuous variables of sex, age, length of time attending the clinic, the summary scores of the three dimensions of social support from the ISEL (appraisal, assistance and belonging), physical (SF-12, physical health scale) and mental health severity (CSI) were entered as controls for the first model. In block 2, the summary scores for autonomy preferences (total API scale) and perception of autonomy support (HCCQ) were entered to create the second model.

Lastly, semi-structured questions in sequence were used to ask two questions during Time 2 data collection. The two questions were: “What barriers, if any, do you experience following the medication orders given to you by [insert primary care doctor’s name]?” and “What helps, if anything, successfully following the medication orders given to you by [insert primary care doctor’s name]?” These two questions were asked of follow-up participants until responses were becoming redundant. As data were being collected, initial reviews and observations led to initial ideas of meaning (Creswell, 2003), in this case, “lack of resources” as a reason for non-adherence became a consistent idea presented during responses. Therefore, when the data became repetitive and no new, significant, contributions were being made to ideas of meaning, data collection concluded (Dey, 2004). When data collection concluded for the open-ended questions, 38 people had been asked the two open-ended questions. Data were analyzed using a thematic development approach, including discovering themes and subthemes from the text gathered during the interviews, condensing the data to a manageable amount of themes and placing themes in a hierarchy (Ryan & Bernard, 2003). Initially, data were looked at as a whole. All responses were read by the researcher, in an attempt to reflect on the larger meaning of the data (Creswell, 2003), and then a coding process began. The data were organized into categories, labeling them with meaningful ideas, before actual themes emerged (Creswell, 2003). Once this process took place with all the responses, the data were reviewed in light of the codes. The codes and the meaningful ideas (notes) were taken together and reflected upon. The final step was making an interpretation of the data, where the “lessons learned”, which captures the essence of interpretation

(Lincoln, 1985). The interpretive process ended with emerging themes and subthemes. Finally, quotes from the original responses were used to support the themes.

Sample Size

To calculate adequate sample size for this study, several factors were considered. The first was anticipated effect size for a behavioral science research study. Due to the lack of effect-size reporting and the minimal literature around this concept, rationale was drawn from Cohen (J. Cohen, 1992), who developed a standard for effect size (ES) that remains somewhat consistent among indexes in psychological research. He refers to these effect sizes as small, medium, and large, where medium ES is large enough to be observed by the naked eye, and is generally accepted as the average ES across various fields. Because social and behavioral sciences often neglect to report effect size values, using Cohen's recommendation has added some consistency in the literature (J. Cohen, 1992). In similar studies that examined decision-making for persons with SMI, effect size was reported to be from .17 (O'Neal et al., 2008) to .20 (Puschner et al., 2010). For this study, a medium effect size of .15 (multiple regression analysis) was used based on Cohen's rationale and related literature. Power level was set at .80 and significance level was set at .05.

Using G-Power (Erdfelder, Faul, & Buchner, 1996), a software program for determining sample size for an *a priori* power analysis, the required sample size for medium effect size of .15, with an alpha of .05, a power of .80, and 8 predictors, using hierarchical multiple linear regression was 109. The sample size obtained for this study was 95, and given the same parameters for effect size and alpha, it revealed a resulting

power of .79 for hypothesis 1. For hypothesis 2, the sample size was 56 and the resulting power was .43.

Chapter 4: RESULTS

Background of Study Participants

Participants for this study were 95 adults with severe mental illness attending a primary care clinic (integrated into a community mental health center) for their physical healthcare needs. Ninety-seven patients from the clinic were recruited, but two were unable to pass the consent quiz, and therefore did not complete Time 1 measures. As seen in Table 3, participants were mostly Caucasian (93.7%) and males were slightly more represented (51.6%). The average age of participants was 46.2 years. Forty-two percent of the sample had a schizophrenia spectrum diagnosis as their primary mental health issue, with 22.1% having a primary diagnosis as bipolar disorder and 20% having major depression. For physical health diagnoses, a third (32.6%) of the sample had hypertension, with 13.7% having hypertension as their primary diagnosis. Obesity was also diagnosed for nearly a third (29.9%) of the sample, with 17.9% having obesity as their primary diagnosis. Lung diseases (e.g. COPD, asthma) accounted for 26.3% of the sample, with 16.8% of the sample having a lung disease as a primary diagnosis. Eighteen percent of the sample had diabetes, with 10.5% having diabetes as their primary diagnosis. Average length of time participants had been attending the clinic was 7.2 months.

Table 3.

Study Sample Background Characteristics (N=95)

Demographic	Frequency (%)	Mean (SD)	Range
Sex			
Male	49 (51.6%)		
Female	46 (48.4%)		
Age		46.2 (12.4)	22-82
Ethnicity			
American Indian/Alaskan Native	1 (1.1%)		
African American	4 (4.2%)		
Caucasian	89 (93.7%)		
Other	4 (4.2%)		
Race			
Hispanic	4 (4.2%)		
Not Hispanic	91 (91.8%)		
Primary Mental Health Diagnosis			
Schizophrenia	40 (42.1%)		
Bipolar	21 (22.1%)		
Depression	19 (20.0%)		
Other	15 (15.8%)		
Secondary Mental Health Diagnosis			
Personality Disorder	5 (5.6%)		
Alcohol Dependence	3 (3.2%)		
Polysubstance Dependence	4 (4.2%)		
Primary Physical Health Diagnosis			
Obesity	17 (17.9%)		
Lung Diseases	16 (16.8%)		
Hypertension	13 (13.7%)		
Diabetes	10 (10.5%)		
Other *	39 (41%)		
Secondary Physical Health Diagnosis			
Obesity	7 (7.4%)		
Lung Diseases	2 (2.1%)		
Hypertension	14 (14.7%)		
Diabetes	3 (3.2%)		
Tertiary Physical Health Diagnosis			
Obesity	4 (4.2%)		
Lung Diseases	7 (7.4%)		
Hypertension	4 (4.2%)		
Diabetes	4 (4.2%)		
Months Attending Clinic		7.2 (7.0)	0-29

*Other physical health diagnoses were varied could not be subsumed into new categories.

Table 4 provides an overall description of the types of social support. Almost all participants (n=91) reported having some sort of social support. Most reported that their social support was informal- coming from family and/or friends (n=81). Only ten reported that their primary support came from formal support, namely mental health professionals such as case managers, and four reported no social support.

Table 4.

Types of Social Support (N=95)

Type	N	%
Informal	81	
Family	70	73.7%
Friends	8	8.4%
Neighbor	2	2.1%
AA Sponsor	1	1.1%
Formal	10	
Mental Health Providers	10	10.5%
No Support	4	4.2%

Of 95 participants, 56 completed the three-month follow up (Time 2) measures. In order to examine whether there were any significant differences between those who completed both Time 1 and 2 measures and those who completed only Time 1 measures, the key background and study variables were compared between these two groups. Due to the small number of participants, response categories for some variables were collapsed for analysis. Table 5 displays the results of these analyses.

Table 5.

Differences between study completers and non-completers

Variable	Total (N=95)	Completers (N=56)	Non-Completers (N=39)	<i>t</i> or χ^2	P-value
Age (years) (mean, SD)	46.2 (12.41)	43.2 (10.34)	48.32 (13.28)	-2.01	.05*
Sex (males, N, %, %)	49 (51.6%)	27 (48.2%)	22 (56.4%)	.62	.43
Mental health diagnosis				.80	.78
Schizophrenia group (N, %)	40 (41.2%)	17 (30.3%)	25 (64.1%)		
Depression group (N, %)	40 (41.2%)	17 (30.3%)	22 (56.4%)		
Physical Health Diagnosis				5.07	.28
Obesity (N, %)	17 (17.9%)	30 (76.9%)	21 (37.5%)		
Lung diseases (N, %)	16 (16.8%)	8 (20.5%)	6 (10.7%)		
Hypertension (N, %)	13 (13.7%)	5 (12.8%)	8 (14.3%)		
Diabetes (N, %)	10 (10.5%)	7 (17.9%)	3 (5.4%)		
Other (N, %)²	39 (41%)	6 (10.7%)	1 (2.6%)		
Length of time at clinic (months, mean, SD)		4.90 (6.1)	8.82 (7.12)	-2.80	.00***
Mental health severity (mean, SD)	20.68 (12.48)	20.49 (12.39)	20.82 (12.65)	-.13	.89
Physical health severity (mean, SD)	40.43 (13.77)	44.99 (12.94)	37.26 (13.54)	2.79	.00*
Medication adherence Time 1 (mean, SD)	2.66 (1.19)	2.67 (1.11)	2.66 (1.25)	.024	.98
Autonomy Preferences (mean, SD)	42.02 (6.41)	42.08 (6.12)	41.98 (6.65)	.07	.94
Perceived Autonomy Support (mean, SD)	36.01 (14.11)	38.13 (4.68)	34.57 (17.79)	1.20	.23

* $p < .05$., *** $p < .001$.

Study completers and non-completers were significantly different in age, length of time attending the clinic, and physical health severity (See Table 5). Completers were younger, had significantly fewer months attending the clinic and had higher physical health severity than non-completers. There were no significant differences for completers and non-completers on sex, mental and physical health diagnoses, mental health severity, autonomy preferences, perceived autonomy support, medication adherence and social support.

Correlations

Pearson r correlations were run between all the continuous independent variables and the dependent variables to identify the extent to which the independent variables were correlated with the dependent variables and with each other. Table 6 displays these correlations. The dependent variable for the first hypothesis, autonomy preferences for physical healthcare decision-making, had negative significant correlations with perception of autonomy support from physician ($r = -.21, p < .05$), and medication adherence at Time 2 ($r = -.31, p < .05$), and a positive correlation with being male ($r = .34, p < .001$). In other words, reporting more desired autonomy was associated with being male and reporting lower levels of perceived support from their physician. Correlation with appraisal of social support approached significance ($r = -.19, p = .060$). The dependent variable for hypothesis 2, medication adherence at Time 2, had several significant correlations: autonomy preference ($r = -.31, p < .05$), age ($r = .31, p < .05$), perception of autonomy support ($r = .30, p < .05$), severity of mental health symptom ($r = -.46, p < .01$), and medication adherence at Time 1 ($r = .62, p < .01$). In other words, patients who reported higher medication adherence at Time 2 were older, perceived more

autonomy support from their physician, and reported higher adherence at Time 1. Alternatively, participants who reported lower adherence at Time 2 desired more autonomy in their decision-making and had more severe mental health symptoms.

Table 6.

Correlations between variables.

	1	2	3	4	5	6	7	8	9	10	11	12
1) Autonomy Preference	1.00	.34**	-.09	.06	-.21*	-.19	.03	-.05	-.03	-.17	-.31*	-.06
2) Sex		1.00	-.06	.07	-.07	-.04	.01	-.21*	.03	-.12	-.09	-.11
3) Age			1.00	-.23*	.04	-.07	-.20*	-.13	-.16	.16	.31*	.12
4) Physical Health Severity				1.00	.21*	.05	.27*	.18	-.14	-.11	.20	-.09
5) Autonomy Support					1.00	.22*	.11	.25*	-.19	.20*	.30*	.16
6) Social Support Appraisal						1.00	.65**	.66**	-.35*	.26*	.11	.18
7) Social Support Assistance							1.00	.72**	-.29**	.09	.15	.19
8) Social Support Belonging								1.00	-.35**	.21*	.18	.29**
9) Mental Health Symptom									1.00	-.21*	-.46**	-.21*
10) Med Adherence Time1										1.00	.62**	.06
11) Med Adherence Time 2											1.00	.17
12) Months at Clinic												1.00

* $p < .05$; ** $p < .01$.

Model: Hypothesis 1

A multiple regression analysis was conducted to see how well the predictors of age, sex, mental health severity, perceived physical health severity, perceived social support, and length of time attending the clinic predicted physical health decision-making autonomy preferences.

Initially, data were double-checked for multicollinearity by observing the tolerance and VIF values for the predictor variables. According to Field (2009), tolerance values below .10 and VIF values above 10 indicate multicollinearity. After the highly correlated social support variables of assistance and belonging were removed, none of the predictor variables had values that exceeded tolerance or VIF limits. Therefore, multicollinearity was not considered a threat.

Table 7 displays the statistics for the regression model used for the first analysis. The six independent variables regressed on the dependent variable showed a significant overall model ($F(6, 88) = 2.99, p < .01$). The predictor variables collectively accounted for 17% ($R^2 = .17, p < .01$) of the variance in the dependent variable of autonomy preferences, however, only two were significant. The variables with the most predictive value according to their significance and beta weights were appraisal of social support (ISEL appraisal subscale) and sex. Appraisal of social support had a negative relationship with the dependent variable, while being male had a positive relationship. In other words, the more someone perceived that they had someone to talk to about their problems (appraisal of support), the less they desired autonomy in their physical health decision-making. Additionally, males desired more physical healthcare decision-making autonomy than females. These results do not support the original hypothesis that stated

women and people with higher levels of perceived social support would desire more autonomy in their physical health decision-making. Other predictors such as older age and less severe physical and mental health symptoms did not significantly contribute to the model, and the low zero-order correlations suggest that they are not significant predictors of autonomy preferences.

Table 7.

Summary of Regression Analysis for Variables Predicting Physical Health Decision-Making Autonomy Preferences (N=95)

Variable	<i>B</i>	<i>SE B</i>	β
Age	-.05	.05	-.11
Sex (Male)	4.14	1.25	.33**
Social support-Appraisal	-.21	.09	-.24*
Mental health symptoms	-.07	.06	-.14
Physical Health Severity	.00	.05	.01
Months Attending Clinic	.00	.09	.00
<i>R</i> ²		.17	

* $p < .05$. ** $p < .01$. *** $p < .001$.

Model: Hypothesis 2.

Hierarchical multiple regression (HMR) was performed by entering the first block of predictor variables including age, sex, mental illness severity, perceived physical illness severity, perceived social support, and length of time attending clinic. The second block included the predictors of perceived autonomy support from primary care physician and autonomy preferences. These predictors were regressed upon the dependent variable of medication adherence at Time 2, while the first block of predictors was held constant. Table 8 displays the statistics of the HMR. The first model was significant, $F(7, 49) = 8.74, p < .001$, and explained 55.5% of the variance. When the predictors of support for decision-making autonomy and desired autonomy preferences were added, the model was significant $F(9, 47) = 6.77, p < .001$ and explained 56.4% of variance. However, adding the two additional predictors explained only additional .09% of variance and the increase was not significant $F(2, 47) = .51, p = .61$. In the first model, the strongest predictor was medication adherence at Time 1 ($\beta = .51, p < .001$), then mental illness severity ($\beta = -.33, p < .01$), and physical health severity ($\beta = .21, p < .05$). At Time 2, significant predictors were also medication adherence at Time 1 ($\beta = .49, p < .001$) and mental illness severity ($\beta = -.35, p < .01$), but physical health severity was not significant. In other words, when the first block of predictors was held constant, those who had low adherence at time 1, had more severe mental health symptoms and reported lower adherence at time 2.

Table 8.

Summary of Hierarchical Multiple Regression Analysis for Predictor Variables of Physical Health Decision-Making Autonomy Preferences (N=56)

Variable	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
Age	.01	.01	.16	.01	.01	.14
Sex	-.03	.22	-.01	.06	.24	.03
Social support: Appraisal	-.02	.02	-.14	-.03	.02	-.18
Mental illness severity	-.03	.01	-.33**	-.03	.01	-.35**
Physical health severity	.02	.01	.21*	.02	.01	.20
Months at Clinic	.01	.02	.05	.01	.02	.05
Time 1 Medication Adherence	.46	.01	.51***	.44	.01	.49***
Physician Autonomy Support				.00	.01	.04
Autonomy Preference				-.02	.02	-.01
<i>R</i> ²			.56			.56

* $p < .05$. ** $p < .01$. *** $p < .001$.

Open-ended themes around medication adherence.

During the Time 2 data collection, participants were asked about the barriers and facilitators to medication adherence for physical health care. A thematic analysis revealed five major themes: behavior-related facilitators, personal support facilitators, resource barriers, and pharmacy-related facilitators and barriers. Quotes from the participants are used to further evidence the themes. Table 9 displays the themes and sub-themes.

Table 9.

Facilitators and Barriers to Physical Health Medication Adherence (N=38)

Behavioral Facilitators (N=24)
<ul style="list-style-type: none">• Using a medication planner• Placing medications in a convenient and consistent area in the home• Synchronizing taking medications with an event (e.g. the evening newscast)
Personal Support Facilitators (N=10)
<ul style="list-style-type: none">• Reminders from loved ones to take medications• Taking medications at the same time as loved ones
Pharmacy-related Facilitators (N=8)
<ul style="list-style-type: none">• Medications are pre-packaged• Convenient access to the pharmacy• Pharmacy allows co-pays to be late
Resource Barriers (N=16)
<ul style="list-style-type: none">• Not enough money to pay co-pays• Transportation issues getting to the pharmacy• Do not have the things they need to take meds consistently (e.g. alarm clock, medication planner)
Pharmacy-related Barriers (N=4)
<ul style="list-style-type: none">• Medications are not filled correctly• Miscommunication between the doctor and the pharmacy• Prescriptions are sent electronically instead of written down

Behavior-related facilitators. The most cited facilitator was adopting behaviors that made adherence to their physical health medications easier. Several participants reported that certain medication-taking behaviors aid in staying adherent. These activities make it easier to remember, such as placing medications in a common area where they can be easily seen, syncing taking medications with another event throughout the day, or using a medication box/planner. For example, one participant reported: “I only take my meds twice a day, and I eat twice a day, so I take my meds when I eat.” Another stated: “I take my meds with the newscast. The news is on in the morning, noon and at night, and that’s when I take them.” Conveniently placing the medications also seemed to assist in taking them at the correct time. For example, one participant stated: “My meds are prescribed at

bedtime, and I keep them there right next to my bed.” Similarly, someone reported: “I only take one med in the morning, so I take it with my morning coffee and I keep it in the kitchen.” Several people indicated that using a medication box helps. One person stated: “I use a pill organizer and I take my meds at the exact same time every day.”

Personal support facilitators. Participants acknowledged that having family, friends or staff who assist them in various ways in taking their medications was an important facilitator. Several stated that their loved ones use verbal reminders or cues to either take medications or to check and see if the medications were taken. One participant noted: “My wife reminds me. If she doesn’t remind me, I forget” and another stated: “My sister reminds me, she asks me if I’ve taken it. She lives with me so she is always around.” One participant stated that a friend comes over and “reminds me, and helps me to set up my meds.” Three participants said that their loved ones also take medications and that they synchronize. One person noted: “My roommate helps me, she keeps them in one place, and when she takes hers, I take mine.” Another participant offered: “My husband takes his the same time I take mine, so we take them together.”

Resource barriers. The most frequently reported barrier to medication adherence was lack of resources. Nine people stated that they have financial barriers to obtaining medications. Several reported having to manipulate how they take their medications to make it stretch. One participant noted: “Money plays an issue- some meds I only take once a day instead of twice a day, and sometimes I still run out before I can get more.” Another person reported that not having medical coverage is the problem, “Lack of insurance and money is a barrier, sometimes I run out [of meds] before I can get more.” There were other financial problems related to getting medications. One person stated

that his mother was his payee and she would “forget to pay my pharmacy bill and it’s hard to access my medication when she hasn’t paid.” Another participant offered that “I don’t always have the money for the co-pays...I have to pay the bills too.” A respondent stated he “missed my morning doses often” because “I cannot wake up in the morning.” He stated he wanted to “buy an alarm clock” to help him wake up, but cannot because of not having enough money. One person indicated that she “wants a med box, but doesn’t have the money to buy one.” Similarly, five people reported that they do not have transportation to get their medications from the pharmacy. One participant noted that after she pays her bills and co-pays, she often does not have money “for gas to get to the pharmacy.” Others stated that they have trouble finding a ride.

Pharmacy-related facilitators and barriers. Several participants reported that factors related to the pharmacy they used helped or hindered medication adherence. One helpful service reported was receiving medications pre-packaged from the pharmacy and therefore doses are automatically prepared. One participant noted: “I couldn’t keep track of my meds if they weren’t pre-packaged.” Another benefit was easy access to the pharmacy. Three participants stated that living near the pharmacy helps to obtain medication, and two reported they use the “in-house pharmacy” at the mental health center and it is “convenient” to have it “right there.” Lastly, one participant noted the benefit that the pharmacy understood her financial situation, and the “pharmacy allows me to pay my co-pays late, when I have the money.”

Several participants reported pharmacy-related barriers. Two stated that they had problems getting their medications filled properly, and one specifically said: “I switched pharmacies because of the problems I had with the in-house one.” Additionally, one

participant spoke of preferring written prescriptions versus having them called-in by the doctor or nurse, because “sometimes the doctor’s office and the pharmacy get their wires crossed.”

Chapter 5: DISCUSSION

Summary and Overview of Findings

The first aim set forth in this study was to identify what factors predicted physical health decision-making autonomy preferences for people with SMI. Data were gathered on the variables of sex, age, perceived social support, physical health severity, mental health severity, and length of time attending the clinic. As discussed in the introduction, and further evidenced in the literature review, understanding people's decision-making autonomy preferences could assist those providing primary care in advancing decision-making styles that are compatible with those preferences (Street et al., 2012). This compatibility could lead to a more engaged relationship between doctor and patient, and to improved adherence to prescribed treatment. Therefore, a second aim in this study was to observe whether perceived decision-making autonomy support from a physician, and decision-making autonomy preferences, could predict medication adherence.

For the first hypothesis, correlations and multiple regression were used to analyze the contribution of the six predictor variables on the dependent variable. Pearson's *r* correlations showed a significant relationship between the dependent variable autonomy preferences and sex. Restated, males desired more autonomy in their physical healthcare decision-making. In the multiple regression analysis, the predictors accounted for 17% of the variance. There were two significant predictors, appraisal of social support (having someone to talk to about your problems), and sex. In other words, the more participants perceived having someone to talk to about their problems, the less autonomy in decision-making they desired. Also, males desired more autonomy than females, consistent with the correlation result.

The *a priori* hypothesis stated that women would prefer more autonomy in their physical health decision-making. According to the research on people with SMI and healthcare decision-making, women with SMI want a more active role in physical healthcare decision-making (Arora & McHorney, 2000), and those that take an active role in making their healthcare decisions prefer a shared decision-making approach from their physicians (Levinson et al., 2005). Additionally, Dwight-Johnson and colleagues (2000) suggest that women with SMI prefer more healthcare decision-making autonomy than their male counterparts, including deciding forms of treatment. Contrary to the literature, the original hypothesis that women prefer more autonomous decision-making was not supported. Additional analyses looking at whether the women in this sample had less social support or more severe mental health symptoms did not reveal any more insight as to why they desired less autonomy. Taking a closer look at the data in this sample could reveal some alternative explanations. We previously highlighted the inverse relationship between social support and desired autonomy in decision-making: that those with someone to talk to about their problems desire less autonomy. A subsequent question is: do women have more social support and therefore desire less autonomy in this sample? The literature provides evidence that women with SMI indeed do have more social support than men (S. E. Rogers et al., 2004; Thoits, 2011), however, current literature does not explore how the social support of women with SMI impacts desired autonomy in physical healthcare decision-making. When further analyzing the data of this sample, it was discovered that there were no significant differences in appraisal of social support ($t = .420, p = .68$) or types of social support, (e.g. formal or informal), $\chi^2(2, N=95) = 4.52, p = .10$. between men and women. Another explanation to consider is whether the women

in this sample had more severe mental illness. The research elucidates that having more severe mental health symptoms is a factor in decision-making (Tan, 2009; Wong et al., 2000). It stands to reason that the sicker someone is, the less involved they are, or want to be, in making important healthcare decisions (Levinson et al., 2005). However, in this sample, there were no differences in severity of mental illness symptoms ($t=-.302, p=.76$) for men and women. Sex differences in decision-making autonomy preferences in physical healthcare should be further explored. This data can be used as a foundation for more questions regarding the nature of this relationship.

A theoretical explanation could be that women with SMI might feel less empowered than men to make healthcare decisions, so that they prefer less autonomous decision-making. When reviewing the literature specifically highlighting empowerment in physical health decision-making for persons with SMI, there is evidence that suggests women with mental illness might have lower self-esteem, related to self-stigma, and therefore feel less empowered (Rüsch, Lieb, Bohus, & Corrigan, 2006). This could be better explored in future research: exploring whether women with SMI feel empowered to make decisions, and what kinds of factors could contribute to increased empowerment.

Those who perceived themselves as having someone to talk to about their troubles, which is defined as the *appraisal* of social support (S. E. Rogers et al., 2004), desired *less autonomy* in their physical health decision-making. This was contrary to the hypothesis, which stated that the more social support someone had, the more autonomy they would desire. The sample for this study reported a high amount of perceived social support, inconsistent with the literature which has previously reported that people with SMI have less perceived support (Kilbourne et al., 2007). Of the participants perceiving

having social support, 84% reported having informal support (family, friends, AA sponsor, neighbor or pastor). While appraisal of support was a significant predictor, the other two subscales of support (someone to provide practical help when needed) and belonging (feeling a part of a social group) did not predict desired autonomy in the regression analyses, and the correlations also showed near zero relationship with autonomy.

If making physical healthcare decisions seems stressful or overwhelming, having someone to talk to could help someone feel as though they do not have to make the decision alone. Assistance and belonging may not have similar applications in decision-making and feelings of desired autonomy. Assistance is having practical support (e.g. someone helping to provide transportation, money) and belonging is more of a social construct- belonging to a group of friends (S. E. Rogers et al., 2004). If people who have someone to talk to desire less autonomy, it could be that they view their support system as co-decision makers, and that they do not *have* to make their decisions alone, and thus desire less autonomy. Another consideration is the formal support received by persons engaged in mental health services, and the decisions that may have been facilitated by their case managers, nurses and psychiatrists. If their mental health team uses a more paternalistic approach in providing mental health services, specifically, the psychiatrist telling the client what medications to take, and the team making sure that medication regime is adhered to (Deegan & Drake, 2006), as opposed to a shared decision-making and patient-centered approach to care (Drake, 2010), the client might perceive primary care services in the same light. The expectation might be that the decisions will be made for them.

For the second hypothesis, Pearson's r correlation was used to observe the significant relationships of the predictor variables with the dependent variable, and hierarchical multiple regression was used to analyze the unique contribution of autonomy preferences and perceived autonomy support on the variance of medication adherence at Time 2. Correlation analysis revealed that higher medication adherence at Time 2 was associated with being older, being adherent to medication at Time 1, perceiving physician support for their autonomy, desiring less decision-making autonomy, and having less severe mental health symptoms. Although this study reveals that medication adherence increases with age, the literature reveals that non-adherence among people who are older with mental illness range from 45%-75% (Zivin & Kales, 2008). However, these studies all refer to mental health medications. Literature that reports adherence rates to physical health medications for older adults with mental illness is lacking in the literature.

The literature also addresses the relationship between perceived autonomy support and medication adherence. It seems likely that when a doctor supports a patient's decision-making, the patient's treatment adherence could increase. This has been found in the general population, but not in the SMI literature. Among patients with diabetes, it has been suggested that increased physician support improves their medication adherence (G.C. Williams et al., 1998), and it has even been offered that successful models of improving patient adherence include autonomy support (Delamater, 2006). However, if the sample in this study desires less autonomy while being more adherent, it is possible that patients view medication taking through the lens of "compliance" (Deegan, 2007). In other words, instead of taking medications as a "choice", patients might not feel autonomous, or desire autonomy, but instead, do what is expected of them. They might

feel that they have the support of their physician for their autonomy as long as they are compliant with their treatment regime (Deegan & Drake, 2006).

In the hierarchical regression model, when controlling for the background variables, decision-making autonomy preferences and perceived autonomy support from physician did not significantly predict medication adherence. A major reason for the lack of findings for hypothesis 2 was the lack of adequate power for the study. The Time 2 sample size was small, as a result of loss to follow-up, which resulted in a power of .43 for the second analysis. An underpowered study can fail to find significance even when it exists (Maxwell, 2004). Another possible reason for lack of findings for hypothesis 2 is the large number of predictor variables compared to the sample size. For the HMR analysis, nine predictor variables were used with a sample size of 56.

Two variables from Time 1 measures were significant in predicting medication adherence in the regression analysis: medication adherence and mental health symptom severity. It stands to reason that there would be some consistency in medication adherence at Time 1 and Time 2, as there were only three months in between measures, and that people's medication-taking behavior may remain stable over short periods of time. Also, similar to the correlational findings, higher adherence at Time 2 was predicted by less severe mental health symptoms. Literature validates this finding, as symptoms can impact a person's ability to adhere to their medication regime (J. Adams & Scott, 2000), and, symptoms are more likely to be less manageable with low adherence (Gray, Wykes, & Gournay, 2002). This is substantiated in the literature regarding mental health medication adherence (Velligan et al., 2009), however, there is no literature base regarding physical health medication adherence for people with SMI. This finding raises

the question: are people with severe mental illness, whose symptoms are more difficult to manage, equitably non-adherent to mental health and physical health medications, or are there differences? In other words, do people perceive adhering to their mental health medications differently than their physical health medications? And to what extent do exacerbated mental health symptoms impact this perception?

The qualitative analysis provided some insight into what helps and hinders physical medication adherence for people with SMI. The sample in this study cited the most helpful factor in taking physical healthcare medication consistently was having personal support. Many participants stated that the verbal reminders from family or friends were the key factor to taking their medications on time and correctly. Additionally, several offered that they take their medications *with* their loved ones when *they* take *their* medications- in other words, like a buddy system. These two open-ended questions asked about medications prescribed by their primary care physician, which would indicate their physical health medications. However, it is possible that their habits in taking their physical health and mental health medications are similar. It may have been more helpful to add a question about whether the participants perceived any differences in facilitators and barriers to adherence to physical health and mental health medications.

The literature is clear regarding adherence issues for persons with SMI and their mental health medications. For example, participants stated that they wanted to have a voice in what kind of medication they took, which could increase adherence (Woltmann, 2010) and that side-effects of mental health medications could influence whether or not people were adherent (Fleck, Keck, Corey, & Strakowski, 2005). Lastly, studies of

adherence to mental health medications have shown that non-adherence could result from a perceived lack of need - either the persons feel like they are not ill and therefore, do not need to take the medications, or the medications are not helping (J. Adams & Scott, 2000). More exploration would need to be done with in-depth interviews or other research methods to observe the similarities and differences between patterns of adherence for physical and mental health medications. In fact, it would be interesting to see if a person had to *choose between* medications, which they would purchase or take, and for what reasons. Specifically, one of the major responses to barriers was resources. If resources were limited, and they could only afford certain medications, which would they purchase? How would they make this decision? We know that resources barriers have prevented people with SMI seeking primary care services, and that integrated care programs have improved accessibility (Druss, Rohrbaugh, Levinson, & Rosenheck, 2001), however, that is only one piece of the larger puzzle of improved physical health outcomes for people with SMI. If they have trouble accessing the very treatment prescribed by their primary care doctor, how effective can integrated care be on its own?

Social workers in the mental health field have a unique opportunity to address this issue. Working closely with consumers of mental health services that also have comorbid physical health issues, they can assist in extending the effectiveness of medical services by removing barriers to accessing medications. They can also provide a line of communication between the physical health doctors and the patients. When doctors are unaware of a patient's resource limitations, they may not understand the complete picture of adherence issues. This communication may allow the doctor, patient and social worker to operate as a team to help the person with SMI with goals of improved health.

Limitations of Study

Several limitations have already been presented in this chapter. However, others are also noteworthy for mention. A limitation when designing the study was the lack of literature in the area of *physical health decision-making for persons with SMI*. Studies exist that have observed the relationships between similar factors and mental health decision-making, but the primary care setting has gone largely understudied to date. This point also creates a strength of this study, in that it makes a contribution to a currently growing body of literature.

A limitation while conducting the study was the difficulty in recruiting participants in the clinic. Patients of the primary care clinic at the mental health center were approached at the time of their appointment, and if they agreed to participate, the interview was conducted after the appointment was completed. However, the physician consistently ran late, sometimes his appointments were an hour behind. There were people who agreed to participate when approached, who could not stay for the interview due to running short on time. Therefore, the IRB was amended to be able to conduct the interview before the appointment. This did not always work, either, because people would often forget to come in early for the interview. Another issue that impacted recruitment was the “no-show” rate. The research staff would pull the morning schedule in order to see how many patients would be attending clinic that had not yet been recruited, and frequently, several did not come in to their appointment.

Another limitation was the number of participants lost to follow-up at Time 2. Thirty-nine people did not respond for reasons such as declining to further participate, did not answer the phone after a month of attempts, or phone was disconnected. Different

attempts to contact the participants might have resulted in more responses. Mailing the follow-up questionnaire, or contacting their mental health case managers to track down participants may have produced more responses. The follow-up period was short (three months) and only one month past the three month mark was allotted as a reasonable time for follow-up. Study completers were younger and had significantly fewer months attending the clinic and had higher physical health severity than non-completers. It is possible that as a new patient at the clinic, the patients felt participating in a survey about their physical healthcare might provide them another way to voice their opinions and ideas. During the interviews, several participants would talk about their experiences as they answered the survey questions, indicating that they had more to say. It is interesting to find out that those with higher physical health severity would be more willing to complete the study than those who had less severe physical illnesses. It could be that those with more severe physical illness were more likely to be at home when the researcher called for follow-up, thus presenting more of an opportunity to be reached, and may have also been more likely to continue seeing the doctor- therefore, contact information would have been current and they may have accepted phone calls from the clinic, versus ignoring them. There were no significant differences for completers and non-completers on sex, mental and physical health diagnoses, mental health severity, medication adherence and social support.

Finally, participants recruited were largely Caucasian (94%) and non-Hispanic (91%). Therefore, the analysis could not include differences in groups based on race or ethnicity, as this was not a diverse group of participants. This could be explained by the location of the clinic. The clinic was located at a suburban site of the CMHC, which has

fewer non-White consumers, versus their downtown location. The lack of ethnic and racial diversity was a limitation for this study, given the literature, which highlights the potential differences in decision-making preferences driven by varied cultural backgrounds.

Implications for Social Work Practice

Social workers in mental health and a variety of medical settings could benefit from the findings of this study. Mental health social workers often find themselves facilitating access to medical care with people with severe mental illness (Rees, Huby, McDade, & McKechnie, 2004). If these social workers make assumptions based on what they have experienced from a mental health setting perspective, they could miss opportunities to empower their consumers toward more informed and autonomous physical healthcare decision-making. This study suggests that there may be variables to consider when exploring how a person prefers to make their physical healthcare decisions (e.g. alone, with a doctor, with family). Social workers can explore autonomy preferences with their consumers and in doing so, can encourage healthy decisions and treatment adherence.

Additionally, the qualitative findings from this study could help mental health social workers understand some reasons persons with SMI are not adherent to medications. Social workers might use motivational techniques and resource linkage to help their consumers become or stay adherent to physical health medications. There could be a variety of simple fixes, such as helping someone to buy a medication planner or an alarm clock. This study could also assist social workers in medical settings, not familiar with the autonomy preferences of people with SMI, appropriately meet their

needs. For example, medical social workers could make more informed decisions when facilitating discharge planning from a hospital, as releasing someone with a week's worth of medication samples and a written prescription might not help someone adhere in the long run. Medical social workers might need to take extra steps in ensuring at-home support in taking medications, pharmacy access, and the removal of financial barriers, such as Medicaid coverage or monetary assistance with co-pays. These findings also encourage exploring all these issues with consumers. Regardless of the setting, social workers should assess a consumer's desire to participate in decision-making for all forms of treatment, and should work with them on the best way to become informed on medications and treatment options.

Social workers can also use this information to pursue conversations with physicians about how to best serve people with SMI. Some primary care and other medical doctors approach treatment decision-making from a paternalistic, "what I say goes, because I'm the expert" style. However, our study suggests that people with SMI have different autonomy preferences in decision-making. Social workers can intervene with physicians, helping bridge the communication gap between doctor and patient.

This study revealed a significant relationship between autonomy preferences and having someone to talk with about problems (appraisal of support), that is, when someone perceives having others to talk to, they have less desired autonomy. This could mean that when people feel they have someone they can discuss their problems with, they may be used to making decisions in consultation with others, they may also feel comfortable talking and making decisions with their doctors. This could encourage a shared decision-making approach. Therefore, it may benefit social workers to identify

whether people with SMI have someone to talk to about their problems, and engage support systems in the medical decision-making process. If a consumer having someone to talk to means they desire less autonomy, perhaps they perceive *needing* someone to talk to in order to make decisions. Therefore, it may be important for social workers to assist consumers in building their support networks if none or very little support is present. However, this is only one way of interpreting the data. It is also possible that having someone to talk to about healthcare problems means that the support person is *relied upon* to be the decision-maker. Desiring less autonomy could result in depending on others to make the decisions, instead of making the decision oneself. In this case, the patient may want the physician to make the entire decision. Because the literature suggests that people with SMI desire a shared decision-making approach to healthcare (J. R. Adams et al., 2007), it is essential for social workers to assess these autonomy preferences and empower consumers toward increasing autonomy.

Implications for Future Research

The limitations of this study prohibited generalization and explanations of the phenomenon discussed. This study took a more exploratory approach. A larger sample with a longer time allowance for follow-up could help to determine patterns in people's decision-making and medication adherence. Observing other treatment outcomes, other than medication adherence, would also be important, for example, following a diabetic or heart-healthy diet. Understanding these patterns could better facilitate social workers' ability to support long-term health and positive treatment habits. However, this study does lay the foundation that relationships exist between factors such as sex, social support, and physical health decision-making autonomy preferences. This study also

points to more questions that could continue to guide research in the fields of mental health, physical health, and integrated care, questions such as “what kind of social support best facilitates medication adherence?” and “what kinds of facilitators and barriers exist to adhering to physical health treatment other than medication?” Additionally, consistent with previous literature, the most common physical illnesses among people with SMI in this study are obesity, lung diseases, hypertension and diabetes. Future research could identify specific disease-related issues, for example, what helps a person with SMI who has brittle diabetes successfully adhere to their insulin injections.

This study also highlighted a correlation between perception of autonomy support from the physician and medication adherence. To continue to explore this relationship, other variables, such as returning to appointments or follow-up on other doctor’s orders (e.g. going to the lab, getting x-rays), could be added to future studies as outcome variables, strengthening the importance of supporting a person’s autonomy. Primary care and other medical physicians may feel inhibited in their relationships with people with SMI and might make decisions *for* them, as opposed to engaging them toward shared decision-making. Therefore, more work should be done to explore this relationship and the effect on the health behavior of persons with SMI. Future research could look at this process- how engaging patients with SMI in their decision-making autonomy preferences in primary care influences the doctor-patient relationship, as well as health behaviors, such as wellness activities.

The Time 1 variables were not reassessed at Time 2. Therefore, it was not possible to observe any change in the three month interval on any of the key predictor

variables, such as physical or mental health severity, or social support. Changes in these variables could have changed the outcome of the study. If this study were to be replicated, it might be wise to re-evaluate these variables again at Time 2.

Conclusion

Although this study has a number of limitations, it contributes to a very limited literature base on the needs of people with SMI in primary care, and more narrowly, how certain factors can influence a person's decision-making autonomy preferences. More information about the relationship of these factors can assist social workers, physicians and family members in empowering those with SMI toward participation in their healthcare decision-making, increased autonomy in making choices that they feel are best for them and their lifestyles, and increased medication adherence. There is a long way to go in uncovering what the most important factors are in decreasing the morbidity and mortality for persons with SMI, and this study explored only a couple of smaller angles. It is critical that research funding be earmarked to unravel the mystery of how to increase the wellness and longevity of people with severe mental illness.

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- Woltmann, E. M. W., R. (2010). Shared Decision Making in Public Mental Healthcare: Perspectives from Consumers Living with Severe Mental Illness. *Psychiatric Rehabilitation Journal, 34*(1), 29-36.

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CURRICULUM VITAE

Jennifer Wright-Berryman

EDUCATION

- 2014 Ph.D., Indiana University, Indianapolis, Indiana
- 2002 Master of Social Work, Indiana University School of Social Work,
Indianapolis, Indiana
- 1996 Bachelor of Science, Speech and Hearing Sciences, Purdue University,
West Lafayette, Indiana

ACADEMIC APPOINTMENTS

- 2014 University of Cincinnati, School of Social Work: Assistant Professor
- 2013-2014 University of Cincinnati, Blue Ash College: Assistant Professor
- 2011-2013 Indiana University School of Social Work: Associate Faculty
- 2009-2010 Indiana University School of Social Work: Research Assistant
Data entry, cleaning and analysis for Assertive Community Treatment
(ACT) in Indiana. Data entry, cleaning and analysis for Illness
Management and Recovery (IMR).
Program evaluation for IMR at Adult and Child Mental Health Center.
- 2006-2008 Ivy Tech Community College: Adjunct Faculty
- 2004-2005 Indiana University School of Social Work: Field Supervisor
Supervised students in their field placements, coordinating their
placement, providing clinical and administrative supervision, and assisting
with needs during placement.

PROFESSIONAL EXPERIENCE

- 2005-2013 Adult and Child Mental Health Center,
ACT Center of Indiana: Research Coordinator
- Grant writing contribution
 - Program Evaluation
 - Research coordination, data collection and manuscript preparation
 - Funding proposals
 - Training
 - Consultation

Current Projects

- Qualitative Study on the Successful Factors that Contribute to Mental and Physical Health Recovery
- Decision-Making Preferences in Physical Healthcare for Persons with SMI, Instrument Factor Analysis and other validation

Funded Projects:

- State Division of Mental Health and Addiction (DMHA) Illness Management and Recovery (Evaluator, Adult and Child Mental Health Center)
- Primary Care Behavioral Healthcare Integration Health Information Technology (Evaluator, Adult and Child Mental Health Center)
- Comparison of Fidelity Assessment Methods (Fidelity Assessor, Roudebush VAMC)
- CommonGround/Shared Decision-Making (Implementation Coordinator, NIMH R34)

Unfunded Projects:

- IMR discharge secondary data (survey) analysis
- Inside/Out: A social work service learning experience. Qualitative secondary data content analysis.

Past Funded Projects:

- IMR Web- consumer and clinician qualitative interviews of a computerized version of IMR. Manuscript under review. Role: Research Assistant.
- Indiana Phone Fidelity Comparison Methods. Manuscript in publication. Role: Self-report fidelity assessor.

ACT Center of Indiana: Consultant and Trainer

- Consultation and training support for Assertive Community Treatment teams in Indiana
- Fidelity assessment and reporting to State of Indiana
- Team growth and goal achievement
- State standard development and consultation
- In agency crisis training and consultation

Adult and Child Mental Health Center: Team Leader, Branigin Subacute Unit

- Clinical and administrative supervision of thirteen mental health technicians
- Training and consultation in agency for crisis interventions
- Developed programs of recovery and coordinated recovery efforts using a client-centered approach, motivational interviewing and stages of change.

1996-2005 Quinco Behavioral Health Systems: Lead Clinician, Clinical Supervisor, Crisis Clinician and State Hospital Liaison

- Clinical supervision to case management team
- Therapeutic, evidence-based interventions for outpatient
- Oversight of State Operated Facility admissions and discharges and clinical supervision of community reintegration.
- Development, including design and implementation of recovery group for young adults with severe mental illness group.

AWARDS AND RECOGNITIONS

April, 2010. The Jerry Powers Spirit of Inquiry Award for Excellence in Research. Received at the Annual PhD Spring Symposium (100th Anniversary), Indiana University School of Social Work, Indianapolis, IN.

LICENSURES AND CERTIFICATIONS

- Therapeutic Options Instructor, 2010-2013
- Licensed Clinical Social Worker, 2005-present
- Licensed Social Worker 2002-2005
- Certified Online Instructor, 2006
- Certified Crisis Prevention Trainer, 2006
- MSW Field Instruction Certification, 2003, 2004

PROFESSIONAL ORGANIZATIONS AND COMMITTEES

2008-2009 Student representative for the Social Work PhD committee
2000-2003 Staff representative to Stigmabusters, a consumer-led advocacy group
2008-2009 Chair, Forensic Subcommittee, Adult and Child Mental Health Center
1999-2006 National Association of Social Workers

JOURNAL PUBLICATIONS

Rollins, A. L., McGrew, J. H., Kukla, M., McGuire, A. B., Flanagan, M. E., Hunt, M. G., Leslie, D. L., Collins, L. A., **Wright-Berryman, J. L.**, Hicks, L. J., & Salyers, M. P. (2014, under review). Comparison of fidelity assessment methods: Reliability and validity. *Administration and Policy in Mental Health and Mental Health Services Research*.

Rollins, A.L., **Wright-Berryman, J.L.**, Henry, N.H., Quash, A.M., Benbow, K., Bonfils, K.A., Hedrick, H., Miller, A.P., Firmin, R., & Salyers, M.P. (2014, under review) Managing physical and mental health conditions: Consumer perspectives on integrated care. *Journal of Social Service Research*.

Wright-Berryman, J.L., Salyers, M.P., O'Halloran, J.P., Diazoni, A. & Mueser, K.T. (2013). Consumer and Provider Responses to a Computerized Version of the Illness Management and Recovery Program. *Psychiatric Rehabilitation Journal*, 36, 4.

McGrew, J., White, L., Stull, L., **Wright-Berryman, J.L.** (2013). A comparison of self-reported and phone-based fidelity for Assertive Community Treatment (ACT): A pilot study in Indiana. *Psychiatric Services*, 64, 3.

Wright-Berryman, J., McGuire, A., & Salyers, M. (2012). A review of consumer-provided services on Assertive Community Treatment and intensive case management teams: Implications for future research and practice. *Journal of the American Psychiatric Nurses Association*, 17, 1, 37-44.

PROFESSIONAL PRESENTATIONS

Wright-Berryman, J. (2012, April). *Inside Out: A social work classroom service learning experience*. Poster presentation at the 2012 PhD Spring Symposium, Indiana University School of Social Work. Indianapolis, Indiana.

Wright-Berryman, J. (2011, April). *A review of consumer provided services on Assertive Community Treatment and intensive case management teams: Implications for future research and practice*. Poster presentation at the 2011 PhD Spring Symposium, Indiana University School of Social work. Indianapolis, Indiana.

Wright-Berryman, J. (2010, April). *How do students' attitudes toward serious mental illness affect their perceptions of help-seeking behavior for first episode psychosis?* Poster presentation at the 2010 PhD Spring Symposium, Indiana University School of Social Work. Indianapolis, Indiana.

- Wright, J. (2009, June). *Knowledge and Skills for Effective Work with Forensically-Involved Consumers*. Presentation at the Assertive Community Treatment Conference, Washington, D.C.
- Wright, J. (2009, April). *Leaving Prison with Serious Mental Illness: A Case Study*. A poster presented at the PhD Spring Symposium, IU School of Social Work. Indianapolis, Indiana.
- Wright, J. (2009, April). *Leaving Prison with Serious Mental Illness: A Case Study*. A paper presented at the Mental Health in Corrections Conference, Kansas City, Missouri.
- Wright, J. (2008, June). *Stages of Change and Treatment*. Presentation at the National Mental Health Conference: Managing Mental Health from Corrections to Community, Indiana Department of Correction, Indianapolis, Indiana.
- Wright, J. (2008, May). *Knowledge and Skills for Work with Forensic Consumers*. Presentation at the Assertive Community Treatment Conference, ACT Association, Indianapolis, Indiana.
- Wright, J. (2004). *Strengths-Based Case Planning*. Presentation at the Bartholomew County Probation Department. Columbus, Indiana.
- Wright, J. , Bauermeister, K., & Beam, J. (2004). *Working Effectively with Transitional Age Youth*. Presentation at the Quinco Leadership Academy. Columbus, Indiana.

PROFESSIONAL DEVELOPMENT

Conferences and Workshops Attended

Structural Equation Modeling (August 2012). Gregory Hancock, University of Maryland. Indiana University Purdue University Indianapolis.

Therapeutic Options Instructor Certification Training (October 2010). Therapeutic Options, Inc., Philadelphia, Pennsylvania.

Mental Health Recovery: Practice, Services and Research. (October, 2010). New York University, New York City, New York.

ACTA National Conference. (June 2009). The Assertive Community Treatment Association National Conference. Washington, D.C.

National Mental Health in Corrections Conference. (July 2008). Indiana Department of Corrections. Indianapolis, IN.

ACTA National Conference. (June 2008). The Assertive Community Treatment Association National Conference. Indianapolis, IN.

Mental Health in Corrections Conference. (April 2008). Forest Institute of Psychology. St. Louis, MS.

Person-Centered Planning Train the Trainer. (June, 2007). Central Indiana Mental Health Initiative on Person-Centered Treatment Planning with National Trainers and Authors Neil Adams and Diane Grieder. Indianapolis, IN.

ACTA National Conference. (May 2007). Assertive Community Treatment Association National Conference. Grand Rapids, MI.

Crisis Prevention Institute Train the Trainer. (August, 2006). International Association of Nonviolent Crisis Intervention program for certified trainer. Indianapolis, IN.

Contributing work to grants and proposals

- State of Indiana Division of Mental Health and Addiction Illness Management and Recovery Proposal (2012, funded)
- SAMHSA Meaningful Use Primary Care Behavioral Healthcare Integration Health Information Technology (2011, funded)
- Center for Medicare Medicaid Services Innovative Healthcare Services (2011-2012, unfunded)
- Substance Abuse and Mental Health Services Administration (SAMHSA) Homelessness Grant (2010, unfunded)