

Spring 5-2020

## SHARED DECISION MAKING IN THE CARE OF POST-ACUTE PSYCHIATRIC INDIVIDUALS WITH SERIOUS MENTAL ILLNESS

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SHARED DECISION MAKING IN THE CARE OF POST-ACUTE PSYCHIATRIC  
INDIVIDUALS WITH

SERIOUS MENTAL ILLNESS

by

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DEAN, THE UNIVERSITY OF TEXAS  
SCHOOL OF PUBLIC HEALTH

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Natalie J. Maples, BS, MA, DrPH  
2020

## DEDICATION

This dissertation is dedicated to Eric Gilbert, Stefanie Martinez and Kelly Hamilton. I cannot thank you enough for your never-ending encouragement and support.

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INDIVIDUALS WITH SERIOUS MENTAL ILLNESS

by

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Presented to the Faculty of The University of Texas

School of Public Health

in Partial Fulfillment

of the Requirements

for the Degree of

DOCTOR OF PUBLIC HEALTH

THE UNIVERISTY OF TEXAS  
SCHOOL OF PUBLIC HEALTH

Houston, Texas  
May, 2020

## ACKNOWLEDGEMENTS

A special thanks to my advisor and dissertation chair Dr. Melissa Valerio-Shewmaker for the continuous support, patience, and guidance throughout my DrPH studies. I also want to thank committee members Dr. Eric Jones and Dr. Robert Morgan for their encouragement, insightful comments, and hard questions. I want to give immense thanks to my external reviewer, Dr. Erin Espinosa, for dedicating her time to reviewing my dissertation and providing thoughtful critique. Lastly, I want to acknowledge and thank my boss, mentor and close friend for over two decades, Dr. Dawn Velligan, for her valuable review and expert feedback.

# SHARED DECISION MAKING IN THE CARE OF POST-ACUTE PSYCHIATRIC INDIVIDUALS WITH SERIOUS MENTAL ILLNESS

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Severe mental illness in adults refers to a group of mental health conditions including schizophrenia and schizoaffective, bipolar and major depressive disorders. These conditions are often characterized by recurring symptoms, multiple hospitalizations, and significant disability. The public health concern with these conditions is amplified because many individuals with severe mental illness fail to engage in outpatient treatment. Methods to support greater rates of participation in outpatient treatment are needed. Encouraging participation in medical decision-making is viewed as one method to optimize patient empowerment, increase engagement in care and decrease the negative outcomes that often characterize this population. Shared Decision Making (SDM) is a collaborative and structured approach to patient-provider communication viewed as a negotiation between mutual experts with the goal of balancing empirical information with patient values and preferences.

This was a cross-sectional mixed methods study examining SDM in a sample of individuals with severe mental illness who have recently been discharged from emergency rooms and inpatient psychiatric facilities. Extant data on decision-making preferences and a variety of

clinical, demographic and communication variables were analyzed on 258 individuals with severe mental illness during a baseline visit at a transitional care clinic serving individuals immediately after hospital discharge. The association between clinical, demographic and communication characteristics and patients' self-reported decision-making preference (active, collaborative, or passive) were examined using chi square and one-way analyses of covariance. In addition, we conducted semi-structured qualitative interviews with 15 individuals with serious mental illness a variety of clinical providers ( $n = 9$ ).

Results from the quantitative analyses indicated that race/ethnicity was significantly associated with the SDM preference group, with African American individuals desiring more active participation in decision making compared to their Hispanic counterparts. Other characteristics were not significantly associated with the patient's baseline decision-making preferences in this context. Qualitative data were analyzed using latent thematic analysis and six themes were identified including: 1) Differences in the Use of SDM, 2) Consideration of Past Experiences, 3) Decisional Power Preferences, 4) Use of SDM in Psychiatry Versus Other Areas of Medicine, 5) Dignity and Disengagement, and 6) External Forces Impacting SDM. These findings indicate race/ethnicity may be an important factor when using a SDM approach. Implications for clinical practice and research using a SDM approach within this treatment setting are further discussed.



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## **BACKGROUND**

Engagement in mental health services following hospitalization is of critical importance for improving the lives of individuals with severe mental illness and reducing long term disability. In this manuscript, we describe the personal and societal costs of severe mental illness, models of care for this population, the importance of shared decision making in the treatment-engagement process, and the barriers and facilitators of shared decision making. Next, we propose a research project designed to better understand patient preferences for different types of decision making during encounters with prescribers and elucidate the process of shared decision making and treatment from the patient and prescriber-staff perspectives.

Severe mental illness in adults refers to a group of mental health disorders often defined by length of illness duration and the disability it produces. These illnesses include disorders that produce psychotic symptoms, such as schizophrenia and schizoaffective disorder, and severe forms of affective disorders, such as major depression and bipolar disorder (SAMHSA, 2016). It is estimated that 4.6% percent of the adult US population is diagnosed with one of these conditions at any given time (NIMH, 2016). Serious mental illness is one of the leading causes of disability worldwide according to the global burden of disease disability weights (Kessler et al, 2009; WHO, 2006). The course of this group of disorders is often characterized by recurring exacerbations and multiple hospitalizations (Moller, 1995). Additionally, recent literature reports people with serious mental illness die 10-20 years earlier than do those not suffering from this group of diseases (University of Oxford, 2014; Lund University, 2013); much of the excess mortality being due to physical illness. The comorbidity of medical illness in this population is well documented, including particularly elevated rates of diabetes mellitus (2-3 fold), metabolic

syndrome (1.5-2 fold), cardiovascular disease (2-3 fold) and viral diseases (5-11 fold), when compared to the general population (DeHert et al, 2011; Sokol et al, 2004).

The per patient lifetime burden of serious mental illness is estimated at \$1.85 million (Seabury et al, 2019). Services with the highest costs include hospitalization and emergency department visits. In an extensive review of psychiatric admissions to 418 U.S. community-based hospitals, it was determined that the three most common diagnoses included depression (27.8%), schizophrenia/schizoaffective disorder (19.5%) and bipolar disorder (19.4%; Stensland et al, 2012). These diagnoses are included in the broader category of serious mental illness. Typical psychiatric hospitalizations for the severely mentally ill last only a few days ( $\bar{x} = 4.4 - 11.1$ ; Stensland et al, 2012), leaving many individuals still experiencing severe psychiatric symptoms at the time of discharge. The recurring hospitalization and emergency care utilization as part of ongoing serious mental illness management coupled with an over-burdened outpatient mental health service care system (Mead, 2002) result in as many as one-half of these individuals failing to connect to sustained outpatient care (Boyer, 1997). This places patients at greater risk of numerous negative outcomes, including repeated emergency department visits and inpatient hospitalizations, homelessness, violence against others and suicide (Dixon et al, 2009; Fisher et al, 2008). According to Pasic and colleagues (2005), high utilization of hospital and emergency services points to a quality of care and access problems in outpatient care that must be addressed. To this effect, it has been suggested that these negative outcomes may decrease within the mental health population if patients have more involvement in psychiatric decision making (Kemp, 2011). Correspondingly, engagement in outpatient services may be enhanced with a higher level of patient empowerment within the patient-physician dyad (McCallister, 2016).

Poor long-term engagement in outpatient treatment contributes to psychiatric re-hospitalization and more frequent emergency department visits (Pasic et al, 2005). There is substantial evidence that psychiatry patients miss approximately 20% of ongoing treatment appointments, and nearly half of patients who miss an appointment drop out of care, leading to premature discontinuation rates in psychosocial treatment, as high as 82% (McMurrin, 2010; Mitchell, 2007; Wierzbicki, 1993). Specific to hospitalization data, Prince (2006) reports that patients who are not engaged in care (i.e. medication appointments) within three months of hospital or emergency department discharge, experience significantly higher re-hospitalization rates than patients who do participate in aftercare treatment (OR=6.9,  $p<0.001$ ). Moreover, medication non-adherence rates often exceed 50% in psychiatric samples (Velligan et al, 2006), with ethnic minorities and younger adults consistently less likely to take medications as prescribed (Rossom et al, 2016; Garcia et al, 2016; Lee et al, 2008).

The importance of treatment engagement and continuity of care between inpatient or emergency room facilities and outpatient services to prevent this revolving door phenomenon has been continually stressed (Mental Health America, 2010). Even minimal contact with aftercare treatment is associated with lower recidivism rates (Silva, 2009); conversely, delays seeking outpatient care following psychiatric hospitalization are linked to poorer outcomes (Prince 2006; Weiden, 2004). Based on these studies, the months immediately post-discharge appear critically important for implementing strategies to improve engagement in outpatient treatment. However, research on the best way to increase post-acute psychiatric patients' long-term engagement with mental health services is mixed and provides no clear direction for treatment improvement.

There is some suggestion from recent published literature on the general population that long-term engagement into outpatient treatment may be assisted by empowerment of the patient in decisions about their care within the patient-provider dyad (McCallister, 2016). Within the seriously mentally ill population specifically, various intervention approaches have been used to increase follow-through adherence to outpatient treatment (Roberts, 2011), but most methods do not emphasize the importance of patients participating in their own treatment decisions. Shared Decision making (SDM) is an exception. SDM is a structured approach to patient-provider communication in medicine that frames the interaction as a negotiation between mutual experts and stresses the balanced use of empirical information and patient preference in decision making (Charles, 1997).

There are few published large-scale studies of SDM in persons with serious mental illness. This lack of information results in a **knowledge gap in several areas**. Two of these gaps are addressed in this proposal.

1) There is little research examining how patient preferences for involvement in the process of treatment decisions with a prescriber relate to clinical and demographic characteristics. Furthermore, there is no published literature addressing how patients' clinical and demographic characteristics relate to their perceptions of the decision-making encounter. In addition, it is unclear how these clinical and demographic characteristics relate to discrepancies in how patients and prescribers view the encounter.



2) There is no published information regarding the feasibility of using an SDM approach in a post-acute psychiatric clinic. The perspectives of both patients receiving SDM and prescribers/staff functioning within this context have not been researched. These questions may be best addressed using in-depth interviews with those participating in the provider–patient interactions.

The specific aims of this study address these gaps and are listed below.

### **Specific Aims**

**Aim #1: Characterize the demographic and clinical differences between groups of patients who desire differing levels of involvement in psychiatric decision making.**

Use pre-existing data on 258 individuals with serious mental illness to characterize patient preferences for types of decision making using the Control Preference Scale into three groups (Active/Collaborative/Passive). Examine group differences on patient demographic and clinical variables, how patients view the initial encounter with prescribers, and the extent to which their view of the encounter differs from that of the prescriber.

**Aim #2: Identify the factors influencing the use of a shared decision-making model in post psychiatric crisis care delivery.**

Assess individual experiences with the shared decision-making model, barriers and facilitators of the approach, and the feasibility of using the model for care delivery from the perspective of prescribers, clinic administrators, therapists nursing staff and patients. This is accomplished via one-on-one interviews with fifteen patients, four prescribers, two therapists, one nurse and two

clinic administrators.

## **Literature Review**

### **Post Hospital Engagement in Care**

There are several models of post-hospitalization care presented in the literature. Dixon and colleagues (2009) use a brief intervention implemented for individuals with serious mental illness at time of hospital discharge focusing on assessing barriers to treatment and facilitating engagement in community-based services. This three month intervention increased show rates to outpatient medication appointments, although no effect was found on rehospitalization. In an older sample of 59 psychiatric inpatients, Kopelowicz (1998) found that patients with schizophrenia who participated in a re-entry program for one month post-discharge were significantly more likely to attend their first aftercare appointment. While one study associated the use of day treatment for individuals with schizophrenia with a significant reduction in future admissions (Kopelowicz, 1998), a review article of four randomized trials concluded there is insufficient evidence to deem such intense treatment effective within this population (Shek, 2010). Additionally, in a study on the use of medication management coordinators providing continuity of care procedures between inpatient and outpatient care for persons diagnosed with severe mental illness, survival curve analyses reveal those in active treatment attended outpatient appointments sooner in comparison to the control group, but no difference was found in time to next psychiatric hospitalization (Maples, 2012). These studies suggest there is no clearly effective strategy leading to improved engagement in outpatient treatment after hospitalization or to improved outcomes, indicating other options need to be investigated. Next, several models are explored to provide a foundation for potential intervention strategies.

## **Chronic Care Models and Framework**

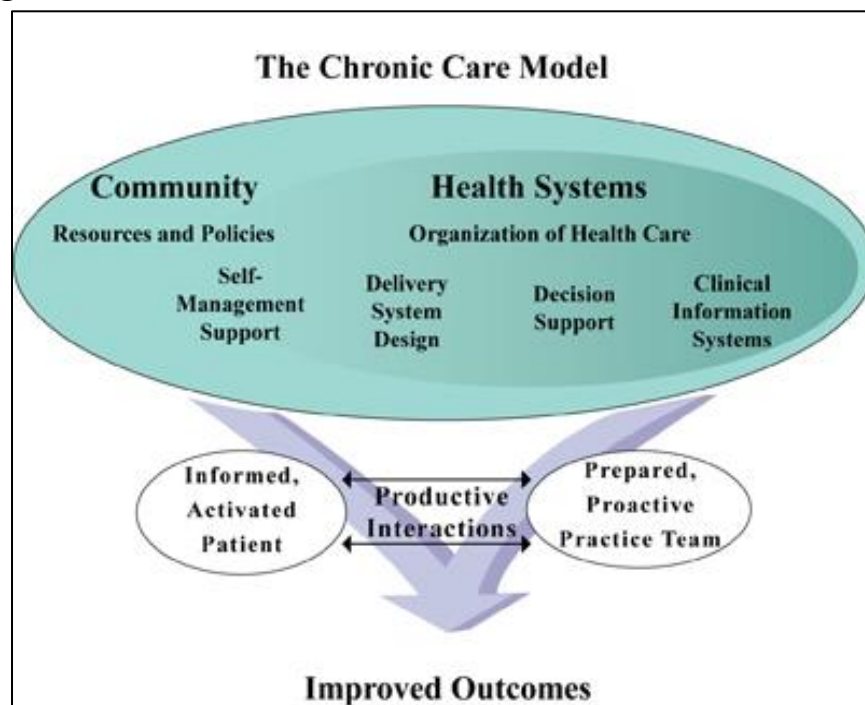
Drawing from the public health literature, we examined multiple models describing the management and delivery of chronic care. Models selected were based on the following parameters: 1) The relationship of the model to chronic relapsing conditions involving high service use and high cost, 2) The inclusion in the model of optimization of patient self-direction and outcomes and 3) The inclusion of a component of training and competency for the professional staff providing care. We excluded models (ecological, social-ecological and exposome) not addressing breaking the repeated cycle of rehospitalization often experienced in this group of illnesses and those without a focus on enhancing empowerment of the individual in treatment. The three models discussed in this proposal include, Wagner's Chronic Care Model, the Institute for Healthcare Improvement Triple Aim Framework and Mulley's Conceptual Framework for Shared Decision making. These models have primarily been discussed with respect to physical illness but remain relevant to severe and persistent mental health disorders as explained below.

### **Wagner's Chronic Care Model**

In a review article by Wagner et al (1996), the authors stress the need for integrated, patient-centered care for chronic illness. Wagner's model (Figure 1) emphasizes that patients be actively involved in their own care, and also emphasizes practice redesign, ongoing education for providers, and meaningful use of information systems (Wagner et al, 1999). This transformative model of health care delivery addresses how to overcome the following deficiencies: practitioners being rushed, a lack of care coordination, the lack of active follow-up, and patients being inadequately trained to manage their illness (Wagner et al, 1996). As seen in Figure 1,

changes in both the community and in the health system itself can lead to a more informed and activated patient, in addition to a more prepared and proactive practice team--with improved outcomes being the primary goal. As seen in the model, changes within the community and the health system that promote access, communication across agencies and patient education must occur together to reach the overall goal of improved patient outcomes. While Wagner's model pertains to the health industry in general, these same principles may apply to the treatment settings of individuals with serious mental illness. Given the information previously presented on comorbidity between serious mental illness and physical health diagnoses—including the increased morbidity and mortality rates—the application for more integrated care, the redesign of practice, and meaningful use of information systems is necessitated in treating this chronically ill population.

**Figure 1. Wagner's Chronic Care Model**

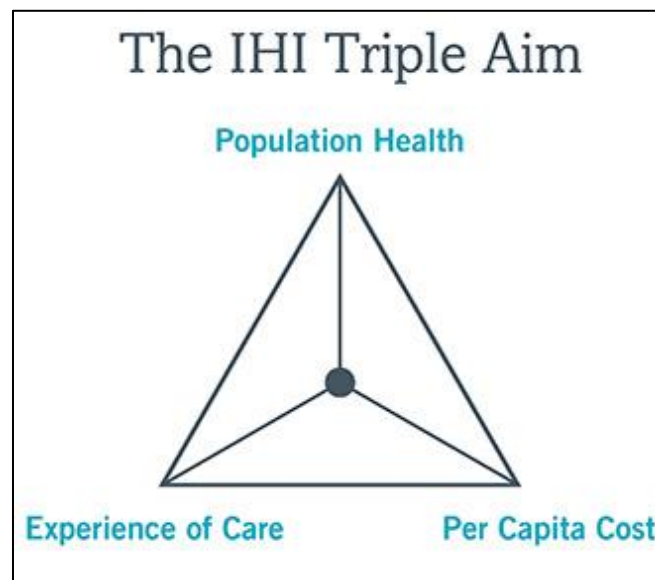


Source: Wagner EH, 1998

## **Institute for Healthcare Improvement Triple Aim Framework**

The Institute for Healthcare Improvement's (IHI) Triple Aim is a framework describing an approach to optimizing health system performance. The Triple Aim consists of: 1) Improving the patient experience of care (including quality and satisfaction), 2) Improving the health of populations; and 3) Reducing the per capita cost of health care (Berwick et al, 2008). These three aims can be seen in Figure 2, a simple yet notable plea for designing healthcare systems. A shared decision-making approach within the seriously mentally ill population is relevant to all three of the Aims outlined in the model. Shared decision making has been found to improve the patient's experience of care by encouraging providers to present more treatment options and involving patients to a greater extent in decisions. This can have an important impact on early engagement in treatment and promoting satisfaction with care. This may help to increase appointment adherence which is often a problem in providing services for this population. Expediting individuals into care immediately following an acute psychiatric exacerbation and engaging them in the decision making process is likely to improve health outcomes and reduce healthcare costs. Most importantly, this framework calls for efforts to improve care and close the treatment gap for individuals with serious mental illness across a variety of settings; an unified behavioral health strategy which includes the patient in helping direct their own care is essential to achieve the Triple Aim.

**Figure 2. The Institute of Healthcare Improvement's Triple Aim**



**Source:** Institute for Healthcare Improvement, 2020

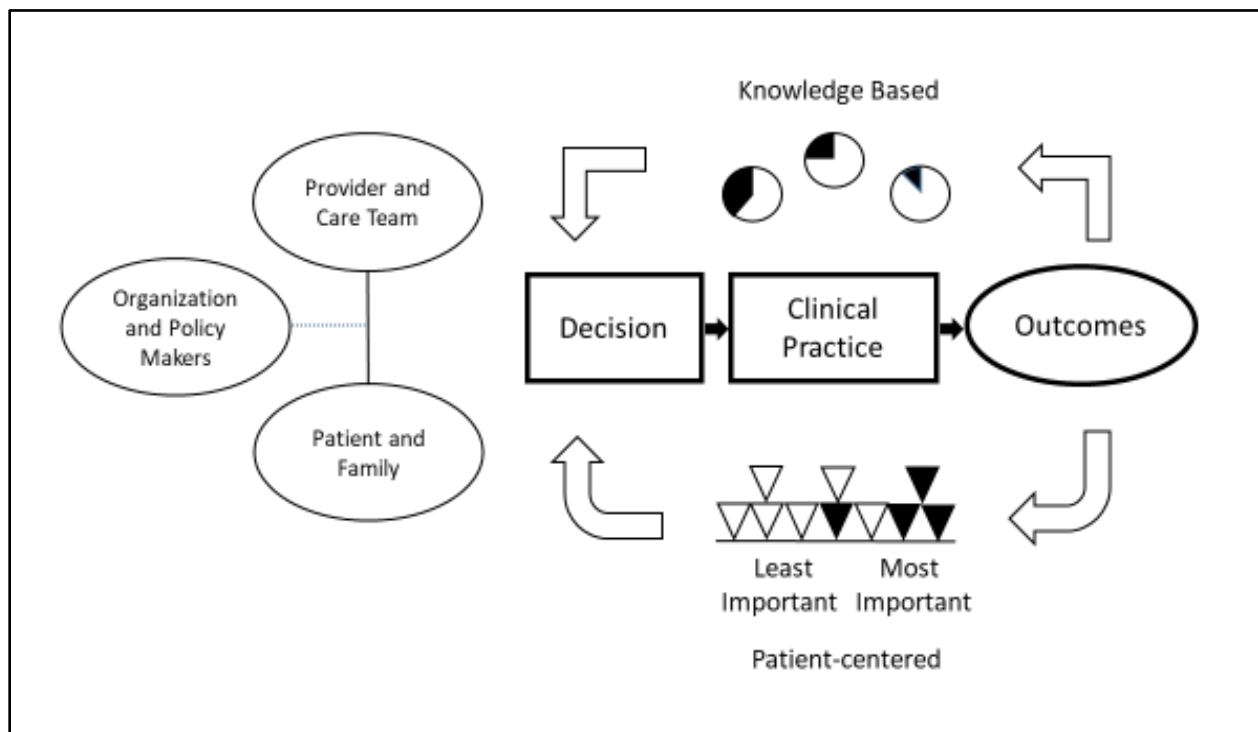
### **Mulley's Conceptual Framework for Shared Decision Making**

The concept of shared decision making is previously and briefly mentioned in this dissertation proposal. The model presented here (Figure 3) is the original published by Mulley (1990) with a target audience of primary medicine. As described by Mulley (1990), SDM is a systems approach to enable continuous improvement in clinical decision making. The model focuses on two key participants, the patient and provider. There is a fundamental social nature in the decision-making task that cannot be completed by the doctor or patient alone, but rather requires productive interactions (and communication) between them. The model focuses on three types of events. First, decisions – the selection of treatment based on patients' well-informed preferences for health outcomes. Second, clinical practice – where the treatment is implemented. Third, health outcomes – the expected result of treatments. The model includes two major feedback loops to indicate how learning occurs in the system. The top loop feeds knowledge about the likelihood of outcomes to providers to promote evidence-based medicine. The bottom

loop feeds knowledge about the patient's subjective assessment of experiences with those outcomes back to the point of decision making to support more informed choices.

In this shared decision-making model, prescribers are primarily responsible for knowing and appropriately applying the knowledge base. Patients are primarily responsible for contributing well-informed subjective assessments of possible health states relevant to decisions and for reporting outcomes and experiences with and assessment of these health states. The responsibility on key participants is high, but also at the center of success in such a model. The complexity and responsibilities required raise questions as to appropriateness for application within a post-acute psychiatric population. However, the three concepts postulated – decisions, clinical practice and health outcomes, certainly remain relevant whether in a mental or physical health population. Additionally, current clinical practice guidelines advocate for all clinicians, regardless of public health sector, to involve clients in decision making processes and allow for client preferences, along with the evidence, to guide decisions where possible. This model provides the opportunity to optimize patient self-direction in mental health treatment and outcomes.

**Figure 3. Mulley's Conceptual Framework for Shared Decision Making**



Source: Sepucha and Mulley, 2009

In conclusion, the frameworks presented in this literature review are all consistent with the mission of The Center for Medicare and Medicaid Innovation for **improved care delivery systems**, as part of the Affordable Care Act (Shrank, 2013; Barr et al, 2010). However, they simultaneously raise questions on applicability and achievability of several synchronous complex processes needed to achieve better outcomes for patients. Next, a body of literature is presented on shared decision making, the principal subject for the remainder of this proposal.

### **Shared Decision Making**

Research suggests that long term engagement into outpatient treatment may be assisted by empowerment of the patient in decisions about their care within the patient-provider dyad. Patients who feel they are playing an active role in their treatment typically have better



engagement and outcomes than patients who experience themselves as passive recipients of care (Greenfield, 1988; Seeman 1983; Stewart 2001). Unfortunately, across diagnoses and conditions, patients more typically engage with providers in a passive manner (Britten, 2000; Towle, 2003), and lack of engagement is related to poor adherence with prescribed regimens. Poor adherence has severe consequences for individuals immediately following hospitalization or crisis care, often leading to recidivism and decreased quality of life (Velligan, 2009).

Although various intervention approaches have been used to increase follow-through adherence to outpatient treatment in serious mental illness (Roberts, 2011), most methods do not emphasize the importance of patients participating in their own treatment decisions. Shared Decision making is an exception. SDM is a structured approach to communication in medicine that frames the interaction as a negotiation between mutual experts (patient and provider) and stresses the balanced use of empirical information and patient preference in decision making (Charles, 1997). Within the physical medicine field, there is substantial evidence that SDM increases patient participation in and adherence to treatment and may decrease adverse events and unnecessary procedures (Dowell, 2007; Stewart, 1995; Wennberg, 2007). SDM also appears to increase patients' knowledge about and realistic understanding of the targeted illness (Auerbach, 2001). SDM is compatible with evidence-based medicine in its emphasis on the use of empirical information to make treatment decisions (Guyatt, 2001), and with the serious mental illness consumer recovery movement in its emphasis on patient-centered care (Drake, 2010).

SDM is well operationalized, with specific components and clinician competencies detailed in the literature (Campbell, 2007; Elwyn, 2005). SDM coaching is an approach where clinical staff,

following standard SDM concepts, help empower patients with the goal to enhance patient communication skills, knowledge and options for communication with their prescribers. Coaching visits occur prior to the medication appointment and are one-on-one meetings that address patients' treatment and diagnosis questions, informational needs, goals, medication concerns and strategies for communication. In light of the research on chronic care presented above, SDM may be effective with chronic conditions, such as psychiatric illness, because the focus of SDM is to help the individual be a more educated and involved consumer of health services, with the inherent opportunity to direct more of their own care.

### **Barriers to SDM Implementation with Serious Mental Illness**

Despite the apparent promise of SDM, there is a low level of adoption and implementation of this practice within the delivery of mental health care, relative to other areas of medicine. The delivery of mental health services remains for the most part a provider-dominated decision-making climate, reflecting poor uptake of this practice (Curtis, 2010; Shumway, 2003). Possible reasons for the insufficient adoption of SDM within this population are further explained. Table 1 summarizes barriers to SDM implementation and dissemination in the seriously mentally ill population. These factors are further illuminated below.

**Table 1. Summary of Potential Barriers to SDM Implementation in Seriously Mentally Ill Population**

Summary of Potential Barriers to SDM Implementation in Seriously Mentally Ill Population	
Prescriber/Systemic Factors	<ul style="list-style-type: none"> <li>• Overworked physicians</li> <li>• Insufficient provider training/knowledge in SDM</li> <li>• Deficient medical information systems</li> </ul>

	<ul style="list-style-type: none"> <li>• Physician time constraints</li> <li>• Lack of applicability to population</li> <li>• Inappropriate clinical situation (i.e. crisis clinic)</li> </ul>
Patient Factors	<ul style="list-style-type: none"> <li>• Mixed opinions on amount of involvement in decision process</li> <li>• Patient perceptions of clinician failures at using SDM</li> <li>• Inability of patient to accurately articulate information (Possible need for decision support aids)</li> </ul>
Illness/Symptom Factors	<ul style="list-style-type: none"> <li>• SDM participation requires higher cognitive load</li> <li>• Persons with serious mental illness may suffer from cognitive impairment or judgment difficulties</li> <li>• Depression makes decision making more difficult</li> <li>• Mania may lower the threshold for risk tolerance</li> <li>• Schizophrenia may lead to passive acceptance (i.e. apathy) or rigid non-compliance (i.e. paranoid delusion)</li> </ul>

### Prescriber/Systemic Factors

It is difficult to separate prescriber and systemic barriers to SDM implementation as they appear to be integrally intertwined. Efforts to increase patient involvement in decisions about their care face barriers such as overworked physicians, insufficient provider training, deficient medical information systems, physician time constraints, a deemed lack of applicability due to patient characteristics and inappropriate clinical situations (Legare, 2008; Towle, 2006). From the standpoint of efficiency, when SDM is used in prescriber-patient interactions, visits are perceived by prescribers to take more time than does a standard psychiatry appointment (Burton, 2010)—and doctors cite this as one factor that limits their use of SDM (Legare, 2008; Towle, 2006). While the need for SDM content varies in each prescriber-patient appointment (i.e. patient experiencing side effects or is decompensating versus no complaints), all prescriber-patient interactions should include some component of SDM when following the model correctly. As

physicians use SDM only about 10% of the time (Braddock, 1997; Elwyn, 2003), efficiency appears to be an important perceived obstacle to the feasibility and dissemination of SDM.

Despite a desire to know more about their diagnosis, treatment options and side effects (Beisecker, 1990; Degner, 1997), psychiatric patients report that prescribers often do not provide sufficient information or explain it in an understandable manner (Garfield, 2004). A large interview-based study on perceived obstacles and needs in providing SDM in public mental health corroborated this patient perspective, concluding that mental health providers require additional training in effective patient communication—above and beyond the kind of training they receive for other chronic and acute physical health conditions (Mahone, 2011).

### Patient Factors

There are mixed reviews on patients' desires for more information on care options and amount of involvement in the medical decision-making process (Legare, 2008, Legare, 2006). During a baseline office interview in the general (non-psychiatric) population, one study found 25% of patients want an active role where they are primarily responsible for the decision, 53% want a collaborative role and 21% want a passive role that gives the prescriber more power in the decision making process. Additionally, Mahone (2011) suggests that in addition to the need for more provider training, patients' perceptions of clinician failures at using SDM may be due in part to illness-related information processing deficits in the patient, recommending increased training for patients in articulating their expert information during treatment sessions. To aid in information exchange and knowledge building, reviews of SDM in mental health have called for

the use of decision support aids and other scaffolding techniques to support patient preferences in decisions about their care (Deegan, 2006).

### Illness/Symptom Factors

In addition to prescriber, systemic and patient factors, symptoms that typically accompany serious mental illness cause concerns about patients' abilities to fully participate in SDM. SDM requires a certain amount of cognitive capacity to understand treatment options and weigh their pros and cons against one's own preferences. Many individuals with serious mental illness suffer from cognitive impairments that may hinder their ability to complete this complex cognitive processing. Further, some psychiatric conditions specifically affect judgment and decision making, calling into question the decisional capacity of psychiatric patients to make informed decisions about their care (Appelbaum, 2006; Hamann, 2003). Additionally, depression makes decision making more difficult; mania may lower the threshold for risk tolerance; schizophrenia may alternately lead to passive acceptance or to rigid adherence to one idea (Moritz, 2006), such as a paranoid fear regarding medication.

### **Strengths of SDM Implementation in Serious Mental Illness**

While there are obvious barriers to SDM implementation, SDM has many strengths and evidence supports the use such an approach for those with serious mental illness. Table 2 summarizes these strengths and the information is expanded on below.

**Table 2. Summary of Strengths to SDM Implementation in Seriously Mentally Ill Population**

Summary of Strengths to SDM Implementation in Seriously Mentally Ill Population
---

Prescriber/Systemic Factors	<ul style="list-style-type: none"> <li>• Support through the New Freedom Commission on Mental Health and other government policy reports</li> <li>• High incidence of patient non-adherence, partially due to dissatisfaction</li> <li>• For rational/purposeful medication non-compliance, SDM may constitute a reasonable approach to remaining engaged in care while continually re-evaluating the potential role of medication</li> <li>• SDM represents a non-threatening approach for prescribers to clarify motivation</li> </ul>
Patient Factors	<ul style="list-style-type: none"> <li>• Reports reveal nearly 90% of patients want information on diagnosis, treatment options and side effects</li> <li>• Specific demographic factors may contribute to patients' preference to play a more active role in decision making</li> <li>• Patient experience and knowledge of illness, type of decision needed and attitude towards involvement affect desire to be active in decisions and care</li> </ul>
Illness/Symptom Factors	<ul style="list-style-type: none"> <li>• Evidence that persons with serious mental illness frequently make competent and prudent treatment decisions</li> <li>• Medication taking is often part of a deliberate self-care plan</li> <li>• Persons with serious mental illness express a strong desire to be informed about illness and treatment options</li> </ul>

### Systemic Factors

Research on SDM in psychiatry has received support through the New Freedom Commission on Mental Health (New Freedom Commission, 2003), and other recent government policy reports (Institute in Medicine, 2001; IoM, 2005). SDM may be of particular benefit in serious mental illness because of the high incidence of patient non-adherence with treatment due to factors including dissatisfaction with side effects from antipsychotic and mood stabilizing medications, poor insight into illness and functional and motivational impairments. Competent

adults with serious mental illness sometimes choose to decline medication and suffer symptoms rather than endure side effects, or to limit their use to periods of symptom exacerbation (Donovan, 1992; Angermeyer, 2001). For these patients, SDM may constitute a reasonable approach to remaining engaged with care providers and take advantage of treatment options such as case management and/or alternative medications and psychotherapy, while continually re-evaluating the potential role of antipsychotic medication. For patients with poor insight or functional impairment, SDM represents a non-threatening approach to clarifying motivations and options for improving quality of life.

### Patient Factors

In surveys, nearly 90% of patients in the general population want information on their diagnosis, treatment options and side effects (Beisecker, 1990; Degner, 1997). However, it is unknown whether this preference translates to those with severe mental illness, especially to those experiencing an acute psychiatric exacerbation. In a 2006 review of patients' preferences for involvement in decision making, Say et al (2006) report demographic variables, including being younger, better educated and female were consistently found to be associated with a preference for a more active role in decision making. The authors add that patient experience of illness, the type of decision they need to make, the amount of knowledge they have acquired about their illness and their attitude towards involvement, also affect desire to be involved in care.

### Illness/Symptom Factors

Contradicting the risks related to symptomatology, there is evidence that adults with serious mental illness frequently make competent and prudent treatment decisions (Grisso, 1995; MacDonald et al, 2017). For example, a study of medication decision making in schizophrenia found that nearly 87% of patients prescribed injectable (depot) antipsychotics chose to continue (Bunn, 1997). In a large study of patient self-care in serious mental illness, when patients made firm decisions about whether or not to take medication they typically did so as part of a deliberate self-care plan. Also, despite frequent behavioral passivity, patients with serious mental illness express a strong desire to be informed about their illness and treatment options, and to be active participants in their treatment decisions (Adams, 2007; Arora, 2000; De las Cuevas, 2001).

## **Feasibility**

While few large-scale studies exist on the use of SDM within the seriously mentally ill population, at least two studies demonstrate promise. A trial that provided a medication decision aid and coaching for communication with doctors to inpatients diagnosed with schizophrenia (N=107) found that the intervention was feasible and well tolerated by patients and was associated with a trend toward decreased rehospitalization (Deegan, 2006). A second inpatient trial (Hamman, 2011) randomized patients with schizophrenia or schizoaffective disorder to either an SDM intervention (N=32) or cognitive training (N=29). The SDM intervention comprised five sessions addressing motivation for decision making participation and role-play practice to improve communication skill. SDM was found to be feasible and was associated with increased desire for participation in treatment decisions relative to cognitive training, a finding that remained at six-month follow-up.



In summary, there is a body of evidence in the published literature on shared decision making. Despite promising data on the use of SDM, the uptake of this practice is poor within services provided to the seriously mentally ill population. A better understanding of the factors related to shared decision-making styles in different patients and issues related to its implementation may be critical to maximizing individual patient outcomes. Currently, there is insufficient evidence on how much involvement severely ill psychiatric patients desire to have in their patient-provider interactions regarding psychiatric decisions. While previous studies have found factors such as age and gender to impact the desired level of involvement in care, it is unclear if these results translate to the population of individuals with severe mental illness. Moreover, there is no evidence to date on how factors such as the level of psychiatric symptomatology, level of insight and ethnicity are related to patient's desire to participate in treatment. Furthermore, little is known about the opinions of those engaging in SDM within a post-acute psychiatric clinic and how these beliefs by patients or providers may hinder or facilitate the uptake of SDM within this population. This lack of information results in a gap in the current knowledge base on the viability of SDM usage within this population and a post-acute psychiatric clinic.

### **Public Health Significance**

Specific to mental health, The President's New Freedom Commission (PNFC) on Mental Health identified patient-directed care as one method of service delivery that could improve the quality and outcomes of mental health (PNFC, 2003). The Commission called for nothing short of fundamental transformation of the mental health care delivery system in the United States, from one dictated by bureaucratic and financial incentives to one driven by consumer and family

needs that focuses on building resilience and facilitating recovery. In its October 29, 2002, Interim Report to the President, the Commission declared that the mental health service delivery system must be robust and responsive to consumers' needs because its failings may lead to "unnecessary and costly disability, homelessness, school failure and incarceration." The report points out that mental illnesses and emotional disturbances are treatable, and that recovery should be the expectation. Successfully transforming the mental health service delivery system to promote recovery hinges on treatments that are consumer driven. Finally, the report underscores the importance of giving consumers real and meaningful choices about treatment options.

Based on the body of research presented throughout, methods of increasing patient engagement that incorporate treatments driven by the consumer are of national public health significance. A myriad of poor patient outcomes coupled with high financial costs for those diagnosed with serious mental illness promote research on the barriers, facilitators and feasibility of novel interventions in this population, including patient-level factors surrounding treatment involvement. Research supports the promise of SDM for enhancing engagement in post-acute treatment despite multiple levels of barriers. SDM interventions appear to be feasible yet more research is needed to empirically determine provider and patient opinions and feasibility in adopting these practices into a post-acute psychiatric crisis setting. Additionally, research on how patient preferences in decision making during the provider-patient dyad affect satisfaction with communication and care delivery will advance the practice of SDM in the seriously mentally ill population.

## **Objectives**

The overall objectives of this study are to investigate the association between the patient's level of desire to participate in treatment decisions and demographic/clinical factors including, ethnicity, and degree of symptomatology and insight. The study also examines how initial preference for decision-making style relates to how the initial visit with the prescriber is perceived by both the patient and the prescriber. In addition, qualitative data on the use of a shared decision-making approach during post-acute psychiatric medication appointments is obtained. This study explores multi-level staff and patient opinions on the barriers, facilitators and feasibility of using shared decision making within a clinic setting, information not currently found in the published literature. In this effort, the study addresses the gap in research regarding the use of shared decision making within a seriously mentally ill population receiving post-acute psychiatric care.

## **Conceptual Model**

Following the review of the literature, a conceptual model (Figure 4) was created to inform the proposed research that incorporates prior conditions and new research to complete Aims 1 and 2. Within the model, assumed components of SDM include prescriber training, SDM coaching, equality within the patient-prescriber dyad and patient-centered care. Other prior conditions include the knowledge base presented in the literature review on both barriers and strengths to SDM implementation. In Figure 4, the lower portion of this study's conceptual model focuses on new research including all data gathered from qualitative interviews and existing quantitative data. The conceptual model also includes possible outcomes gleaned from the data analysis. The model additionally incorporates constructs from the chronic care models

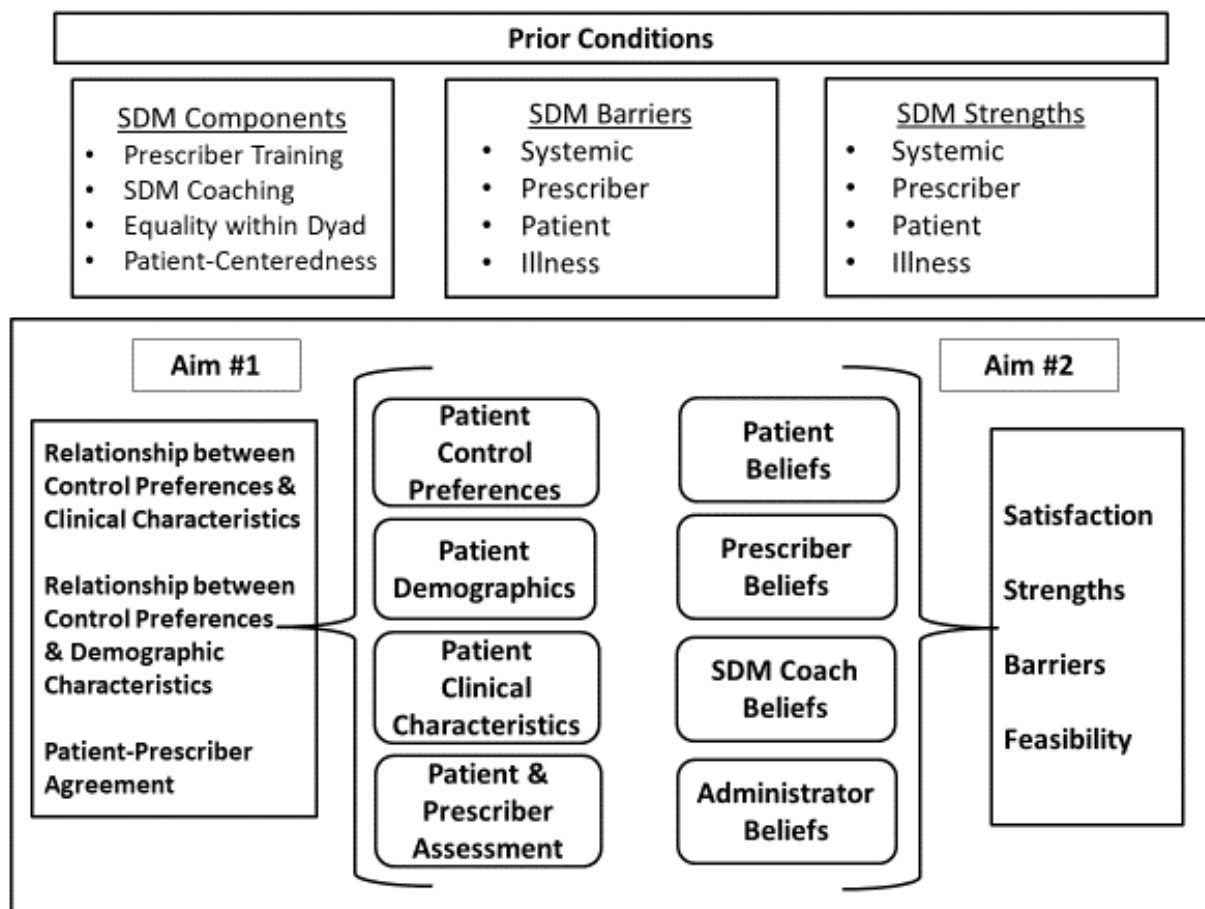
previously presented and elements of the SDM literature review. Details specific to Aim 1 and Aim 2 are further explained.

For Aim 1, previous literature reports data on the extent to which patients desire involvement in their own care and how this preference is related to age and gender. However, studies in the general population have been inconsistent with respect to these relationships. Additionally, it is unclear how these relationships will translate to an acutely mentally ill population. Moreover, there is little information on patient-prescriber agreement on communication during SDM medication visits and how this may relate to patient preferences or demographic characteristics. These are included in this study's conceptual model (Figure 4) and will be addressed in the quantitative portion of this study.

Regarding Aim 2, all three conceptual frameworks emphasize the need for patients to be actively involved in their own care. Wagner (1996) and Mulley (1990) specifically advocate for patient and provider education on treatment options. As part of clinic procedures, patients are provided SDM coaching, consisting of help to empower patients with the goal of enhancing patient communication skills, knowledge and options for communication with their prescribers. Clinic staff was trained in SDM practices including respect for the patient, equality within the dyad and patient-centeredness. These key communication skill-building components also align with the IHI and Mulley's (1990) recommendations to improve patient experiences, increase the exchange of information, and help empower the patient to be more involved in their own treatment decisions. Through the qualitative interviews (Aim 2), the concepts endorsed by previous medical frameworks will be investigated within a post-acute psychiatric population to

help improve the current knowledge gap within this population. Time and resources associated with the delivery of SDM will also be explored in the qualitative interview portion of this study addressing the IHI construct of cost of healthcare and a possible barrier to SDM implementation.

**Figure 4. Conceptual Model of using Shared Decision making in Post-Acute Psychiatric Clinic**



## METHODS

### Study Design

This was a cross-sectional mixed methods study examining shared decision making in a

sample of individuals with severe mental illness who have recently been discharged from emergency rooms and inpatient psychiatric facilities. The specific aims were as follows:

**Aim #1: Characterize the demographic and clinical differences between groups of patients who desire differing levels of involvement in psychiatric decision making.**

**Aim #2: Identify the factors influencing the use of a shared decision-making model in post psychiatric crisis care delivery.**

### **Study Site**

The study site was a Transitional Care Clinic funded by an 1115 Medicaid Waiver, area hospitals and charitable organizations. Participants in the study were drawn from a convenience sample who participated in a research study examining outcomes in engagement-focused care versus usual care between the years of 2014 and 2016 (Patient-Centered Outcomes Research Institute (PCORI); Contract number: IH-1304-6506) as well as a de novo sample of individuals actively receiving treatment at The Transitional Care Clinic. The clinic provides a wide range of services including medication management, evidence-based psychotherapy and case management. All clinic prescribers were trained in utilization of SDM within a patient-prescriber dyad and general SDM practices for prior to data collection for the original parent study.

### **Sample**

Aim 1 for the current was based on quantitative data collected at baseline as part of the

original parent study, but not analyzed to examine the questions proposed here. Aim 2 required the de novo collection and examination of qualitative interview data from current patient and clinic staff populations at the Transitional Care Clinic. These interviews were not part of the original trial but added by the PI (Maples) to enhance understanding of the main trial results. All aims for this dissertation are fully different than those of the original research study.

The quantitative patient sample included a convenience sample of 258 individuals with severe mental illness who attended post-acute psychiatric hospitalization appointments at The Transitional Care Clinic during the original study. Severe mental illness was defined as DSM5 primary diagnosis of schizophrenia, schizoaffective disorder, bipolar disorder, depression, unspecified psychosis and unspecified mood disorder were included. Due to the nature of this being the first clinic visit, some providers used an unspecified diagnostic category until more information regarding history and symptoms were clearer. Severe mental illness, rather than clinical diagnosis, defined the study population as research demonstrates that diagnosis is often unreliable and unstable over time and is a poor predictor of clinical outcomes (Cuthbert et al. 2013). By virtue of their acceptance into this clinic, participants are over 18 years of age, have been recently discharged from an inpatient psychiatric unit or triaged from an emergency room, and received a diagnosis of severe mental illness. and a diagnosis of severe mental illness as defined above.

The patient sample for key informant interviews (Aim 2) was recruited at The Transitional Care Clinic. Trained clinic staff approached patients during routine medication visits at the clinic to obtain initial verbal consent allowing the PI contact them regarding the study.

The PI followed up to provide a full description of the study protocol and procedures. If the individual agreed to participate, they were invited to partake in an interview at a time and date convenient to them. All interviews were completed at the clinic.

Qualitative interviews were also conducted with clinic staff. Additional key informants interviewed included clinic administrators, therapists, nursing staff and prescribers. Prescribers included a mixture of three psychiatrists and one nurse practitioner. These clinic staff were approached via email by the PI and asked of their interest to participate in the study. If interested, the PI proceeded with a review of the study and scheduling the qualitative interview. Study participation was voluntary and did not impact the person's employment status or annual evaluation. Interviewed staff were not supervised or under any authority of the PI.

For patient interviews, sampling was deemed to reach saturation at 15 patients, or the point to which we had achieved informational redundancy. That is, no new information or themes were emerging from the data (Patton, 2002). Simple random sampling was used to identify a patient subset. There were approximately 300 eligible participants weekly with a diagnosis of severe mental illness seeking treatment at the transitional care clinic. A random digit was generated and clinic staff approached every fifth person based on the generated number. Staff continued to approach incoming patients until the desired number of 15 consented and interviewed subjects was obtained.

Staff interviews were conducted with four prescribers (three psychiatrists, and one nurse practitioner), two therapists, one nurse and two clinic administrators following a semi-structured



qualitative interview. All pertinent clinic staff were approached to participate in the interview. All approached staff agreed to the interview. The proposed staff sample size was small, due entirely to the number of employed staff members involved in patient treatment, but saturation was still reached with no new themes emerging after the ninth interview.

## **Quantitative Assessments**

**Demographic Data:** Patient level demographic data available for the quantitative analyses included age (at time of baseline medication appointment), ethnicity, gender and diagnosis at time of first clinic appointment.

In the quantitative portion of this study, we examined patient demographic and clinical characteristics at baseline in relation to the level of control an individual reported wanting to assume when decisions were being made about medical treatment. We additionally examined patient and prescriber quantitative ratings of prescribers' in-session communication gathered after each baseline medication visit. Specific quantitative measures are described below.

**Control Preferences Scale (CPS).** Patient preference for participation in SDM is an important potential moderator because not all patients wanted to play an active role in their treatment decisions. This domain is measured with the Control Preferences Scale (CPS; Degner et al, 1997; Appendices A & B). The control preferences construct is defined as "the degree of control an individual wants to assume when decisions are being made about medical treatment" (Degner et al, 1997). This scale presents patients with five cards that each present a statement describing a different role in decision making. Statements include: (A) I prefer to make decisions about which treatment I receive; (B) I prefer to make the final decision about my treatment after

seriously considering my doctor's opinion; (C) I prefer that my doctor and I share responsibility about which treatment is best for me; (D) I prefer that my doctor make the final decision about which treatment will be used but seriously consider my opinion; (E) I prefer to leave all decisions regarding my treatment to my doctor. Cards were presented to the patient in pairs in a pre-specified order (B, D, C, A, and E) until the five statements are rank ordered. This assessment took approximately five minutes to complete. Sorting produced six different possible categorizations of how involved patients wanted to be in decisions. These included: 1) Active-Active, 2) Active-Collaborative, 3) Collaborative-Active 4) Collaborative-Passive 5) Passive-Collaborative and 6) Passive-Passive (Appendix A). Note that all control preferences data had already been collected as part of the original study. For the purposes of the current study, we collapsed the six classifications into three: Active (Category 1-2), Collaborative (Categories 3-4), and Passive (Categories 5-6).

The CPS is the most frequently used measure of patients' preference for different levels of control in medical treatment decisions. The psychometric properties of the CPS have been established across a variety of medical and behavioral health conditions and across languages and cultures. The measure is reliable across time and observer, has moderate internal consistency; and good convergent validity (Degner et al, 1997; De las Cuevas & Peñate, 2016; Singh et al, 2010, Garfield et al, 2007).

**Matched Pair Instrument (MPI).** Patient and prescriber ratings of prescribers' in-session communication was obtained using the Matched Pair Instrument (MPI; Campbell et al, 2007; Appendices C & D), a dyadic instrument comprised of 19 statements that assess the

content and process of a prescriber's communication skills from each patient's perspective. Each skill on the MPI is rated on a 5-point scale with higher scores indicating stronger agreement with the statement. The prescriber and patient completed a version immediately following the encounter. A total score for each participant is derived. In addition, a difference score between provider and patient ratings was calculated. The absolute value of this score reflected the average distance between patients and providers in their perceptions of communication during the session. Campbell et al (2007) demonstrate good internal consistency and reliability of this scale over time and a systematic review of 20 measures of physician-patient communication evaluated the psychometric properties of the MPI as similar to other instruments assessing this construct. However, the review recommended further psychometric testing for all of the instruments reviewed. In part, the MPI was chosen over other possibilities due to the evaluation of the advisory board for the transitional care clinic. They recommended the MPI as being relatively simple for patients to complete and having high acceptability.

**Expanded Brief Psychiatric Rating Scale (BPRS).** The Expanded Brief Psychiatric Rating Scale (BPRS) was used to characterize psychiatric symptoms amongst patients the (Ventura et al, 1993; Appendix E). This scale is a 24-item interview-based measure that captures a range of psychiatric symptoms rated on 7-point Likert scales, with higher scores indicating more severe symptomatology. This scale is summed to yield a total score and four factor scores (agitation-mania, depression-anxiety, positive symptoms, and negative symptoms; Appendix F). Positive symptoms refer to an excess or distortion of normal function. Examples include hallucinations and delusions. Negative symptoms refer to a decrease or absence of normal function. Examples include lack of/reduced emotion, loss of interest and apathy. The reliability

of BPRS over time and across raters has been established over decades of use (Ventura et al, 1993). The instrument has been validated across a variety of languages and cultures (Shafer et al, 2017). In addition, the measure is sensitive to change in treatment and correlates with global measures of psychopathology such as the Clinical Global Impression (Leucht et al., 2006).

**Scale to Assess Unawareness of Mental Disorders (SUMD).** The abridged version of the Scale to Assess Unawareness of Mental Disorders (SUMD; Amador et al, 1994; Appendix G) was used to measure patient insight into having a psychiatric illness. This semi-structured open interview evaluates three items including global insight, insight into illness and insight into symptoms on a 5-point Likert scale with higher scores indicating lower insight. The SUMD is widely used in clinical trials and epidemiological studies and the abbreviated version has demonstrated good internal consistency and external validity (Michel et al, 2013).

## **Qualitative Assessments**

We conducted semi structured open-ended interviews with both clinic staff and current patients attending The Transitional Care Clinic.

### **Patient and Staff interviews**

Interviews for patient participants were conducted by the principal investigator (Maples) and lasted approximately 30-40 minutes. They were conducted in person in the clinic and patient participants were paid for their time. Prior to the interviews, the PI explained the purpose of the interview and the importance of open sharing of opinions.

The interview was developed by the PI in collaboration with experts in the Department of Psychiatry, and the stakeholder advisory board of the Transitional Care Clinic to address specific themes in the theoretical model. It follows a semi-structured format which began with general open-ended questions regarding the patient's experiences with mental health care and proceeded to more specifically address shared decision making and its impact upon care. Topics addressed included the patients' experiences with satisfaction with prescriber interaction and impact of the SDM process on medication visit outcomes. Both the staff and patient versions of the interview guide can be found in Appendices H and I, respectively. Interviews were audio recorded and all audio tapes were transcribed by research staff. Audio files were permanently deleted after transcription.

Clinic staff participants were interviewed using a semi-structured interview schedule developed by the PI in conjunction with experienced researchers in the Department and the stakeholder advisory board of the transitional care clinic. Important domains were identified and agreed upon, summarized by the PI, and collated into a semi-structured interview guide. The interview guide consists of questions about staff experiences using shared decision making as a practice within the transitional care clinic, including feasibility and utility. The interviews were carried out by the PI and lasted approximately 30 minutes. Interviews were conducted in person at the staff member's office.

#### Avoidance of bias

Selection bias during qualitative interviews is a possibility. Patients who agree to participate in the qualitative interviews may feel more emotional, either good or bad, about the

treatment at the crisis clinic. Information bias, a bias arising from measurement error, is also a consideration. This is possible with self-report data resulting in a differing quality, or amount of accuracy, in information between the three comparison groups. Information bias is also possible from the staff sample, again due to self-report data affecting the accuracy of information obtained. Another potential confounding variable needing consideration is provider's level of shared decision making during actual practice. While all providers have been equally trained in the SDM process, providers use different methods based on their own medical training, personal beliefs or years' experience. An additional confounder includes the severity of acute exacerbation within the patient population. While all patients attending the Transitional Care Clinic have recently been discharged or averted from a psychiatric hospitalization, there are differing levels of symptom severity (i.e. suicidal ideation versus suicide attempt) which may affect the desired level of involvement in the patient-provider dyad and the perception of the encounter.

## **Data Management**

All extant quantitative data was entered into a relational database meeting HIPAA requirements, using software that provides for double entry and numerous internal validity checks. All data are stored in HIPAA compliant password protected computer databases by subject numbers. No identifying information such as social security numbers, names or birthdates are included in the database. Data is maintained and backed up daily to prevent data loss and ensure full data retrieval for analyses. Security is maintained through a network manager. Quantitative data was analyzed using the Statistical Analysis Software (SAS version 9.3; SAS; Cary Institute).

## **Data Analysis**

### Quantitative Data Analysis

For analysis of quantitative data, we combined categories from the Control Preferences Scale into three larger groups reflecting their preferred SDM style; 1) Active, 2) Collaborative and 3) Passive. The primarily Active Group includes those patients who fell into either the Active-Active or Active-Collaborative categories. These patients tend to prefer to make most of the decisions with very little or no input from the doctor. The Collaborative Group includes patients who fell into either the Collaborative-Active or Collaborative-Passive categories. These patients prefer a very collaborative interaction where decisions are equally based on doctor patient input. The primarily Passive Group includes those patients who fell into either the Passive-Collaborative or Passive-Passive categories. These patients prefer interaction where their doctor has the majority of weight in decision making.

Chi square analyses were used to examine group differences (Active/ Collaborative/ Passive) by gender and ethnicity to determine whether there is an increased likelihood that one gender or specific ethnic groups have a preference for specific styles of medical decision making. One-way analyses of variance were used to examine CPS group differences (Active/Collaborative/Passive) on continuous measures including age, BPRS total score, BPRS factor scores, insight into having a psychiatric illness (SUMD total score), MPI difference scores and MPI patient rating. All tests were two-tailed. Demographic and clinical data are used to determine if differences exist between groups of patients who desire differing levels of involvement in psychiatric decision making. The measures specific to SDM allow us to examine

how patients view the initial encounter with prescribers, and the extent to which their view of the encounter differs from that of the prescriber.

### Sample size and Power Analysis

A power analysis was conducted on categorical and continues variables in a group of 258, split into three unequal groups - Active, Collaborative and Passive, representing approximately 26%, 53% and 21% of the population, respectively. The power analysis on fixed effect in the analysis of variance and covariance, with three groups, a total subject size of 258, and effect size of 0.2, the power of the F test on means at  $\alpha=0.05$  criterion is 0.82. This indicates we have sufficient power to detect differences across the three groups created from the control preferences scale (Cohen, 1988).

### Qualitative Analysis

To analyze interview data, we use an iterative process that consists of three steps: “noticing, collecting, and thinking” (Seidel, 1998). Interviews were audio recorded and transcribed by research staff and were coded by the PI and another faculty member in the same University and Department. Latent thematic analysis was used to analyze this exploratory data (Braun & Clarke, 2006) and NVivo 12 software was used to organize the data (NVivo 12, QSR International Pty Ltd, 2018). Each participating group (patient and provider) was analyzed independently and then the group data were combined. Using inductive category development, the codes from all transcripts were thematically clustered to serve as the basis for higher level categories, of which there were 12. Inductive categorization allowed for coding the data without trying to fit it into a pre-existing coding frame, or the researcher’s analytic preconceptions



(Braun & Clarke, 2006). This flexible method is used to identify patterns of meaning within data among participants and is not allied to any particular framework. We looked for themes especially relevant to differences in experiences of and preferences for SDM (e.g. desired balance of power); satisfaction with provider visits, including length of visits; how previous experiences affect current desire for and use of SDM; and consequences of not using an SDM approach. All codes were then grouped into these categories by the two researchers. Following thematic latent analysis (Braun & Clarke, 2006), the 12 semantic categories were further analyzed at the latent level to identify higher order themes, of which there were six. Any areas of disagreement were resolved by discussion until consensus was reached.

#### Sample size for Qualitative Analysis

Sample size for patient interviews is projected to reach saturation at n=15. Sample size for the staff interviews are set by number of current staff members.

#### **Strengths and Limitations of the Study**

This study contributes to the limited published literature on shared decision making within the mental health field. Additionally, this is the first evaluation of the perceptions and preferences of individuals with serious mental illness and their providers regarding SDM in a clinic serving a population immediately following a psychiatric crisis or hospitalization.

Strengths in this study include the sample size of the quantitative data, psychometric properties and variety of the quantitative assessments, in depth interview guides and the use of two coders for qualitative data.

While there are many strengths to this study, limitations are also present. In the quantitative analyses, the data is retrospective and we are unable to add to the current sample. Additionally, we are limited to the baseline visit without any follow up data for these participants. The cross-sectional nature of this study does not allow for examination of difference in SDM styles over time. A relatively smaller percentage of African American study participants make it difficult to generalize from these results. In addition, all qualitative interviews are performed in one clinic. Interviewing patients and providers in different areas may extend the variability of responses.

### **Human Subjects and Safety Considerations**

The safety of participants was monitored using procedures developed in the Division of Community Recovery, Research and Training over decades. Detailed training in good clinical practice and informed consent procedures helps to ensure appropriate protection of human subjects. The principal investigator has been trained in clinical research interview techniques, including methods to obtain data in a non-threatening manner. All subjects, including staff, are told they are free to withdraw from participation in the interview at any time. The principal investigator has twenty years' experience working with individuals with severe mental illness, including expertise in semi-structured interviews with this population, and has trained more than 50 staff in maximizing participant confidentiality and comfort. Prior to participating in the PCORI study all patients went through an informed consent process which included an assessment of the ability to give consent. Potential participants needed to answer specific questions to determine whether they understood the study and what would be expected of them. If they were unable to correctly answer these questions, some additional training was provided.

If potential participants were still unable to answer questions, they were not allowed to sign informed consent for the study.

Sources of Research Material. We examined data collected as part of the original PCORI study and we collected information from subjects via in person interviews. All data collected is used for the purpose of research.

### Recruitment

For Aim 1, no recruitment occurred as preexisting data was be used. For Aim 2, 15 patients were interviewed. Trained clinic staff familiar with the patients requested initial patient participant consent during in-person medication visits to The Transitional Care Clinic. For further description of the study, including full consenting procedures, the principal investigator followed up with those giving verbal consent. Individuals were invited to participate in an interview at a time and date convenient to them. Nine clinic staff members were interviewed. Provider participants were recruited via email from the PI requesting participation in the study. Staff were informed of the purpose of the interview and accepting staff were interviewed in their office at a time and date convenient to them.

### Informed Consent

The research study was deemed exempt by UT Health San Antonio's Institutional Review Board (IRB) due to no collection of identifying information. The consent form would have been the only piece of identifying information able to be tied back to either patient or staff participants. As such and per the request of the IRB, the PI created a checklist of pertinent

information of the study and this checklist was presented to the participants. Each participant was given a checklist to take with them including the contact information of the PI should they have questions after the interview. The 24 participants were asked to participate in an interview about shared decision making. They all provided verbal consent to audio record the interview and were made aware that transcripts of the audio tapes were made. Participants were informed that no identifying information was retained and only an identification number would appear on the transcript. All participants were informed that to further protect confidentiality; audio tapes were to be erased following transcription. All participants were informed that only researchers had access to the tapes and transcripts; no others involved with the Transitional Care Clinic or UT Health San Antonio are aware of their answers, and their responses cannot affect their status in at the Transitional Care Clinic or employment at UT Health San Antonio.

The existing quantitative data used in this dissertation was gathered from a preexisting PCORI-funded research study. All subjects signed an informed consent form and the study was approved by UT Health San Antonio IRB.

### Confidentiality

Participant information will not be shared with anyone outside the research team. Participants were not identified by name during the taping. A study ID is attached to each participant's transcript. All participant information from the original trial is contained in a HIPPA compliant database with no PHI attached.

### Compensation

Patients participating in qualitative interviews were paid \$30 for their time. Clinic staff participating in qualitative interviews were not be reimbursed for their time. Interviews were conducted during normal business hours and is intended to further the knowledge of the research within this topic area for future publication and possible grant applications, dependent on findings.

#### Potential Risks and Procedures to Minimize Risks

Risks of study procedures can include distress and heightened sensitivity that can occur as part of participation in clinical interviews; and potential breaches in confidentiality. While the possibility of such events is low given the procedures taken to minimize risk, the PI monitored these situations. The potential for these risks was reduced by adherence to guidelines of good clinical practice and formal supervision and training of personnel. If subjects became upset when discussing their treatment, the PI was available to consult with them.

Information is not be disseminated without the patient's written consent. Case records are kept in a secure location in password-protected files. Access to these files is restricted only to our research staff. Computer based information is identified by numbers and codes only. No names appear in the data files. The database is password protected. The risks to patients in this study are balanced by the importance of the information that will be obtained on treatments to improve mental health outcomes. We have used similar assessment procedures for more than 2 decades. The PI and research staff are experienced in conducting trials with individuals with serious mental illness.

The analysis proposed is presented in two formatted journal articles. Each will follow author instructions from a peer-reviewed journal and will be presented as a full paper. These will be followed by a chapter that will summarize the two papers and the implications for practice.

## **JOURNAL ARTICLE I**

### **Patient Preferences in Decision Making within a Post-acute Psychiatric Clinic**

**To be submitted to Patient Preferences and Adherence Journal**

## Abstract

Severe mental illness in adults refers to a group of mental health conditions including schizophrenia and schizoaffective, bipolar and major depressive disorders. These conditions are often characterized by recurring symptoms, multiple hospitalizations, and significant disability. The public health concern with these conditions is amplified because many individuals with severe mental illness fail to engage in outpatient treatment. Desperately needed are ways to support greater rates of participation in outpatient treatment. Encouraging participation in medical decision-making is viewed as one method to optimize patient empowerment, increase engagement in care and decrease the negative outcomes that often characterize this population. Shared decision-making is a collaborative and structured approach to patient-provider communication viewed as a negotiation between mutual experts with the goal of balancing empirical information with patient values and preferences. As part of an engagement-focused research study, data on decision making preferences and a variety of clinical, demographic and communication variables were collected from 258 individuals with severe mental illness during a baseline visit at a clinic serving individuals immediately after hospital discharge. The association between clinical, demographic and communication characteristics and patients' self-reported decision-making preference (active, collaborative, or passive) were examined using chi square and one-way analyses of covariance. Results indicated that race/ethnicity was significantly associated with SDM preference group, with African American individuals desiring more active participation in decision making compared to their Hispanic counterparts. Other characteristics including age, gender, symptom acuity, diagnosis, insight into illness, patient and provider agreement on communication during the visit and patient rating of communication during the visit were not significantly associated with the patient's baseline



decision-making preferences in this context. These findings indicate race/ethnicity may be an important factor when using a shared decision-making approach. More research is needed to determine how decision-making preferences relate to other clinical or situational factors.

**Keywords:** Severe Mental Illness, Mental Health, Shared Decision Making, Control Preferences Scale, Transitional Care Clinic

## Introduction

Severe mental illness in adults refers to a group of mental health disorders often defined by length of illness duration and the resulting functional impairment it produces. These illnesses include disorders that produce psychotic symptoms, such as schizophrenia and schizoaffective disorder, and severe forms of affective disorders, such as major depression and bipolar disorder.<sup>1</sup> It is estimated that 4.6% percent of the United States adult population is diagnosed with one of these conditions at any given time.<sup>2</sup> Severe mental illness is one of the leading causes of disability worldwide according to the global burden of disease disability weights.<sup>3,4</sup> The course of this group of disorders is often characterized by recurring exacerbations and multiple hospitalizations.<sup>5</sup>

The per patient lifetime burden of serious mental illness is estimated at \$1.85 million.<sup>6</sup> Services with the highest costs include hospitalization and emergency department visits. In an extensive review of psychiatric admissions to 418 U.S. community-based hospitals, the three most common diagnoses included depression (27.8%), schizophrenia/schizoaffective disorder (19.5%) and bipolar disorder (19.4%).<sup>7</sup> These diagnoses are included in the broader category of severe mental illness. Typical psychiatric hospitalizations for individuals living with severe mental illness last only a few days ( $\bar{x} = 4.4 - 11.1$ ),<sup>7</sup> while many still experience severe psychiatric symptoms at the time of discharge. The recurring hospitalization and emergency care utilization—as part of ongoing illness management coupled with an over-burdened outpatient mental health service care system<sup>8</sup>—result in as many as one-half of these individuals failing to connect to sustained outpatient care.<sup>9</sup> This places patients at greater risk of numerous negative outcomes, including repeated emergency department visits and inpatient hospitalizations,

homelessness, violence against others and suicide.<sup>10,11</sup> According to Pasic and colleagues (2005),<sup>12</sup> high utilization of hospital and emergency services points to quality of care and access problems in outpatient care that must be addressed. To this effect, it has been suggested that these negative outcomes may decrease within the mental health population if patients have more involvement in psychiatric decision making.<sup>13,14</sup> Correspondingly, engagement in outpatient services may be enhanced with a higher level of patient empowerment within the patient-physician dyad.<sup>15</sup>

Various intervention approaches have been used to increase follow-through attendance at outpatient treatment,<sup>16</sup> but most methods do not emphasize the importance of patients participating in their own treatment decisions. Shared Decision Making (SDM) is an exception. SDM is a structured method to patient-provider communication in medicine that frames the interaction as a negotiation between mutual experts and stresses the balanced use of empirical information and patient preference in decision making.<sup>17</sup> SDM is a systems approach to enable continuous improvement in clinical decision making.<sup>18</sup> The model focuses on two key participants, the patient and provider. There is a fundamental social nature in the decision-making task that cannot be completed by the doctor or patient alone, but rather requires productive interactions and communication between them. In a shared decision-making model, clinical providers are primarily responsible for knowing and appropriately applying the knowledge base. Patients are primarily responsible for contributing well-informed subjective assessments of possible health states relevant to decisions and for reporting outcomes and experiences with, and assessment of, these health states. Patients are additionally tasked with providing their values and preferences related to medical decisions. The responsibility placed

upon key participants is high, but that responsibility also lies at the center of success in such a model. Additionally, current clinical practice guidelines advocate for all clinicians, regardless of public health sector, to involve patients in decision making processes and allow for patient preferences, along with the evidence, to guide decisions where possible.

Research on SDM in psychiatry has received support through the New Freedom Commission on Mental Health,<sup>19</sup> and other government policy reports.<sup>20,21</sup> SDM may be of particular benefit in severe mental illness because of low follow-through with treatment due to factors including dissatisfaction with side effects from antipsychotic and mood stabilizing medications, poor insight into illness, and functional and motivational impairments. Despite these challenges, the majority of people experiencing mental illnesses express a desire to participate in making decisions regarding medications and hospitalizations,<sup>22-25</sup> and there is evidence that adults with severe mental illness frequently make competent and prudent treatment decisions.<sup>26,27</sup> Drake and colleagues (2010)<sup>28</sup> pose that SDM is an essential component in treatments focusing on recovery for individuals with severe mental illness, calling it an ethical imperative. Despite the apparent promise of SDM, there is a low level of adoption and implementation of this practice within the mental health care delivery system, relative to other areas of medicine. Efforts to increase patient involvement in care decisions face barriers such as overworked physicians, insufficient provider training, deficient medical information systems, physician time constraints, perceived lack of efficiency in the practice, a deemed lack of applicability due to patient characteristics and symptoms, and inappropriate clinical situations.<sup>29,30</sup> Slade (2017)<sup>31</sup> also cites a lack of support tools, integration of SDM with other recovery-related interventions, and sensitivity to cultural changes as problematic for SDM implementation in mental health.

At the patient level, demographic characteristics may make someone more or less interested in participating in this collaborative approach. In a review of patients' preferences for involvement in decision making, research revealed demographic variables, including being younger, better educated and female were consistently found to be associated with a preference for a more active role in decision making.<sup>32</sup> However, in a comparison of older and younger individuals with severe mental illness, it was concluded older persons have a stronger desire for involvement in decision making than do their younger counterparts.<sup>23</sup> Demographics related to decision making preferences within this population remain unclear.

A better understanding of the factors related to shared decision-making styles for different patients, and a better understanding of issues related to its implementation may be critical to maximizing individual patient outcomes. Currently, there is insufficient evidence on how much involvement individuals with severe psychiatric conditions desire to have in their patient-provider interactions regarding psychiatric care decisions. While previous studies have found factors such as age and gender to impact the desired level of involvement in care, results are inconclusive. Moreover, there is no evidence to date on how factors such as the level of psychiatric symptomatology, level of insight and ethnicity are related to patient's preference for involvement in the process of treatment decisions. A Cochrane review on the use of SDM in the mental health population highlighted the necessity for more research in this area.<sup>33</sup>

## **Materials and Methods**

### **Setting and Design**

The study site was the Transitional Care Clinic (TCC) providing a wide range of services to

individuals recently discharged or deferred from a psychiatric hospital or crisis setting. Services provided include medication management, evidence-based psychotherapy and case management for individuals with severe mental illness. Between the years of 2014 and 2016, a research study was conducted on the effects of engagement-focused care versus usual care (Patient-Centered Outcomes Research Institute (PCORI); Contract number: IH-1304-6506). A key component in engagement-focused care was training in, and use of, SDM practices by all clinic providers prior to study initiation. As part of the engagement-focused research, data on decision-making preferences and a variety of clinical, demographic and communication variables were collected from 258 individuals with severe mental illness during a baseline visit at a clinic serving individuals immediately after hospital discharge.

## **Participants**

The patient sample included a convenience sample 258 individuals with severe mental illness who attended a post-acute psychiatric hospitalization appointment at the Transitional Care Clinic as participation in the parent study. By virtue of their acceptance into this clinic, participants are over 18 years of age, have been recently discharged from an inpatient psychiatric unit or triaged from an emergency room, and received a diagnosis of severe mental illness. One participant was missing over half of the study data and was excluded from analyses. Patient follow-up appointments at the clinic typically occurred 1-14 days post discharge. Severe mental illness is defined as a Diagnostic and Statistical Manual of Mental Disorders – 5<sup>th</sup> Edition (DSM-5)<sup>34</sup> primary diagnosis of schizophrenia, schizoaffective disorder, bipolar disorder (with and without psychotic features), depression (with and without psychotic features), unspecified psychosis and unspecified mood disorder. The analyses of pre-existing data for this research study was

approved by both the UT Health Houston Committee for the Protection of Human Subjects and the UT Health San Antonio Institutional Review Board.

### **Data Sources and Measures**

**Demographic Data:** Patient level demographic data available for analyses included age, ethnicity, gender and diagnosis as charted at the time of first clinic appointment immediately following hospital discharge.

**Control Preferences Scale (CPS).** Patient preference for participation in SDM ~~is~~ was measured with the Control Preferences Scale.<sup>35</sup> The control preferences construct is defined as "the degree of control an individual wants to assume when decisions are being made about medical treatment".<sup>35</sup> This scale presents patients with five cards that each present a statement describing a different role in decision making. Statements range from, *I prefer to make decisions about which treatment I receive* to *I prefer to leave all decisions regarding my treatment to my doctor*. Cards are presented to the patient in pairs in a pre-specified order (B, D, C, A, and E) until the five statements are rank ordered. Sorting produces six different possible categorizations of how involved patients want to be in decisions. These include: 1) Active-Active, 2) Active-Collaborative, 3) Collaborative-Active 4) Collaborative-Passive 5) Passive-Collaborative and 6) Passive-Passive. For the purposes of the current study, we collapsed the six classifications into three: Active (Category 1-2), Collaborative (Categories 3-4), and Passive (Categories 5-6). For analysis of control preference data, we combined categories from the Control Preferences Scale into three larger groups reflecting their preferred SDM style; 1) Active, 2) Collaborative and 3) Passive. The primarily Active Group includes those patients who fell into either the Active-

Active or Active-Collaborative categories. These patients tend to prefer to make most of the decisions with very little or no input from the doctor. The Collaborative Group includes patients who fell into either the Collaborative-Active or Collaborative-Passive categories. These patients prefer a very collaborative interaction where decisions are equally based on doctor patient input. The primarily Passive Group includes those patients who fell into either the Passive-Collaborative or Passive-Passive categories. These patients prefer interaction where their doctor has the majority of weight in decision making.

Matched Pair Instrument (MPI). Patient and prescriber ratings of prescribers' in-session communication was obtained using the Matched Pair Instrument<sup>36</sup> a dyadic instrument comprised of 19 statements that assess the content and process of a prescriber's communication skills from each patient's perspective. Each skill on the MPI is rated on a 5-point scale with higher scores indicating stronger agreement with the statement. The prescriber and patient completed a version immediately following the baseline study encounter. A total score for each participant is derived. In addition, a difference score between provider and patient ratings was calculated. The absolute value of this score reflected the average distance between patients and providers in their perceptions of communication during the session.

Expanded Brief Psychiatric Rating Scale (BPRS). The Expanded Brief Psychiatric Rating Scale (BPRS) was used to characterize psychiatric symptoms amongst patients<sup>37</sup> This scale is a 24-item interview-based measure that captures a range of psychiatric symptoms rated on 7-point Likert scales, with higher scores indicating more severe symptomatology. This scale is summed to yield a total score and several factor scores (depression-anxiety, positive symptoms, and



negative symptoms).

Scale to Assess Unawareness of Mental Disorders (SUMD). The abridged version of the Scale to Assess Unawareness of Mental Disorders<sup>38</sup> was used measure patient insight into having a psychiatric illness. This semi-structured open interview evaluates three items including global insight, insight into illness and insight into symptoms on a series of 5-point Likert scales with higher scores indicating lower insight.

### **Data Analysis**

Univariate descriptive statistics included means with standard deviation and frequencies for all variables. For analysis of control preference data, we combined categories from the Control Preferences Scale into three larger groups reflecting their preferred SDM style; 1) Active, 2) Collaborative and 3) Passive. We present numbers (percentages) of participants in each of the three collapsed control preference groups.<sup>39</sup>

Chi square analyses were used to examine Shared decision-making classification (Active/Collaborative/Passive) by gender (Male/Female) and ethnicity (name here) to determine whether there was an increased likelihood that one gender or specific ethnic group preferred specific styles of medical decision making. As only four patients classified their race as “other” or “mixed” (causing expected frequencies in the associated cells to be too low), we excluded this group and the “unknown” group from subgroup interaction analyses, focusing the examination on the relationship between race/ethnicity (non-Hispanic white, Hispanic, African American) and the three SDM control preference groups (Active, Collaborative, and Passive).

To test the main effects and interaction one-way analyses of covariance were used examining control preference group differences (Active/Collaborative/Passive) on continuous measures including age, clinical symptomatology (BPRS total score and subscale scores), insight into having a psychiatric illness (SUMD total score), matched pair difference scores and matched pair patient ratings. All tests were two-tailed. Demographic and clinical data were used to determine if differences exist between groups of patients who desire differing levels of involvement in psychiatric decision making. The measures of communication allowed for examination of how patients view the initial encounter with prescribers, and the extent to which their view of the encounter differs from that of the prescriber.

## **Results**

The sample was 45.4% male (117/257); with a mean age of 38 (S.D. 11.9). 50% were Hispanic (129/258), 38% non-Hispanic white (99/257), 8% African American, and 3% other or unknown (8/257). Almost 40% were diagnosed with major depressive disorder (103/257), followed by 30% with bipolar disorder (78/257), 16% with unspecified mood disorder (42/257) and 14% with schizophrenia and related disorders (including schizoaffective disorder and unspecified psychosis; 35/257). Twenty-six percent (68/257) of the sample identified as having active control preferences – desiring all or most decision-making responsibility, 53% (137/257) as collaborative – sharing most decision-making opportunities, and 21% (53/257) as passive - ceding most or all decision making to the provider. Demographic characteristics and SDM control preference categories are summarized in Table 1.1

Table 1.2 presents a breakdown of SDM preferences by race/ethnicity. Race/ethnicity demonstrated a significant relationship with patient control preference group ( $X^2$  (4; N=257) =10.18,  $p$  =0.0375). A significant difference was found in medical related control preferences between African American and Hispanic individuals, with African American individuals preferring a more active role than did their Hispanic counterparts ( $X^2$  (1; N=249) =3.97,  $p$  =0.0463). Odds ratio estimates revealed African American individuals are 4.17 times more likely than are Hispanic individuals to be in the Active group ( $1/.241=4.17$ ). No significant differences were found for control preferences between Hispanic and non-Hispanic whites or between African Americans and non-Hispanic whites.

No other demographic or clinical variables investigated distinguished the control preference decision-making groups. We examined the contribution of gender, age, clinical symptomatology (BPRS total and depression-anxiety, positive symptom and negative symptom subscales), diagnosis, patient rating of communication satisfaction, and patient/provider communication satisfaction agreement and found no significant relationships to SDM preferences (all  $p$  values > .05\*). A multinomial logistic regression with stepwise selection was then used to include variables with a 0.3 significant level for entry into the model. No differences were found between the three control preference groups by gender ( $X^2$  (2; N=257) =0.643,  $p$  =0.725), age ( $X^2$  (2; N=257) =0.089,  $p$  =0.957), depression-anxiety subscale ( $X^2$  (2; N=257) =2.238,  $p$  =0.327), positive symptom subscale ( $X^2$  (2; N=257) =3.979,  $p$  =0.137), negative symptom subscale ( $X^2$  (2; N=257) =0.246,  $p$  =0.884), patient communication satisfaction ( $X^2$  (2; N=257) =0.466,  $p$  =0.792), or provider-patient communication satisfaction ( $X^2$  (2; N=257) =0.821,  $p$  =0.664).

## Discussion

This study contributed to the limited published literature on shared decision making within the mental health field. Additionally, this is the first study to investigate the medical decision control preferences in a group of individuals receiving mental health treatment immediately following hospital discharge. Race/ethnicity is an important factor when using a shared decision-making approach. African American individuals were more likely to want to be active or collaborative contributors in the medical decision-making process. There is a complex history of race in the medical profession. Doctors have historically been Caucasian and there is a history of exploitation of African American Americans as well as perhaps engaging this population with directives rather than dialogue. This may have led this population to be more suspicious of providers and, consequently, the desire to more actively participate in medical decision-making. Many disparities are reported in the area of mental health when comparing African Americans to whites, including higher levels of incorrect diagnoses, underrepresentation in research, less access to treatment, more severe symptom ratings, greater functional impairment once diagnosed, and significantly fewer African Americans seeking treatment.<sup>40-43</sup> Additionally, Eliacin et al (2016)<sup>44</sup> reports African Americans are less likely to be engaged in treatment and often perform more poorly on healthcare activities linked to patient engagement, such as communicating effectively with providers and participating in treatment decisions. To this end, active engagement and participation in mental health treatment may represent an important component in addressing many of these inequalities. For example, providers may work to increase patient activation by asking patients to define their goals for mental health treatment including the steps needed to achieve them and identify patient knowledge gaps so further education can be offered. In contrast to African Americans, Hispanic individuals were more

likely to choose a passive role in decision-making. From a historical perspective, Hispanic individuals tend to be respectful of authority and more likely to adhere to a perceived power gradient, making them more likely to cede decision making to a medical provider.<sup>45,46</sup> Research indicates Hispanics are more deferential to authority figures, depending on acculturation, and are less likely to engage in mental health treatment than whites.<sup>47</sup> For these reasons, Añez et al (2008)<sup>48</sup> proposed the application of motivational interviewing principles to Latino cultural values and emphasizes the need to promote a client-centered and culturally congruent therapeutic environment to improve the connection to and participation of these individuals. Markowitz et al (2009)<sup>49</sup> suggests minimizing the emphasis of the medical diagnosis and recognition of the centrality of family as necessary cultural adaptations when treating Spanish-speaking individuals with depression. Providers may also work to improve their Hispanic patients' self-efficacy in making sound medical decisions by dividing tasks and offering feedback and reinforcement for each aspect of illness self-management. It is evident that baseline decision making preferences need to be considered when providing mental health care. Patients of all races/ethnicities need to be aided on how to engage in the process of SDM and providers need to ensure they communicate the importance of active and collaborative participation, even in situations that may be new for individuals in treatment. This may involve recognizing the patient's knowledge, allowing sufficient time for participation or explaining the benefits of participating in treatment including improved health outcomes and better quality of life.<sup>50</sup> In line with the emerging paradigm of patient-centered care, culturally appropriate decision making needs to be emphasized. This may include decision aids and coaching manuals with culturally congruent language and examples and further training for mental health professionals.

Race/ethnicity is an important consideration when using a shared decision-making approach, yet other demographic, clinical and communication characteristics were not predictive of control preference style in this context. It may be other factors are more important in determining the extent to which someone wants to contribute in psychiatric decision making. The participants in this study had in common a recent acute psychiatric hospitalization or crisis. Perhaps given this often traumatic and stressful event, other characteristics, such as age, gender and symptom acuity become less important as related to shared decision-making preferences. In a review of non-psychiatric patient preferences for involvement in medical decision making, Say et al (2005)<sup>32</sup> report demographic variables, including being younger and female as consistently associated with a preference for a more active role in decision making. These findings were not corroborated in this study, although it may hold true for the general population. Other possible explanations not explored in this study include previous experiences in the mental health system, including hospitalizations, and personality traits.

Previous experiences with the mental health system may affect how individuals interact with current and future providers of care. In a group of 588 individuals with severe mental illness in Europe, Cosh et al (2017)<sup>40</sup> report a significant association between active (versus collaborative or passive) involvement in decision making and longer hospitalization durations.

Correspondingly, these authors report patient-rated preferences for passive or shared decision making styles were associated with shorter hospital admissions.<sup>40</sup> This finding suggest that patients with less severe illnesses, who are less likely to have inpatient admissions, prefer sharing decision making with providers while those with more severe illnesses prefer additional input in decisions. The number and length of previous hospitalizations were not evaluated in this study

and future research should examine whether active decisional preference is a marker of patients who are less well or whether there is a causal association between active decision preferences and more hospital admissions. Apart from experiences in the mental health system, research suggests personality traits such as, extraversion, agreeableness, conscientiousness, neuroticism, and openness to experience are related to desire to make medical decisions.<sup>51</sup> Flynn (2007)<sup>52</sup> found that higher rates of conscientiousness and openness to experience and lower levels of agreeableness and neuroticism related to preferring the most active decision-making style compared with the least active decision-making preference. These studies demonstrate the need to examine personality characteristics when studying decision-making preferences.

### **Limitations**

Multiple tests of statistical significance were utilized in these analyses and may have increased the likelihood that the relationship between race/ethnicity and control preference group was due to chance. The cross-sectional nature of this study did not allow for examination of difference in SDM styles over time. A relatively smaller percentage of African American study participants make it difficult to generalize from these results. The control preference groups were determined by one self-reported assessment. While the Control Preferences Scale is a validated instrument, it is possible that more sensitive scales or use of more than one scale is needed.

### **Conclusion**

Despite the limitations described above, the study highlighted that SDM preferences are different across individuals in this treatment setting. These preferences need to be considered in approaching SDM education for patients and providers and in creation of culturally informed

decision aids and manuals. The concept of shared decision making is not a new one, however, we are experiencing a paradigm shift with more emphasis in self-directed care in the mental health system. Both providers and patients want to share in medical decision making, but neither may be completely certain how to appropriately engage in collaborative exchange. This may be especially true for providers and their patients who have recently been discharged from an inpatient setting. Using culturally congruent decision aids and increasing patient activation and self-efficacy in making medical decisions may be viable methods of engaging individuals in care, thereby increasing collaborative decision-making. SDM has been demonstrated to improve outcomes for people across many areas of mental and physical health and must be implemented with thoughtful consideration of patients to realize its full potential. More research is needed as this is the first published attempt we are aware of to examine these demographic, clinical and communication variables within this population.

### **Acknowledgments**

The data used in these analyses was gathered as part of a research study examining outcomes in engagement-focused care versus usual care between the years of 2014 and 2016 (Patient-Centered Outcomes Research Institute (PCORI); Contract number: IH-1304-6506).

### **Disclosure**

The author reports no conflicts of interest in this work.



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**Table 1.1 Demographic characteristics and SDM collapsed control preference category (N=257)**

Characteristic	N	%
Race or ethnicity		
Non-Hispanic White	99	38.4
Hispanic	129	50.0
African American	21	8.3
Other/Mixed	5	1.9
Unknown*	3	1.1
Male	117	45.35%
Diagnosis		
Major Depressive D/O	102	39.7
Bipolar Disorder	78	30.3
Unspecified Mood D/O	42	16.3
Schizophrenia & Related D/O	35	13.6
Age (M±SD years) (range 18-66)	37.95	11.9
Collapsed SDM preference category		
Active	67	26.1%
Collaborative	137	53.3%
Passive	53	20.6%

\*Note: Data not captured at first visit and patient did not return to clinic, so data remains unknown

**Table 1.2 Breakdown of SDM preferences by race/ethnicity (N=257)**

Race/Ethnicity	Active N (%)	Collaborative N (%)	Passive N (%)
Non-Hispanic white	27 (27.3)	58 (58.6)	14 (14.1)
Hispanic	26 (20.2)	67 (51.9)	36 (27.9)
African American	9 (42.9)	9 (42.9)	3 (14.3)
Other/Mixed	4 (1.6)*	1 (0.4)	0 (0.0)
Unknown	1 (0.4)	2 (0.8)	0 (0.0)

\*Note: There is a possibility these 4 patients are a mix of African American, thereby increasing the overall likelihood of African Americans choosing a more active role in decision-making.

## **JOURNAL ARTICLE II**

**Perspectives of Patients and Providers in Using Shared Decision Making in Psychiatry**

**To be submitted to Community Mental Health Journal**



## **Abstract**

There is increased interest over the last decade in the use of Shared Decision Making with individuals with serious mental illness to improve engagement in treatment and patient outcomes. We conducted semi-structured qualitative interviews with 15 individuals with serious mental illness treated in an outpatient transitional care clinic serving people immediately after discharge from a psychiatric hospitalization. Parallel interviews were conducted with a variety of clinical providers ( $n = 9$ ). Using latent thematic analysis six themes were identified including: 1) Differences in the Use of SDM, 2) Consideration of Past Experiences, 3) Decisional Power Preferences, 4) Use of SDM in Psychiatry Versus Other Areas of Medicine, 5) Dignity and Disengagement, and 6) External Forces Impacting SDM. Implications for clinical practice and research using a shared decision-making approach within this treatment setting are further discussed.

**Keywords:** Severe mental illness, serious mental illness, shared decision making, transitional care clinic, mental health

## **Introduction**

Engagement in mental health services following psychiatric hospitalization is of critical importance for improving the lives of individuals with severe mental illness and reducing long term negative outcomes, such as hospitalization, homelessness and suicide (Velligan, 2009; Pasic et al, 2005). Patients who feel they are playing an active role in their treatment typically have better engagement and outcomes than patients who experience themselves as passive recipients of care (Alegrai, et al, 2014; Stewart, 2001). Although various intervention approaches have been used to increase engagement in outpatient treatment in serious mental illness (Roberts, 2011), most methods do not emphasize the importance of patients participating in their own treatment decisions. Shared Decision Making (SDM) is an exception. SDM is a structured approach to communication in medicine that frames the interaction as a negotiation between mutual experts (patient and provider) and stresses the balanced use of empirical information and patient preferences and values in decision making (Charles, 1997). SDM is compatible with evidence-based medicine in its emphasis on the use of empirical information to make treatment decisions (Guyatt, 2001), and with the serious mental illness consumer recovery movement in its emphasis on patient-centered care (Drake, 2010). Furthermore, the process of recovery from mental health conditions depends on patients taking personal accountability for medical decisions, including those about medications and types of therapies.

SDM is well operationalized, with specific components and clinician competencies detailed in the literature (Campbell, 2007; Elwyn, 2005). Several of the fundamental SDM principles aim to help the individual in treatment become more aware a medical decision is needed, offer more than one option from which to choose, communicate the pros and cons of the different options

and support the patient to make informed choices (Sepucha et al, 2010). A shared decision-making method recognizes the expertise gleaned from both providers and patients in making a joint decision. Additionally, research trials demonstrate interventions involving SDM are feasible and well tolerated by individuals with serious mental illness (Deegan, 2006; Hamman, 2011).

### *Barriers to SDM Implementation and Dissemination with Serious Mental Illness*

Despite the apparent promise of SDM, there is a low level of adoption and implementation of this practice within the delivery of mental health care, relative to other areas of medicine (Pollard, 2015; De las Cuevas et al, 2013; Drake et al, 2010; Hamann et al, 2006). Whether in physical medicine or mental health, efforts to increase patient involvement in decisions about their care face barriers such as overworked physicians, insufficient provider training, deficient medical information systems and physician time constraints (Legare, 2008; Towle, 2006). Specific to psychiatry, further complexity is introduced with the potential lack of applicability of SDM due to patient characteristics and inappropriate clinical situations (Solbjør et al, 2013). From the standpoint of efficiency, when SDM is used in prescriber-patient interactions, visits are perceived by prescribers to take more time than does a standard psychiatry appointment (Burton, 2010) and doctors cite this as one factor that limits their use of SDM (Legare, 2008).

Despite a desire to know more about their diagnosis, treatment options and side effects (Hamann et al, 2007; Drake et al, 2010), patients receiving psychiatric care report that prescribers often do not provide sufficient information or explain it in an understandable manner (Lorem et al, 2013; Garfield, 2004). Attitudes about the use of SDM have been found to differ by profession, with physicians being more likely than occupational therapists and pharmacists to communicate about

the pros and cons of medical issues (Chong et al, 2013<sup>b</sup>). At the patient level, difficulties in using SDM may be due in part to illness-related information processing challenges of the individual in treatment (Mahone, 2011; Hamann et al, 2011; Chong et al, 2013; McCabe et al, 2013), suggesting the need for the use of decision support aids and other scaffolding techniques to aid patient preferences in decisions about their care (Deegan, 2006) that may be different from those used for non-mental health patients.

### *Facilitators of SDM Implementation and Dissemination in Serious Mental Illness*

Evidence supports the use of SDM for individuals with serious mental illness (Hamman, 2011; Drake, 2010; Deegan, 2006). Research on SDM in psychiatry has received support through the President's New Freedom Commission (PNFC) on Mental Health and other important government policy reports supporting the notion that transformation of the mental health service delivery system to promote recovery hinges on treatments that give individuals real and meaningful choices about treatment options (President's New Freedom Commission, 2003; Institute of Medicine, 2001). SDM may be of particular benefit in serious mental illness because of the high incidence of patient non-adherence with treatment due to factors including dissatisfaction with side effects from antipsychotic and mood stabilizing medications, poor insight into illness and functional and motivational challenges. For individuals who decline to take medications, SDM may constitute a reasonable approach to remaining engaged with care providers allowing them to take advantage of treatment options such as case management or psychotherapy, while continually re-evaluating the potential role of medication. For patients with poor insight or functional challenges, SDM represents a non-threatening approach to clarifying motivations and options for improving quality of life. Despite evidence of cognitive challenges

and problems with insight, there is evidence that adults with serious mental illness frequently make competent and prudent decisions (MacDonald et al, 2017). For example, in studies of decisional capacity, individuals with schizophrenia (Carpenter et al, 2000) and severe depression (Lapid et al, 2003) performed as well as their non ill counterparts on measures of ability to provide informed consent following an educational intervention (Carpenter et al, 2000). Additionally, the Institute of Medicine (IOM) rebutted the belief that this group of individuals should be assumed to have impairment in decisional capacity when stating, “many people with mental illness, indeed, many with severe mental illnesses, are not incompetent on most measures of competency” (IOM, 2006, p. 112). Despite frequent behavioral passivity, patients with serious mental illness express a strong desire to be informed about their illness and treatment options, and to be active participants in their treatment decisions (Velligan et al, 2017; Adams, 2007; Arora, 2000; De las Cuevas, 2013). Similarly, mental health providers report positive attitudes toward SDM (Seale et al, 2006; Hamann et al, 2009).

Despite promising data on the use of SDM, the uptake of this practice is poor within services provided to the seriously mentally ill population (Pollard, 2015; De las Cuevas et al, 2013; Drake et al, 2010; Hamann et al, 2006). The aim of this study was to identify the factors influencing the use of a shared decision-making model in a transitional care clinic providing treatment to individuals with serious mental illness after a psychiatric crisis or hospitalization.

## **Methods**

### Design

We conducted one-on-one explorative interviews with individuals in treatment and a variety of

clinical providers. Fifteen patients and nine providers participated in one-on-one interviews describing their experiences with medical decision making ~~in~~ at the Transitional Care Clinic and in comparison to previous treatment settings. Topics addressed during patient interviews included experiences with prescriber interactions and impact of the SDM process on medication visit outcomes and recovery. Providers discussed experiences using SDM as a practice in general and, specifically about feasibility and utility for individuals seeking care at the Transitional Care Clinic. The interviewer followed a semi-structured interview guide starting with broader questions and ending with more focused discussions on specific topics.

### Setting and Sample

The study site was a Transitional Care Clinic funded by area hospitals, charitable organizations and an 1115 Medicaid Waiver. The clinic provides a wide range of services including medication management, evidence-based psychotherapy and case management for individuals with severe mental illness recently discharged or deferred from a psychiatric hospital or crisis setting. Severe mental illness is defined as a DSM-5 primary diagnosis of schizophrenia, schizoaffective disorder, bipolar disorder (with and without psychotic features), depression (with and without psychotic features), unspecified psychosis and unspecified mood disorder. As part of an engagement-focused research study conducted from 2014 and 2016 at the Transitional Care Clinic (Patient-Centered Outcomes Research Institute [PCORI]; Contract number: IH-1304-6506), all clinic providers were trained in SDM and continue to be trained in this modality. Provider participants were recruited via email from the first author requesting participation in the study. The nine participating providers included three psychiatrists, one nurse practitioner, one nurse, two psychologists (also served as clinic administrators) and two therapists. Patient

participants were recruited during regular medication clinic visits on two separate days in September, 2019. Individuals presenting at the clinic were asked by clinic staff about their interest in participating. All patients had capacity to provide consent. Interviews for patient and provider participants were conducted by the first author and lasted approximately 20-40 minutes. All interviews were conducted at the clinic and patient participants were paid \$30 for their time.

### Data Collection

Demographics were obtained from the patients and provider participants including age, gender and ethnicity. The semi-structured interview was developed by the authors (NM and DV) in collaboration with experts in the Department of Psychiatry and Behavioral Medicine, and the stakeholder advisory board of the Transitional Care Clinic. Topics addressed included the patients' experiences and satisfaction with prescriber interaction, impact of the SDM process on medication visit outcomes and comparisons to previous healthcare experiences. The provider interview guide consisted of questions about experiences using SDM as a practice within the Transitional Care Clinic, including feasibility, and utility. The interview guide began with broad items to allow the participant to begin thinking about their experiences with SDM, what this method entails, their role in the decision-making process, and the information needed to make this approach successful. The interview then moved on to questions regarding how SDM affects participation in sessions and the impact on outcomes and recovery. All questions were open-ended. For patient participants who displayed distractibility or difficulty understanding, questions were reworded or repeated. After conducting the fifteen patient and nine provider interviews, it was apparent that similar themes were discussed, and no new themes were emerging. Therefore, saturation was deemed to be reached and no further interviews were

conducted. The research study was approved by both the University of Texas Health Science Center at Houston Committee for the Protection of Human Subjects and the University of Texas Health Science Center at San Antonio Institutional Review Board.

### Data Analysis

Interviews were audio recorded and transcribed by research staff and were coded by two authors (NM and DV). Latent thematic analysis was used to analyze this exploratory data (Braun & Clarke, 2006)) and NVivo 12 software was used to organize the data (NVivo 12, QSR International Pty Ltd, 2018). Each participating group (patient and provider) was analyzed independently and then the group data were combined. Using inductive category development, the codes from all transcripts were thematically clustered to serve as the basis for higher level categories, of which there were 12. Inductive categorization allowed for coding the data without trying to fit it into a pre-existing coding frame, or the researcher's analytic preconceptions (Braun & Clarke, 2006). This flexible method is used to identify patterns of meaning within data among participants and is not allied to any particular framework. We looked for themes especially relevant to differences in experiences of and preferences for SDM (e.g. desired balance of power); satisfaction with provider visits, including length of visits; how previous experiences affect current desire for and use of SDM; and consequences of not using an SDM approach. All codes were then grouped into these categories by the two researchers. Following thematic latent analysis (Braun & Clarke, 2006), the 12 semantic categories were further analyzed at the latent level to identify higher order themes, of which there were six. Any areas of disagreement were resolved by discussion until consensus was reached.



## **Results**

### Sample Characteristics

Of the patient participants, ten were female, four male and one nonbinary. Eight were white Hispanic, six were white non-Hispanic and one was African American. Participant characteristics can be seen in Table 2.1. Analysis of patient and provider interviews resulted in six major themes: 1) Differences in the Use of SDM, 2) Consideration of Past Experiences, 3) Decisional Power Preferences, 4) Use of SDM in Psychiatry Versus Other Areas of Medicine, 5) Dignity and Disengagement, and 6) External Forces Impacting SDM.

### Six Themes

A number of important themes emerged from the research. Exemplary quotes from each theme can be viewed in Table 2.2.

#### *Differences in the Use of SDM*

A primary reason in attending appointments at the Transitional Care Clinic is to receive medication for mental health conditions, although many other treatments may be provided in addition to medication management. Specific to discussions of medication, the majority of comments from both patients and providers support the active provision of options including, research data, weighing pros and cons, and collaborative communication. Discussions around medication occur in most medication follow-up visits, even if no changes are needed or made. One patient participant recalled wanting an increase in medication, but that request was not fulfilled. However, a joint discussion still transpired. Prescribers typically offered options each time a medication or therapy was not satisfactory to the patient, whether due to side effects,

potency, or other reasons, and patients were pleased with this communication method. Providers and patients concur that the final decision on taking medication and deciding which medication to take is the responsibility of the patient, although the clinical provider is heavily relied upon for their expert knowledge. The respect given to provider knowledge was apparent from the vast majority of patient participants (12/15). Three patients described the experience of not feeling like a partner in decision making at the Transitional Care Clinic, recounting a lack of perceived power and an absence of a give-and-take conversation around treatment. All interviewed providers endorsed seeking to use a SDM approach, although none endorsed explaining the actual concept or methodology of SDM with patients. Decision aids (media or methods that inform patients about treatment options) are not regularly used by any interviewed providers to assist patients in making decisions, and only three patient participants endorsed a positive attitude about their potential use in mental healthcare.

### *Consideration of Past Experiences*

All patient participants discussed experiencing any number of severe symptoms, such as psychotic episodes, debilitating depression, attempts at self-harm, and brief or long-term hospitalizations. Many (11/15) described previous negative experiences during psychiatric hospitalizations where they perceived having no input on anything, for example, daily schedule, medications taken and discharge date. These experiences created a perception of having no power in these situations. Similarly, providers discuss creating a “disempowered” group of patients because of these types of negative inpatient experiences. Providers further explained these negative, and often traumatic, experiences with no opportunity for input or perceived control shaped how patients believe they may or may not participate in their healthcare

management. They also refer to health disparities often present in the severely mentally ill population, including economic disadvantage, lack of access to healthcare and lower levels of education, as being interrelated to patients' perceptions and understanding of mental healthcare. Providers acknowledged patients may not "know how to ask to be an equal partner" in their mental health treatment because they have essentially been trained not to do so. Comparably, providers also discussed differences in their own education and background influencing their beliefs about a SDM approach to care. There is a difference of opinion amongst providers as to the extent to which SDM is taught to mental health professionals during their formal education. The collaboration is more required for some job roles and providers acknowledged the use or uptake of a SDM approach may be generational, in that more newly trained providers may have received more education on this communication method.

### *Decisional Power Preferences*

Both groups of participants agreed the patient and provider should share decision-making responsibility and many patients cited "50/50" as the appropriate balance of decision-making accountability. Most providers conveyed the patient should have more than 50% of the decisional authority (i.e. 60/40, 75/25), although two stated the situations and decisions varied too much to approximate a percentage. Two providers also introduced the importance of significant others in the patients' lives, such as family members, who are part of the onus to providing input for health-related decisions. While most patient participants prefer nearer to an equal partnership, a small number (3 of 15) preferred to concede power to the provider. These three were all white Hispanic females.

### *Use of SDM in Psychiatry Versus Other Areas of Medicine*

The use of SDM in psychiatry was viewed as more important than its use in non-mental health settings. Providers often cited the lack of a specific test or scan to diagnose and treat ailments. “We don’t have an x-ray machine.” In these situations, patients participating as their own expert is of increased value. Patients described the importance of sharing in decisions as the precursor to a trusting relationship that fosters honesty and recovery. Several patients said they can talk to their current provider about topics they have never discussed previously with other providers—for example, repeated childhood trauma. This aligns with providers’ reports that sharing information is the best way to proceed with appropriate treatment options. The information on how someone is feeling what they have experienced informs the process of how physicians and therapists make treatment decisions. Providers mention pre-established guidelines for medication and therapies based on their knowledge of the case. If patients do not provide accurate or honest information, providers cannot put those protocols into action. In physical medicine, there is often a clearly superior treatment option, for instance in cancer treatment, but this is typically not the case in mental health treatment—thus increasing the reliance on patient involvement. Providers and patients agree it may take more time upfront to engage in discussions that are essential to a SDM approach, but all reported this communication practice saves time later. For example, providers mentioned that extra time spent on discussions within the office may help reduce: 1) extra phone calls to clinic staff because details were omitted, 2) symptom recurrence and possible hospitalization, and 3) patient’s experience of unexpected side effects. Likewise, providers did not believe using a SDM approach uses more resources over the course of treatment. Several providers mentioned a higher likelihood of patients showing up to appointments as a potential cost saving aspect of using SDM.

### *Dignity and Disengagement*

Almost half of the interviewed patients (7/15) describe times, either in this clinic or in previous experiences, where they did not feel their opinions were taken into consideration and stopped seeking treatment or taking medication altogether. Patients described specific times where they requested a change in medication or other treatment and the provider did not consider their request; there was no attempt at discussion. These patients describe stopping all treatment, which led some to an increase in symptoms, suicide attempts and hospitalization. Patients and providers agree it is better to taper off of a medication or other treatment while remaining engaged with care providers. Possible consequences of not allowing patient input is their disengagement from the mental health system, self-harm, rehospitalization, or other negative outcomes. While decisions are sometimes made for individuals in treatment, many (10/15) described being their own expert and believe their personal knowledge must be considered, even if not pursued. There is a dignity in risk. While patients understand there may be negative consequences to reducing or stopping treatment, they want partnership in attaining their health goals, sometimes in opposition of what the providers believes is best practice

### *External Forces Impacting SDM*

The majority of patients and provider participants support the notion of SDM and its use with individuals in a psychiatric setting. However, almost all indicated times when a more paternalistic approach is needed. The need for an authoritative style was linked to recurrent or worsening symptoms or fear for patient safety, including intent of suicide or homicide. All providers and all but one patient agreed the clinical provider, often the physician, carries the

weight of making decisions for the patient when their decisional capacity is impaired due to an “acute exacerbation of symptoms.” Likewise, providers exert a responsibility to their own clinical licenses and training that may be in opposition to what patients want. Most providers listed following clinic (or systemic) rules as a responsibility (i.e., adhering to a rule restricting the prescribing of benzodiazepines) that may negatively impact the provider-patient relationship because the decision is out of their hands. Providers and patients agreed a discussion can still transpire that can minimize the negative feelings associated with not having a full or real choice.

## **Discussion**

This is the first evaluation of the perceptions and preferences of individuals with serious mental illness and their providers regarding SDM in a clinic serving a population immediately following a psychiatric crisis or hospitalization. Results of this qualitative study suggest that patients and providers value SDM, understand its application, and believe it is related to better outcomes. Several important topics are evident and can inform future clinical care and research in this field.

### Implications for Clinical Practice

The study supports the need to ensure that SDM is a routine practice in psychiatric care. Study participants made comments which are supported by research suggesting that a continued paternalistic approach in medical decision making continues to socialize individuals into the role of patient rather than equal partner (Murjic et al, 2015). Patients and providers identified potential serious consequences including, disengagement and abruptly terminating treatment, when patients do not participate in decisions and do not feel heard. Studies of SDM link increased patient involvement to improved treatment adherence and quality of life, while lack of patient involvement is related to lower adherence to treatment, patient satisfaction, and overall

health outcomes (Sepucha & Mulley, 2009). The reports that SDM improved show rates and reduced calls in between appointments is important to patients, providers and the agencies for which they work. Research continually demonstrates no shows increase overall healthcare costs and reduce the gains made from treatment (Kheirhah et al, 2016, Berg et al, 2013).

Both patients and providers in this study assert that trust in the clinical provider and patient honesty is strengthened by the use of SDM. Patients are more likely to share personal information needed to inform treatment options. Research supports that a trusting relationship with a clinical provider can strengthen alliance and prevent crises or other serious negative outcomes (Arnow & Steidtmann, 2014; Howgego et al, 2003). To improve partnerships, clinical providers can offer options and have a conversation, even when yielding to the patient's request is not feasible. As part of this conversation, providers must consider there is a certain dignity in risk-taking, even when not medically supported (i.e. getting off medication). Providers can state the pros and cons of certain decisions, but the final decision is the patients, assuming decisional capacity is intact. Although there is less of an emphasis of SDM in mental health care (Pollard, 2015; De las Cuevas et al, 2013; Drake et al, 2010; Hamann et al, 2006), the findings of this study suggest the use of a SDM approach is more important in this field compared to traditional somatic care. Psychiatric care is dependent on the nature of communication and this is instrumental in whether care is deemed effective. When you do not have a clearly superlative treatment, often the case in psychiatry, the reliance on SDM becomes more important (Morant et al, 2016). As mental health treatment increasingly reaches toward a recovery-oriented system of care, Barry & Edgman-Levitan argue that SDM is the highest form of patient-centered care.

### Implications for Research

There is a need for more effectiveness studies on the influence of training in SDM practices for both patients and providers. Patients may benefit from learning about the methodology of SDM to level the playing field. That is, more explicitly explaining the concept, what it means, the benefits and the responsibilities involved. Likewise, in the increasingly diversified field of healthcare, practitioners enter their jobs with differing amounts of education on SDM practices. The effect of attempts to improve providers' knowledge on this practice and implementation of SDM within the healthcare field remains insufficient (Legare et al, 2018). Implementation science research on the uptake of SDM strategies into organizational culture and climate is needed. Additionally, investigation of racial and ethnic differences in decision-making preferences can better inform clinical providers on how to individualize communication on decisional authority. While this study has too small a sample to draw conclusions on demographic information, the tendency for white Hispanic females to cede their autonomy needs further investigation. In somatic medicine, most interventional research on SDM has focused on decision aids to help patients build their preferences or to facilitate any kind of patient engagement (O'Connor et al, 2011) with far fewer attempts in the use of this strategy in mental health (Drake et al, 2010). The use of decision aids was not endorsed in this study but may be important in empowering patients to make more independent and informed choices.

While many important themes and implications for future work were found from this research, several limitations are present. All interviews were performed in one clinic with individuals who spoke English. Interviewing patients and providers in different areas and those who speak other languages may have extended the variability of responses. Only one of 24 total participants were African American limiting the generalizability of these findings. Additionally, the concept of



SDM was new to several of the patient participants and it is possible that our explanations influenced their answers.

In conclusion, shared decision making was viewed positively by all providers and most patients, although there is a wide range of opinions in the amount of power either person should have in medical decision making. Some patients are more likely to cede their control to the provider, resulting in the need for providers to adapt their approach to presenting information and eliciting patient engagement. Trust and honest communication is foundational to improved patient outcome and shared decision making is a tool to foster necessary engagement.

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**Table 2.1 Participant Characteristics**

	Patients ( $n = 15$ )	Providers ( $n = 9$ )
Age	$M = 41.2$ (SD = xx)	$M = 48.9$ (SD = 9.1)
Gender	4 m, 10 f, 1 nb	4 m, 5 f
Ethnicity	white Hispanic (8)	white Hispanic (4)
	white non-Hispanic (6)	non-Hispanic white (5)
	African American (1)	African American (0)



**Table 2.2. Exemplary Quotes from Six Themes**

<b>Differences in the Use of SDM</b>	
	“Yeah, we’ll talk about it, and then he’ll tell me about other medications, and then we pretty much kind of make the decision together.” patient
	“Well, I was doing good and everything, but all of a sudden, I started getting itches, and I just started feeling weird and stuff, so I was like, ‘Okay, it’s not for me. I don’t think this one’s working, doc.’ And he’s like, ‘Okay. We’ll try something else.’” patient
	“I’ve been tempted. Real tempted [to stop all medication]. But the doctor here also says ‘It’s your choice.’ And that’s a real shared decision in saying he doesn’t think it’s a great idea. He really don’t...But, he still let’s me make the final decision.” patient
	“I’ve had a lot of really good luck with collaborative decision making in this office.” patient
	“But he’s just very determined. If he decides something that’s what it is. He has a lot more power. There’s no partnership.” patient
	“The goal is for them [patients] to be equal partners without any power differential or hierarchy.” provider
	“By discussing the available and data driven treatments with the advantages and disadvantages for each treatment, it allows the client to be informed of their options for treatment and allows them the opportunity to give input on how they want to be treated?” provider
<b>Consideration of Past Experiences</b>	
	“I was detained for, I felt for being honest... I told her exactly how I felt...and I ended up being detained and hospitalized. And I’m like, Well, the hell with this. I’m not gonna talk to these people ever again.” patient
	“It’s terrible. They don’t even care. They just give you these prescriptions, thank you, bye-bye.” patient
	“I’ve been here a while and it’s not fun, changing from one doctor and starting over. And I don’t want to do that, but I do want my doctor to understand me. I want to because the feeling of a panic attack is horrible. He [the doctor] doesn’t listen.” patient
	“It didn’t start off well. I was very angry. I was angry with the cops, I was angry with everybody and angry when I came in here. I came into the clinic very angry and did not want to be here. It was a forced situation. patient
	“A lot of them [patients] said we didn’t know this was something that we should do because for so long we were told that we were unable to make decisions.” provider
	“Hearing the patient’s point of view really opened my eyes to how they were disempowered and how all the control was essentially put on someone else in their past.” provider

“I’ve seen patients surprised and really engaged in thinking about stuff that they weren’t expecting to be thinking about.” provider
“A lot of them shied away from <i>having input</i> and a lot of them said that’s not my place. I should never tell a doctor what to do.” provider
“Learning SDM practices takes time and practice for those who were trained to be more paternalistic.” provider
<b>Decisional Power Preferences</b>
“I think it should be a mix of both...Because you know what’s best for yourself, and then, well, the doc knows what’s best for you medically through her license. So I think it should be both. It’s a good thing. There’s a balance there.” patient
“No – I don’t think so. I guess because of what did happen to me and that caused me to be here...I think it should still be both because if it was more one-sided – I don’t know how that would work because that’s giving more power to the other person over your life. I think it should still be discussed by both parties equally.” patient
“The doctor should have slightly more because he’s the book smart. He’s done all the education to be the doctor.” patient
“...because I say of course he knows better than me. I’m gonna say this and that. Who am I? I’m just there, so I come here for the help, you know. And that’s it.” patient
“We should have less than 50%, unless the patient is exhibiting problems with decisional capacity at that time.” provider
“It may be something like the patient has 65%, doctor has maybe 25%, and then other has 10%, which could include people like family members.” provider
<b>Use of SDM in Psychiatry Versus Other Areas of Medicine</b>
“It [SDM approach] helps a lot because I never talked about my past traumas before.” patient
“It helps build a trust and respect. I’m not like a paycheck or salary. I respect them [providers] more because they show respect to me.” patient
“It [SDM] offered me an opportunity to assess where I was headed and choose if I wanted to return to the path that I’d already set out for myself, or veer off on another course.” patient
“It [SDM] makes patients want to participate in the process and feel engaged in the process. So I think it probably increased appointment adherence and prescribed treatments, which results in improved outcomes.” provider
“The prescriber has the opportunity to build trust with the patient through the SDM process. When the patient is informed about their treatment options, they are more inclined to engage in treatment.” provider
<b>Dignity and Disengagement</b>
“...with regards to medication, there was one time when I introduced the idea of going off medication and he [prescriber] was extremely opposed to the idea of me going off medication...I began experimenting with going off

the medication on my own rather than doing so in an observed environment. So I stopped wanting to come in for mental health treatment, which turned into its own snowball of bad feelings. And really hurt. Then when things became a big problem for me, I wasn't in an environment where I could be assisted, and so by the time that I returned to that environment, it was an emergency situation." patient
"The doctors that I had seen, she pretty much just made the decision for me, whenever I was saying I wasn't feeling good, or whatever, trying to decide what medication to take. She pretty much just made the decision. I don't really like that clinic and I didn't go back." patient
"You need to take me into consideration because I know my body." patient
"Sometimes I wish that, whatever doctor that I'm at, I wish that they could just feel what I'm feeling for just a minute so they could just have a little taste of what I go through." patient
"I really deeply believe in the importance of patients feeling autonomous, feeling that they are the main person guiding their life." provider

#### **External Forces Impacting SDM**

"Yes, when symptoms, like impulsivity make me forget the long-term goal." patient
"...there's an ability for, kind of, a circumnavigation. Like if I'm starting to veer off course there's a way of just circumventing that. I probably wouldn't be going back to school in January if she hadn't done that [made the decision]." patient
"Not in my experience. There is never a time when the doctor should have more say than the patient." patient
"If somebody is talking about self-harm...in those moments the doctor needs to step in, in a much more directive way." provider
"For example, I'll have patients come in and say, 'I want to do this.' And I'll say, Well, I don't completely agree with it, although there is no absolute contraindication. These are the risks associated with it. It's important to me that you accept the risks." provider
"When there's an absolute contraindication, then I say, 'There's an absolute contraindication to this and I won't prescribe it.'" provider

## **OVERALL CONCLUSION**

This study contributed to the limited published literature on SDM within the mental health field. To our knowledge this is the first evaluation of the perceptions and preferences of individuals with serious mental illness and their providers regarding SDM in a clinic serving a population immediately following a psychiatric crisis or hospitalization. Race/ethnicity is an important factor when using a SDM approach. African American individuals were more likely to want to be active or collaborative contributors in the medical decision-making process likely linked to a complex history of race in the medical profession. Many disparities are reported in the area of mental health when comparing African Americans to whites, including higher levels of incorrect diagnoses, underrepresentation in research, less access to treatment, more severe symptom ratings, greater functional impairment once diagnosed, and significantly fewer African Americans seeking treatment (Cosh et al, 2017; Cook et al, 2007; Parker & Satkoske, 2012; Oluwoye et al, 2018). Furthermore, Eliacin et al (2016) reports African Americans are less likely to be engaged in treatment and often perform more poorly on healthcare activities linked to patient engagement, such as communicating effectively with providers and participating in treatment decisions. To this end, active engagement and participation in mental health treatment may represent an important component in addressing many of these inequalities.

In contrast to African Americans, Hispanic individuals were more likely to choose a passive role in decision-making or cede their autonomy in decisional control. From a historical perspective, Hispanic individuals tend to be respectful of authority and more likely to adhere to a perceived power gradient, making them more likely to cede decision making to a medical provider (Kemp & Rasbridge, 2004; Gudykunst, 2004). Research indicates Hispanics are more

deferential to authority figures, depending on acculturation, and are less likely to engage in mental health treatment than whites (Patel & Bakken, 2010). For these reasons, Añez et al (2008) proposed the application of motivational interviewing principles to Latino cultural values and emphasizes the need to promote a client-centered and culturally congruent therapeutic environment to improve the connection to and participation of these individuals. Providers may also work to improve their Hispanic patients' self-efficacy in making sound medical decisions by dividing tasks and offering feedback and reinforcement for each aspect of illness self-management.

It is evident that baseline decision-making preferences need to be considered when providing mental health care. Patients of all races/ethnicities need to be aided on how to engage in the process of SDM and providers need to ensure they communicate the importance of active and collaborative participation, even in situations that may be new for individuals in treatment. This may involve recognizing the patient's knowledge, allowing sufficient time for participation or explaining the benefits of participating in treatment including improved health outcomes and better quality of life (Vahdat et al, 2014). In line with the emerging paradigm of patient-centered care, culturally appropriate decision making needs to be emphasized.

While race/ethnicity is an important consideration when using a shared decision-making approach, other demographic, clinical and communication characteristics were not predictive of control preference style in this context. It may be other factors are more important in determining the extent to which someone wants to contribute in psychiatric decision making. The participants in this study had in common a recent acute psychiatric hospitalization or crisis. Perhaps given

this often traumatic and stressful event, other characteristics, such as age, gender and symptom acuity become less important as related to shared decision-making preferences. Other possible explanations not explored in this study include previous experiences in the mental health system, including hospitalizations and personality traits.

The results of this study suggest that patients and providers value the SDM approach, understand its application, and believe it is related to better clinical outcomes. Several important topics are evident and can inform future clinical care and research in this field. Regarding implications for clinical practice, the study supports the need to ensure that SDM is a routine practice in psychiatric care. Patients and providers identified potential serious consequences including, disengagement and abruptly terminating treatment, when patients do not participate in decisions and do not feel heard. Studies of SDM connect increased patient involvement to improved treatment adherence and quality of life, while lack of patient involvement is related to lower adherence to treatment, patient satisfaction, and overall health outcomes (Sepucha & Mulley, 2009). The reports in this study that SDM improved show rates and reduced calls in between appointments is important to patients, providers and the agencies for which they work. Research continually demonstrates no shows increase overall healthcare costs and reduce the gains made from treatment (Kheirhah et al, 2016, Berg et al, 2013).

Both patients and providers in this study assert that trust in the clinical provider and patient honesty is strengthened by the use of SDM. Patients are more likely to share personal information needed to inform treatment options. Research supports that a trusting relationship with a clinical provider can strengthen alliance and prevent crises or other serious negative

outcomes (Arnow & Steidtmann, 2014; Howgego et al, 2003). To improve partnerships, clinical providers can offer options and have a conversation, even when yielding to the patient's request is not feasible. As part of this conversation, providers must consider there is a certain dignity in risk-taking, even when not medically supported (i.e. getting off medication). Although there is less of an emphasis of SDM in mental health care (Pollard, 2015; De las Cuevas et al, 2013; Drake et al, 2010; Hamann et al, 2006), the findings of this study suggest the use of a SDM approach is more important in this field compared to traditional somatic care. Psychiatric care is dependent on the nature of communication and this is instrumental in whether care is deemed effective. When you do not have a clearly superlative treatment, often the case in psychiatry, the reliance on SDM becomes more important (Morant et al, 2016).

Regarding implications for future research, there is a need for more effectiveness studies on the influence of training in SDM practices for both patients and providers. Patients may benefit from providers more explicitly explaining the concept of SDM, what it means, and the benefits and the responsibilities involved. Likewise, in the increasingly diversified field of healthcare, practitioners enter their jobs with differing amounts of education on SDM practices. The effect of attempts to improve providers' knowledge on this practice and implementation of SDM within the healthcare field remains insufficient (Legare et al, 2018). Implementation science research on the uptake of SDM strategies into organizational culture and climate is needed. Additionally, investigation of racial and ethnic differences in decision-making preferences can better inform clinical providers on how to individualize communication on decisional authority.

There are several limitations to this study that should be noted. Multiple tests of statistical significance were utilized in the quantitative analyses and may have increased the likelihood that the relationship between race/ethnicity and control preference group was due to chance. The cross-sectional nature of this study did not allow for examination of difference in SDM styles over time and a relatively smaller percentage of African American study participants make it difficult to generalize from these results. The control preference groups were determined by one self-reported assessment. While the Control Preferences Scale is a validated instrument, it is possible that more sensitive scales or use of more than one scale is needed. Additionally, all interviews were performed in one clinic with individuals who spoke English. Interviewing patients and providers in different geographic areas and those who speak other languages may have extended the variability of responses.

Despite the limitations described above, the study highlighted that SDM preferences are different across individuals in this treatment setting. These preferences need to be considered in approaching SDM education for patients and providers and in creation of culturally informed decision aids and manuals. The concept of SDM is not a new one, however, we are experiencing a paradigm shift with more emphasis in self-directed care in the mental health system. Both providers and patients want to share in medical decision making, but neither may be completely certain how to appropriately engage in collaborative exchange. This may be especially true for providers and their patients who have recently been discharged from an inpatient setting. Using culturally congruent decision aids and increasing patient activation and self-efficacy in making medical decisions may be viable methods of engaging individuals in care, thereby increasing collaborative decision-making. SDM has been demonstrated to improve outcomes for people



across many areas of mental and physical health and must be implemented with thoughtful consideration of patients to realize its full potential.

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## **APPENDICES**

## Appendix A. Control Preferences Scale - Cards



I PREFER TO MAKE THE FINAL SELECTION  
ABOUT WHICH TREATMENT I WILL RECEIVE.



I PREFER TO MAKE THE FINAL SELECTION  
OF MY TREATMENT AFTER SERIOUSLY  
CONSIDERING MY DOCTOR'S OPINION.



I PREFER THAT MY DOCTOR AND I  
SHARE RESPONSIBILITY FOR  
DECIDING WHICH TREATMENT IS  
BEST FOR ME.



I PREFER THAT MY DOCTOR MAKES THE  
FINAL DECISION ABOUT WHICH  
TREATMENT WILL BE USED, BUT  
SERIOUSLY CONSIDERS MY OPINION.



I PREFER TO LEAVE ALL DECISIONS REGARDING  
MY TREATMENT TO MY DOCTOR.

## **Appendix B: Control Preference Scale Score Sheet**

To score the completed scale, use the top 2 preferred cards to determine which category the patient falls into.

Please circle the appropriate number for the top 2 cards:

- 1 – Active-Active (card order AB or BA) – enter 1 in the data file
- 2 – Active-Collaborative (card order BC) – enter 2 in the data file
- 3 – Collaborative-Active (card order CB) – enter 3 in the data file
- 4 – Collaborative-Passive (card order CD) – enter 4 in the data file
- 5 – Passive-Collaborative (card order DC) – enter 5 in the data file
- 6 – Passive-Passive (card order DE or ED) – enter 6 in the data file

## Appendix C: Matched Pair Instrument (Provider)

Using your opinion of today's appointment, please rate each item using the 5-point scale provided. Circle your response.

	Not at all true	Slightly true	Moderately true	Mostly true	Very true
1. Greeted the patient in a way that made them feel comfortable.	0	1	2	3	4
2. Discussed patient's reason(s) for coming today.	0	1	2	3	4
3. Encouraged patient to express their thoughts concerning any health problems	0	1	2	3	4
4. Listened carefully to what they had to say.	0	1	2	3	4
5. Understood what they had to say.	0	1	2	3	4
6. If a physical exam or lab test was needed, explained what was done and why.	0	1	2	3	4
7. Discussed treatment options with them.	0	1	2	3	4
8. Gave the patient as much information as they wanted.	0	1	2	3	4
9. Checked with the patient to see if the treatment plan was acceptable.	0	1	2	3	4
10. Explained medications, if any, including possible side-effects.	0	1	2	3	4
11. Encouraged the patient to ask questions.	0	1	2	3	4
12. Responded to questions and concerns.	0	1	2	3	4
13. Involved the patient in decisions as much as he or she wanted.	0	1	2	3	4
14. Discussed next steps including any follow-up plans.	0	1	2	3	4
15. Checked to be sure the patient understood everything.	0	1	2	3	4
16. Showed care and concern about the patient as a person.	0	1	2	3	4

17.	Spent the right amount of time with them.	0	1	2	3	4
18.	Overall, I was satisfied with this meeting today.	0	1	2	3	4

## Appendix D: Matched Pair Instrument (Consumer)

Using your opinion of today's appointment, please rate each item using the 5-point scale provided. Circle your response.

	Not at all true	Slightly true	Moderately true	Mostly true	Very true
1. Greeted me in a way that made me feel comfortable.	0	1	2	3	4
2. Discussed me reason(s) for coming today.	0	1	2	3	4
3. Encouraged me to express my thoughts concerning my health problems	0	1	2	3	4
4. Listened carefully to what I had to say.	0	1	2	3	4
5. Understood what I had to say.	0	1	2	3	4
6. If a physical exam or lab test was needed, explained what was done and why.	0	1	2	3	4
7. Discussed treatment options with me.	0	1	2	3	4
8. Gave me as much information as I wanted.	0	1	2	3	4
9. Checked to see if the treatment plan was acceptable to me.	0	1	2	3	4
10. Explained medications, if any, including possible side-effects.	0	1	2	3	4
11. Encouraged me to ask questions.	0	1	2	3	4
12. Responded to my questions and concerns.	0	1	2	3	4
13. Involved me in decisions as much as I wanted.	0	1	2	3	4
14. Discussed next steps including any follow-up plans.	0	1	2	3	4
15. Checked to be sure I understood everything.	0	1	2	3	4
16. Showed care and concern about me as a person.	0	1	2	3	4
17. Spent the right amount of time with me.	0	1	2	3	4
18. Overall, I was satisfied with my visit to the doctor today.	0	1	2	3	4



## Appendix E: Brief Psychiatric Rating Scale (BPRS)

**Instructions:** This form consists of 24 symptom constructs, each to be rated on a 7-point scale of severity ranging from “not present” to “extremely severe”. If a specific symptom is not rated, mark “NA”, Not Assessed. Circle the number headed by the term that best describes the patient’s present condition.

NA	1	2	3	4	5	6	7
Not Assessed	Not Present	Very Mild	Mild	Moderate	Moderately Severe	Severe	Extremely Severe

Rate items 1-10 on the basis of patient’s self-report.

1. Somatic Concerns	NA	1	2	3	4	5	6	7
2. Anxiety	NA	1	2	3	4	5	6	7
3. Depression	NA	1	2	3	4	5	6	7
4. Guilt	NA	1	2	3	4	5	6	7
5. Hostility	NA	1	2	3	4	5	6	7
6. Suspiciousness	NA	1	2	3	4	5	6	7
7. Unusual Thought Content	NA	1	2	3	4	5	6	7
8. Grandiosity	NA	1	2	3	4	5	6	7
9. Hallucinations	NA	1	2	3	4	5	6	7
10. Disorientation	NA	1	2	3	4	5	6	7

Rate items 11-24 on the basis of observed behavior and speech

11. Conceptual Disorganization	NA	1	2	3	4	5	6	7
12. Excitement	NA	1	2	3	4	5	6	7
13. Motor Retardation	NA	1	2	3	4	5	6	7
14. Blunted Affect	NA	1	2	3	4	5	6	7
15. Tension	NA	1	2	3	4	5	6	7
16. Mannerisms and Posturing	NA	1	2	3	4	5	6	7
17. Uncooperativeness	NA	1	2	3	4	5	6	7
18. Emotional Withdrawal	NA	1	2	3	4	5	6	7
19. Suicidality	NA	1	2	3	4	5	6	7
20. Self-neglect	NA	1	2	3	4	5	6	7
21. Bizarre Behavior	NA	1	2	3	4	5	6	7
22. Elevated Mood	NA	1	2	3	4	5	6	7
23. Motor Hyperactivity	NA	1	2	3	4	5	6	7
24. Distractibility	NA	1	2	3	4	5	6	7

## **Appendix F: BPRS Factors and Variables**

**Psychosis**—includes Suspiciousness, Unusual Thought Content, Hallucinations, and Conceptual Disorganization

**Depression**—includes Anxiety, Depression, and Guilt

**Psychomotor Retardation**—includes Motor Retardation, Blunted Affect, and Emotional Withdrawal

**Paranoia**—includes Hostility, Suspiciousness, and Uncooperativeness

## **Appendix G: Scale to Assess Unawareness of Mental Disorder (SUMD); (Abbreviated Version)**

### **1. Awareness of mental disorder.**

In the most general terms, does the subject believe that s/he has a mental disorder, psychiatric problem, or emotional difficulty, etc.?

0	Cannot be assessed
1	Aware: Subject clearly believes that s/he has a mental disorder
2	
3	Somewhat: Is unsure about whether s/he has a mental disorder but can entertain the idea that s/he might.
4	
5	Unaware: Believes s/he does not have a mental disorder

### **2. Awareness of achieved effects of medication**

What is the subject's belief regarding the effects of medication? Does the subject believe that medications have lessened the intensity or frequency of his/her symptoms (i.e. if applicable)?

0	Cannot be assessed
1	Aware: Subject clearly believes medications have lessened the intensity or frequency of his/her symptoms.
2	
3	Somewhat: Is unsure about whether medications have lessened the intensity or frequency of his/her symptoms, but can entertain the idea
4	
5	Unaware: Believes that medications have not lessened the intensity or frequency of his/her symptoms.

### **3. Awareness of social consequences of mental disorder**

What is the subject's belief regarding the reason s/he has been admitted to the hospital, involuntarily hospitalized, arrested, evicted, fired, injured, etc.?

0	Cannot be assessed
1	Aware: Subject clearly believes that the relevant social consequences are related to having a mental disorder.
2	
3	Somewhat: Is unsure about whether the relevant social consequences are related to having a mental disorder.
4	

- |   |   |
|---|---|
| 5 | Unaware: Believes that the relevant social consequences have nothing to do with having a mental disorder. |
|---|---|

## Appendix H. Qualitative Interview Guide - Staff

### Staff Interview Guide (Maples) INTERVIEW GUIDE

#### Staff VERSION – Prescribers

Study Objective	Progression of Questions in Interview Guide
<p><b>OBJECTIVE:</b></p> <p>The overall objective of this study is to collect information from prescribers and other involved staff the use of shared decision making in the post-acute psychiatric treatment setting (transitional care clinic-TCC). The special focus of this interview is to understand staff experiences of shared decision making in general and the Shared Decision Making (SDM) intervention used at the Transitional Care Clinic. In addition, we would like to understand the impact of SDM on the relationship between patients and staff and the outcomes of the patient.</p> <p>Specific objectives are as follows:</p> <ol style="list-style-type: none"> <li>1. Identify and document thoughts about and experiences with shared decision making in general and using shared decision making in patient encounters.</li> <li>2. Clarify the importance of various aspects of SDM from the staff perspective including decision tools, web materials, patient videos and TAC-REVIEW.</li> <li>3. Identify barriers and facilitators to the use of SDM in the post-acute psychiatric clinic setting.</li> <li>4. Identify the impact of SDM on outcomes.</li> </ol>	<p><b>OVERALL FLOW:</b></p> <p><b>Shared Decision Making:</b> Open-ended exploration of SDM in general</p> <p><b>Specific questions about SDM</b></p> <p>↓</p> <p>Basic Understanding Experiences with SDM Thoughts about responsibility and involvement How much and what kind of information is appropriate to provide?</p> <p><b>Shared Decision Making intervention:</b> Open-ended exploration of specific SDM thoughts and impressions of the intervention and its impact upon outcomes.</p> <p>↓</p> <p>Usefulness of coaches Impact on Timing and Length of psychiatric appointments Decision tools Web sites TAC-REVIEW</p> <p>↓</p> <p><b>Barriers to using the intervention:</b> What got in the way of the processes of SDM or its application?</p> <p>↓</p> <p>Percieved limits to patient understanding Percieved limits of competence Limits of materials</p> <p>↓</p> <p>Impact on process and outcomes</p>

## INTERVIEWER INSTRUCTIONS

Your goal as the interviewer is to elicit information on the topics of interest without influencing participant's responses. To do this, begin each topic area with broad, open-ended questions, and then ask more specific questions to clarify and elicit more detail regarding participant's responses.

Begin each topic area by posing questions broadly. Specific wording for the interviewer is denoted in **bold font**. Follow with the more specific questions. It is not necessary to explicitly ask each of the bulleted prompts within a topic area, but you should refer to the bullets to ensure that each topic is addressed with sufficient coverage, rather than focusing on just one or two narrow areas.

## INTERVIEW GUIDE

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### TO BEGIN:

1. Introduce yourself and your association with the study.
  2. Explain purpose of the interview.
  3. Thank participants for their willingness to participate.
  4. Assure the participant of confidentiality, including that this study will not impact employment at TCC, and that neither other the TCC providers nor the SDM coach will learn their answers.
  5. Let them know the general process of how it will proceed.
- 

The purpose of this interview:

**This interview will take approximately 30-45 minutes. I will ask you a variety of questions to help us better understand your experiences with shared decision making in general and how this process works with patients. I will ask about your overall impressions, how SDM impacts the timing and length of encounters, how the specific strategies used impact the visit, and what works or does not work for you in terms of helping the patient understand their options and communicating decisions. I will also ask your opinions about how the use of SDM impacts patient outcomes.**

How this interview will work:

**I will start by asking more general questions then become more specific. I am interested in what you have to say about your experiences, so please respond with whatever is on your mind.**

**I want to remind you this interview is being recorded. I will not use your name from the point that I turn on the recorder, and I will ask you to try and not use your name or the names of specific patients or staff members in any of your responses. This will help keep the interview anonymous.**

**I will use the recording only to remind me of the important things you said so we can use your input. The recordings will be transcribed, and then put together with transcripts from everyone else taking part in these interviews. All recordings will be deleted after they are**

**transcribed. You will not be individually identified in any of the reports that result from these interviews. I ask you for your honest opinion during this interview. Do you have any questions or concerns before we begin?**

## **INTERVIEW ITEMS**

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### **I. FIRST DISCUSSION ITEM**

**Purpose:** Initial, broad item to get participant to begin thinking about their SDM experiences, what it entails, about their role in the process, and the information needed to make it work.

**To start, I'd like you to think about shared decision-making in encounters with patients, what it means and what you think about this approach to patient care.**

- 1. How do you understand shared decision making?**
- 2. In general, what do you think of the shared decision making approach?**
- 3. Do you ever explain shared decision making to patients? If yes, how?**
- 4. How much responsibility do you think you and other doctors should have in decisions about patient's mental health treatment?**
- 5. Are there certain times when you want a lot of patient input into decision making? (Some examples)**
- 6. Are there certain times when you feel you want to be the primary decision maker about the patient's psychiatric treatment? (Some examples)**

### **II. SECOND DISCUSSION ITEM**

**Purpose:** This item is designed to get participants to begin thinking about the SDM training and use of the coach for patients at TCC specifically, what they thought and felt about it.

**Now I'd like you to think about your experiences with SDM training and with SDM coaching specifically at the Transitional Care Clinic.**

- 1. What did you learn in the training? Was this new information?**
- 2. What are some things you like or did not like about the patients participating in shared decision making coaching?**
- 3. What information do you think is needed from the SDM coach to help the patient improve their visit with you?**
- 4. How do you think SDM coaching impacts patient preparedness for visits with you?**

### **III. THIRD DISCUSSION ITEM**

**Purpose:** The purpose of this item is to get the participant discussing any barriers or facilitators they saw or experienced in the use of SDM in their clinic.

**At this point I'd like you to think about things that might make it easy or difficult for you to participate in a shared decision making approach to care at the Transitional Care Clinic.**

(These can be mirror images of the questions above and may be unnecessary if they have already discussed.)

1. What kind of problems do you have in using SDM?
2. What are the difficulties in patients understanding SDM concepts?
3. What are the difficulties in patients taking more responsibility in making medical decisions?
4. What is most helpful about the SDM approach?
5. What is least helpful?
6. How did you feel about the length of sessions with patients when using the SDM model of care? (Did they get longer or take additional effort or resources due to using SDM?)
7. Tell me about the costs of using an SDM approach. Do they outweigh the benefits? (Why?)
8. What kinds of characteristics make it easier or more difficult for patients to engage in SDM?
9. Thinking specifically about the use of SDM at the TCC, how do you feel about how easy or difficult it was to fit this model into your treatment practices? (Why?)
10. Explain the benefits you personally receive in your work from using SDM, if any.
11. There is a movement to integrated models of healthcare. How do you feel SDM fits within this public health priority?
12. Are there any other problems or benefits in using SDM we have not yet talked about?

#### IV. FOURTH DISCUSSION ITEM

Purpose: More specific focus on how SDM changed their participation in sessions with the patient.

**Now let's get a little more focused and talk about how much and in what ways SDM changed the way you interact with patients and vice versa.** (These can be mirror images of the questions above and may not be unnecessary if they have already discussed.)

1. Think of times you treated patients similar to those at the TCC prior to learning shared decision making. What differences do you find in your treatment now?
2. What is different about your communication behavior with patients when using SDM?
3. In what way does SDM impact the way you discuss a specific medication or treatment with patients?
4. How do you think knowing SDM impacts how seriously you take patients' input about medical decisions?
5. What changes have you seen in patient's communication to you as a result of adopting SDM?
6. In using SDM, do you believe the patient feels like an equal partner in decisions about their treatment? (Explain)

#### V. FIFTH DISCUSSION ITEM



Purpose: To gather information about how SDM impacted your outcomes

**Think about how SDM impacts patient outcomes.**

- 1. In what way do you believe SDM may help or hurt your patient's recovery?**
- 2. In what way do you believe SDM may help or hurt your patient's engagement in treatment?**

## Appendix H2. Qualitative Interview Guide - Staff

### Staff Interview Guide (Maples) INTERVIEW GUIDE

#### Staff Version – Other Clinic Personnel

Study Objective	Progression of Questions in Interview Guide
<p><b>OBJECTIVE:</b></p> <p>The overall objective of this study is to collect information from prescribers and other involved staff the use of shared decision-making in the post-acute psychiatric treatment setting (transitional care clinic-TCC). The special focus of this interview is to understand staff experiences of shared decision making in general and the Shared Decision Making (SDM) intervention used at the Transitional Care Clinic. In addition, we would like to understand the impact of SDM on the relationship between patients and staff and the outcomes of the patient.</p> <p>Specific objectives are as follows:</p> <ol style="list-style-type: none"> <li>5. Identify and document thoughts about and experiences with shared decision making in general and using shared decision making in patient encounters.</li> <li>6. Clarify the importance of various aspects of SDM from the staff perspective including decision tools, web materials, patient videos and TAC-REVIEW.</li> <li>7. Identify barriers and facilitators to the use of SDM in the post-acute psychiatric clinic setting.</li> <li>8. Identify the impact of SDM on outcomes.</li> </ol>	<p><b>OVERALL FLOW:</b></p> <p><b>Shared Decision Making:</b> Open-ended exploration of SDM in general</p> <p><b>Specific questions about SDM</b></p> <p>↓</p> <p>Basic Understanding Experiences with SDM Thoughts about responsibility and involvement How much and what kind of information is appropriate to provide?</p> <p><b>Shared Decision Making intervention:</b> Open-ended exploration of specific SDM thoughts and impressions of the intervention and its impact upon outcomes.</p> <p>↓</p> <p>Usefulness of coaches Impact on Timing and Length of psychiatric appointments Decision tools Web sites TAC-REVIEW</p> <p>↓</p> <p><b>Barriers to using the intervention:</b> What got in the way of the processes of SDM or its application?</p> <p>↓</p> <p>Percieved limits to patient understanding Percieved limits of competence Limits of materials</p> <p>↓</p>

## INTERVIEWER INSTRUCTIONS

Your goal as the interviewer is to elicit information on the topics of interest without influencing participant's responses. To do this, begin each topic area with broad, open-ended questions, and then ask more specific questions to clarify and elicit more detail regarding participant's responses.

Begin each topic area by posing questions broadly. Specific wording for the interviewer is denoted in **bold font**. Follow with the more specific questions. It is not necessary to explicitly ask each of the bulleted prompts within a topic area, but you should refer to the bullets to ensure that each topic is addressed with sufficient coverage, rather than focusing on just one or two narrow areas.

## INTERVIEW GUIDE

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### TO BEGIN:

6. Introduce yourself and your association with the study.
  7. Explain purpose of the interview.
  8. Thank participants for their willingness to participate.
  9. Assure the participant of confidentiality, including that this study will not impact employment at TCC, and that neither other the TCC providers nor the SDM coach will learn their answers.
  10. Let them know the general process of how it will proceed.
- 

The purpose of this interview:

**This interview will take approximately 45-60 minutes. I will ask you a variety of questions to help us better understand your experiences with shared decision making in general and how this process works with patients. I will ask about your overall impressions, how SDM impacts the timing and length of encounters, how the specific strategies used impact the visit, and what works or does not work for you in terms of helping the patient understand their options and communicating decisions. I will also ask your opinions about how the use of SDM impacts patient outcomes.**

How this interview will work:

**I will ask general questions, and after each one there will be some time for you to respond. We are interested in what you have to say about your experiences, so please respond with whatever is on your mind.**

**I want to remind you this interview is being recorded. I will not use your name from the point that I turn on the recorder, and I will ask you to try and not use your name or the**

names of specific patients or staff members in any of your responses. This will help keep the interview anonymous.

I will use the recording only to remind me of the important things you said so we can use your input. The recordings will be transcribed, and then put together with transcripts from everyone else taking part in these interviews. All recordings will be deleted after they are transcribed. You will not be individually identified in any of the reports that result from these interviews. I ask you for your honest opinion during this interview.

Do you have any questions before we start?

## INTERVIEW ITEMS

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### VI. FIRST DISCUSSION ITEM

Purpose: Initial, broad item to get participant to begin thinking about their SDM experiences, what it entails, about their role in the process, and the information needed to make it work.

To start, I'd like you to think about shared decision-making in encounters with patients, what it means and what you think about this approach to patient care.

7. How do you understand shared-decision making?
8. How do you feel about someone helping the patient prepare for visits with their doctor and other members of the treatment team?
9. In general, what do you think of the shared decision-making approach?
10. How do you explain shared decision making to patients?
11. How much responsibility do you think doctors should have in decisions about their patient's mental health care?
12. What are some examples of when you think the doctor should be the primary decision maker?
13. What are some examples of when you think the patient should be the primary decision maker?

### VII. SECOND DISCUSSION ITEM

Purpose: This item is designed to get participants to begin thinking about the SDM training and use of the coach for patients at TCC specifically, what they thought and felt about it.

Now I'd like you to think about your experiences with SDM training and with the SDM coach at the Transitional Care Clinic.

5. What did you learn in the training? Was this new information?
6. What are some things you like or do not like about having patients participate in the shared decision making meetings with a coach?
7. What information do you think is needed from an SDM coach to help the patient improve their visit with the doctor?
8. How do you think SDM coaching impacts patient preparedness for doctor's visits?

### VIII. THIRD DISCUSSION ITEM

Purpose: The purpose of this item is to get the participant discussing any barriers or facilitators they saw or experienced in the use of SDM in their clinic.

**At this point I'd like you to think about things that might make it easy or difficult for you to participate in an SDM approach to care.** (These can be mirror images of the questions above and may be unnecessary if they have already discussed.)

- 13. What kind of problems do you have using SDM?**
- 14. What are the difficulties in patients understanding SDM concepts?**
- 15. What are the difficulties in patients taking more responsibility in making medical decisions?**
- 16. What is most helpful about the SDM approach?**
- 17. What is least helpful?**
- 18. How do you feel about addition of and length of the sessions for SDM coaching?**
- 19. Tell me about the costs of using an SDM approach. Do they outweigh the benefits? (Why?)**
- 20. What kinds of characteristics make it easier or more difficult for patients to engage in SDM?**
- 21. Thinking specifically about the use of SDM at the TCC, how do you feel about how easy or difficult it was to fit this model into clinic practices? (Why?)**
- 22. Explain the benefits you personally receive in your work from using SDM, if any.**
- 23. There is a movement to integrated models of healthcare. How do you feel SDM fits within this public health priority?**
- 24. Are there any other problems or benefits in using SDM that we have not yet talked about?**

### IX. FOURTH DISCUSSION ITEM

Purpose: More specific focus on how SDM changed their participation in sessions with the patient.

**Now let's get a little more focused and talk about how much and in what ways SDM changed the way you interact with patients, and how they interact with you or other clinic staff.** (These can be mirror images of the questions above and may be unnecessary if they have already discussed.)

- 7. In what ways do you think SDM coaching changes the way patients try to work with their doctor in decision making?**
- 8. What is different about your communication behavior with patients when using SDM?**
- 9. How do you think knowing SDM impacts how seriously you take patients' thoughts and concerns?**
- 10. What changes have you seen in patient's communication to you or other clinic staff as a result of adopting SDM?**
- 11. Do you think the patient feels like an equal partner in decisions about their treatment? (Explain)**

X. FIFTH DISCUSSION ITEM

Purpose: To gather information about how SDM impacted your outcomes

**Think about how SDM impacts patient outcomes.**

- 3. In what way do you believe SDM may help or hurt patient recovery?**
- 4. In what way do you believe SDM may help or hurt patient engagement in treatment?**

## Appendix I: Qualitative Interview Questions – Patient Version

### Patient Interview Guide (Maples) INTERVIEW GUIDE

#### PATIENT VERSION

Study Objective	Progression of Questions in Interview Guide
<p><b>OBJECTIVE:</b></p> <p>The overall objective of this study is to collect information from patients about their preferences in sharing decisions about their post-acute psychiatric treatment. The special focus of this interview is to understand patient desires and experiences of shared decision making in general and the Shared Decision Making (SDM) intervention used at the Transitional Care Clinic including the prescriber, SDM coach, specific techniques and available resources. In addition, we would like to understand the impact of SDM on the patient's treatment and outcomes.</p> <p>Specific objectives are as follows:</p> <ol style="list-style-type: none"> <li>9. Identify and document patient thoughts about and experiences with shared decision making in general and responses to the shared decision making intervention.</li> <li>10. Clarify the importance of various aspects of SDM treatment including decision tools, web materials, patient videos and TAC-REVIEW.</li> <li>11. Identify barriers and facilitators to the use of SDM in the post-acute psychiatric clinic setting.</li> <li>12. Identify the impact of SDM on outcomes.</li> </ol>	<p><b>OVERALL FLOW:</b></p> <p><b>Shared Decision Making:</b> Open-ended exploration of SDM in general</p> <p><b>Specific questions about SDM</b></p> <p>↓</p> <p>Basic Understanding Experiences with SDM Thoughts about responsibility and involvement How much and what kind of information might be needed?</p> <p><b>Shared Decision Making intervention:</b> Open-ended exploration of specific SDM thoughts and impressions of the intervention and its impact upon outcomes.</p> <p>↓</p> <p>Usefulness of coaches Timing and Length Decision tools Web sites TAC-REVIEW</p> <p>↓</p> <p><b>Barriers to using the intervention:</b> What got in the way of the processes of SDM or its application?</p> <p>↓</p> <p>Limits of information Perceived limits to understanding Time and timing Limits of practitioners Limits of materials</p>

## INTERVIEWER INSTRUCTIONS

Your goal as the interviewer is to elicit information on the topics of interest without influencing participant's responses. To do this, begin each topic area with broad, open-ended questions, and then ask more specific questions to clarify and elicit more detail regarding participant's responses.

Begin each topic area by posing questions broadly. Specific wording for the interviewer is denoted in **bold font**. Follow with the more specific questions. It is not necessary to explicitly ask each of the bulleted prompts within a topic area, but you should refer to the bullets to ensure that each topic is addressed with sufficient coverage, rather than focusing on just one or two narrow areas. Recall that not all information appearing in

## INTERVIEW GUIDE

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### TO BEGIN:

11. Introduce yourself and your association with the study.
  12. Explain purpose of the interview.
  13. Thank participants for their willingness to participate.
  14. Assure the participant of confidentiality, including that this study is not related to the treatment they will receive at TCC, and that neither the TCC providers nor SDM coach will learn their answers.
  15. Let them know the general process of how it will proceed.
- 

The purpose of this interview:

**This interview will take approximately 30-45 minutes. I will ask you a variety of questions that will help us to better understand your experiences with shared decision making in general, how this process goes with your shared decision making coach and prescriber. I will ask about your overall impressions, how the timing and length of SDM sessions work, how the specific things the SDM coach did or the tools she used impacted you, what does and does not work for you in terms of helping you understand your options and communicate your decisions to the treatment team. I will also ask how the SDM sessions impacted your outcomes in treatment.**

How this interview will work:

**I will be asking general questions, and after each one there will be some time for you to respond. We are interested in what you have to say about your experiences, so please respond with whatever is on your mind.**

**I want to remind you that this interview is being recorded. I will try to not use your name from the point that I turn on the recorder, and I will ask you to try and not use your name or the names of friends or family in any of your responses. This will help keep the interview anonymous.**



**I will be using the recording only to remind me of the important things you said so we can use your input. The recordings will be transcribed, and then put together with transcripts from everyone else taking part in these interviews. All recordings will be deleted after they are transcribed. You won't be able to be individually identified in any of the reports that result from these interviews.**

**Do you have any questions before we start?**

## **INTERVIEW ITEMS**

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### **XI. FIRST DISCUSSION ITEM**

**Purpose:** Initial, broad item to get participant to begin thinking about their SDM experiences, what it entails, about their role in the process, and the information needed to make it work.

**To start, I'd like you to think about shared decision-making when making decisions about your psychiatric treatment, what it means and what you think about it.**

- **How do you understand shared decision making?**
- **How do you feel about someone helping you to prepare for visits with your doctor?**
- **In general, what do you think of the shared decision making approach?**
- **Are there certain decisions where you want input from others before you make them? (Some examples)**
- **Are there certain decisions that you want a doctor to make? (Some examples)**
- **How much responsibility do you want to have in decisions about your mental health care?**
- **What information do you think is needed from your coach and doctor to help you make good decisions?**
- **How do you think the information should be presented?**

### **XII. SECOND DISCUSSION ITEM**

**Purpose:** This item is designed to get participants to begin thinking about their SDM experience at TCC specifically, what they thought and felt about it.

**Now I'd like you to think about your experiences with the SDM coach at the TCC.**

**What are some things that you liked or did not like about being in the shared decision making meetings with your coach?**

**You may have experienced different things in SDM or been exposed to different tools depending on your needs. So you may not have experience with many of the things I will list. But if you did use them please let me know what you thought about them, positive or negative. (Were they helpful, not useful...)**

- **Specific tools (handouts)**

- Websites
- Patient videos
- TAC-REVIEW process

### XIII. THIRD DISCUSSION ITEM

Purpose: The purpose of this item is to get the participant discussing any barriers or facilitators they saw or experienced in the use of SDM in their clinic.

**At this point I'd like you to think about things that might have made it difficult for you to participate in SDM and things that helped to move the process along.** (These can be mirror images of the questions above and may be unnecessary if they have already discussed.)

- What kind of problems did you have in participating in SDM?
- What were the difficulties in understanding shared-decision making?
- What kind of problems or gaps were there in the information you received from the coach or prescriber?
- What was most helpful about shared decision making?
- What was least helpful?
- How did you feel about the length of the sessions? How did you feel about how easy or difficult it was to fit the SDM sessions into your visits with your doctor?
- What kinds of things did your doctor do that may have made it harder for you to engage in decisions about your treatment?
- Were there any other problems in using SDM that we have not yet talked about?

### XIV. FOURTH DISCUSSION ITEM

Purpose: More specific focus on how SDM changed their participation in sessions with the prescriber.

**Now let's get a little more focused and talk about how much and in what ways SDM changed the way you spoke with your doctor.** (These can be mirror images of the questions above and may be unnecessary if they have already discussed.)

**Think of times you met with a doctor before shared decision-making? What differences did you find in your treatment?**

- In what ways has your participation in SDM coaching changed the way you work with your doctor?
- In what way did you notice differences in your behavior?
- In what way did you notice differences in your feelings?
- In what way did notice differences in how your sessions went compared with other medical office visits?
- In what way did you notice differences in how prepared you thought you were for the visit with your doctor?
- How do you think SDM impacted how seriously your thoughts and concerns were taken by the provider?
- In what way did you feel more or less comfortable voicing your opinion?

- **In what way did you feel more or less confident about the choices you made?**
- **Did you feel more like an equal partner in your decisions? (Explain)**

**XV. FIFTH DISCUSSION ITEM**

Purpose: To gather information about how SDM impacted your outcomes

**Think about how SDM impacted your outcomes.**

- **In what way did SDM help or hurt your recovery?**
- **In what way did SDM help or hurt your chances of continuing mental health treatment?**