Service Engagement and Serious Mental Illness: The Obstacles and Barriers to Attendance in a Post-Treatment Recovery Outpatient Setting

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Philadelphia College of Osteopathic Medicine

Department of Psychology

SERVICE ENGAGEMENT AND SERIOUS MENTAL ILLNESS: THE OBSTACLES AND BARRIERS TO ATTENDANCE IN A POST-TREATMENT RECOVERY OUTPATIENT SETTING

Marisa Jeanne Friedman

Submitted in Partial Fulfillment of the Requirements for the Degree of Doctor of Psychology

June 2014
PHILADELPHIA COLLEGE OF OSTEOPATHIC MEDICINE
DEPARTMENT OF PSYCHOLOGY

Dissertation Approval

This is to certify that the thesis presented to us by ___Marisa Friedman________
on the ___16th___ day of ____April, 2014____, in partial fulfillment of the requirements for
the degree of Doctor of Psychology, has been examined and is acceptable in both
scholarship and literary quality.

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Abstract

This qualitative study examined the factors that affect treatment adherence and service engagement in individuals with serious mental illnesses (SMI). A semistructured interview was used to collect data from treatment adherent and treatment nonadherent adults with SMI. What factors make one more or less likely to disengage from treatment? What boundaries stand in the way of quality mental-health care, and how do adults with SMI overcome these barriers? Service engagement in the population with SMI in the study was explained according to three healthcare behavioral models, the health belief model, the network episode model, and the demoralization framework model. Data collected from the narratives of 12 participants suggest that provider factors, including treatment style, theoretical orientation, and communication style, can be protective factors against systemic barriers. In light of the results of narrative data, health behavioral models that emphasize process-oriented behaviors in consideration with a broader social structure are better predictors of healthcare engagement than are rational, value-expectancy models.

Keywords: serious mental illness, service engagement, treatment adherence, treatment barriers, provider treatment style, shared decision making, demoralization, hope, empowerment, meaning-making, recovery, healthcare behavioral models
# Table of Contents

List of Figures .................................................................................................................. viii
List of Tables ..................................................................................................................... ix

Introduction ....................................................................................................................... 1

Statement of the Problem ............................................................................................... 1

Literature Review ............................................................................................................. 6

The impact of untreated SMI on the individual and society ........................................ 6

Noncontinuity of care in the population with SMI ....................................................... 8

Compliance, adherence, and service engagement ....................................................... 10

Service engagement/disengagement risk factors ....................................................... 11

Service engagement/disengagement protective factors ............................................. 16

Service engagement and healthcare decision behavioral models ......................... 19

Health belief model (HBM) ......................................................................................... 20

Network episode model (NEM) .................................................................................. 24

Demoralization framework model (DFM) ................................................................. 27

Purpose of the Study ..................................................................................................... 30

Research Questions ..................................................................................................... 33

Method ........................................................................................................................... 33

Overview ....................................................................................................................... 33

Research Design and Design Justification ............................................................... 34

Participants .................................................................................................................... 38

Inclusion and exclusion criteria ................................................................................. 39

Recruitment .................................................................................................................... 40

Measures ......................................................................................................................... 42

Procedure ....................................................................................................................... 42

Biases ............................................................................................................................... 44

Results ............................................................................................................................. 47

Consumers Who Attended Follow-up Care ............................................................... 48

Systemic and provider factors .................................................................................... 48

Franz’s story .................................................................................................................... 48

Micah’s story ................................................................................................................... 49

James’s story ................................................................................................................... 49

Keith’s story .................................................................................................................... 50

Perceived need factors ............................................................................................... 51

Consumers Who Did Not Attend Follow-up Care .................................................... 51

Systemic barriers and provider factors ..................................................................... 51

Bernard’s story .............................................................................................................. 51

David’s story .................................................................................................................. 52

Eduardo’s story .............................................................................................................. 53
List of Figures

Figure 1  Flow of participant recruitment........................................41
## List of Tables

<table>
<thead>
<tr>
<th>Table</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table 1</td>
<td>Sociodemographic Factors</td>
<td>61</td>
</tr>
<tr>
<td>Table 2</td>
<td>Clinical Factors</td>
<td>63</td>
</tr>
<tr>
<td>Table 3</td>
<td>Perceived Need Factors</td>
<td>64</td>
</tr>
<tr>
<td>Table 4</td>
<td>Systemic Barriers</td>
<td>66</td>
</tr>
<tr>
<td>Table 5</td>
<td>Provider Factors</td>
<td>68</td>
</tr>
</tbody>
</table>
**Introduction**

Serious mental illnesses (SMI), a group of disorders characterized as any mental disorder that leads to “substantial interference” with “one or more major life activities,” were once considered chronic and untreatable conditions (Kessler et al., 2001, p. 990). Since the 1990s, a growing number of consumers and practitioners have been embracing the belief that people with SMI can lead satisfying and productive lives by developing new meaning and purpose in life beyond the effects of the mental illness (Russinova, 1999). Such findings have been validated as evidence based; for example, a large national survey conducted by the Center for Psychiatric Rehabilitation at Boston University showed empirical evidence for the professional achievements of people with SMI (Ellison, Russinova, Lyass, & Rogers, 1998). Medical professionals, service providers, and healthcare policy-makers alike now recognize that recovery from SMI is a laudable and achievable goal (Jacobson & Curtis, 2000). Indeed, recovery-oriented care is the current guiding principle in the understanding and treatment of SMI (Russinova, 1999). Despite these changes, approximately 40% of individuals with SMI are rehospitalized within one year of discharge (Klinkenberg & Caslyn, 1996).

**Statement of the Problem**

Randomized, controlled trials on the determinants of relapse have revealed that a great number of individuals with SMI discharged from inpatient treatment fail to attend their first outpatient appointment (Kessler et al., 2001; Klinkenberg & Caslyn, 1996; Vermeire, Hearnshaw, Van Royen, & Denekens, 2001). This disruption in continuity of
SERVICE ENGAGEMENT AND SERIOUS MENTAL ILLNESS

care leads to exacerbation of the illness, increased rehospitalization rates, and increased costs for the mental-health system in general (Insel, 2008; Kessler et al., 2008; Wang, Demler, & Kessler, 2002). Previous research has examined risk factors for service disengagement and strategies to improve adherence; however, most of the variables examined are inconsistently correlated with adherence behavior and thus cannot be used to adequately predict healthcare-seeking behavior (Vermeire et al., 2001). One of the cited reasons for the inability of previous explanatory models to predict service engagement is that they have failed to include the patients’ perspective and subjective attitudes towards a prescribed treatment (Vermeire et al., 2001). The patient’s viewpoint is essential in explaining healthcare behavior because most individuals are not clinicians and do not know diagnostic nomenclature; therefore, they do not necessarily bring a clinical perspective to the help-seeking process (Leaf et al., 1988). Often patients and providers do not know how much, or even why, their perceptions differ (Vermeire et al., 2001). Recent research trends have increasingly emphasized the necessity to understand the experiential world of persons with SMI in order to provide adequate treatment. A richer, more detailed understanding of service engagement can be achieved by going directly to the population of interest and eliciting their personal beliefs regarding their behavior. Although there exists a growing body of empirical research into service utilization among consumers with SMI, literature regarding subjective, personal accounts of service engagement is lacking.

The Recovery movement has made a significant impact on the treatment of SMI, and its principles and philosophical underpinnings are being implemented in policies and
practices of mental-health systems across the United States (Beale & Lambric, 1995; Jacobson & Curtis, 2000; Oades et al., 2005; Young & Ensing, 1999). Initially, the concept of recovery emerged from subjective accounts of people who had experienced SMI and were able to overcome its negative impact (Russinova, 1999).

In the recovery paradigm, consideration of what the individual with SMI has to say about his or her experiences, struggles, and paths to service engagement is of utmost importance. In psychological terms, *recovery* refers to a return to functional ability. Recovery does not necessarily mean living symptom free; rather, it refers to the ability to reclaim one’s life and validate oneself by giving meaning to the experience of SMI (Jacobson & Curtis, 2000). For people who choose to engage in mental-health services, recovery-oriented care consists of a collaborative process between patient and provider, emphasizing the importance of change, goal setting, and consumer empowerment (Oades et al., 2005). While older models of mental-health care implied that treatment is a largely passive process imposed on an individual by a professional provider, recovery is an active process of the affected individual gaining and maintaining control over his or her life (Borg & Kristiansen, 2004).

As healthcare providers increasingly acknowledge the patient’s fundamental right to autonomy and self-determination, recovery strategies have focused on the involvement of the patient in the negotiation of treatment goals (Vermeire et al., 2001). For professionals, the recovery paradigm means a reorientation from a provider who functions as an expert and prescribes treatment (the medical model) to a trusted collaborator who guides the therapeutic process. This new healthcare orientation
conceptualizes service engagement as a person-centered rather than an illness-based approach (Sells, Stayner, & Davidson, 2004), and patients are involved as equal partners in decisions concerning their healthcare (Vermeire et al., 2001). Thus, the focus of service delivery has changed from treating the disorder to treating the whole person (Russinova, 1999).

In addition to expecting recovery-oriented care, individuals with SMI are increasingly viewed by the healthcare industry as consumers rather than as patients (Coursey, Keller, & Farrell, 1995). Two recent reforms have facilitated the transformation of patient to consumer: the advent of managed care and consumer-directed healthcare. When patients buy care in the medical market, the standard hope is that consumers will choose the right goods at the right rates (Hall & Schneider, 2008). This new free-market zeitgeist is even supported by federal law in the form of the Health Care Quality Improvement Act of 1986 (Public Law 99-660). As patients are involved as active consumers and equal partners in decisions concerning their mental healthcare, providers must adjust their role from being the sole decision makers to being expert advisors and consultants (Vermeire et al., 2001).

Much of the previous research on predictors of service engagement tended towards using quantitative methods, such as chart review and structured survey, rather than subjective accounts (Bhui & Bhugra, 2002; Borg & Kristiansen, 2004; Crawford, de Jonge, Freeman, & Weaver, 2003; Folkman & Greer, 2000). Existing studies exploring barriers to service engagement have thus relied on archival data and have generally been atheoretical. However, seeking and receiving healthcare treatment is a complicated
process with varying stages and opportunities for disengagement (Vermeire et al., 2001). Consequently, many studies have analyzed the impact of easily measured variables, such as demographics and diagnosis, while overlooking other aspects of individual vulnerability and system barriers (Kessler et al., 2001; Klinkenberg & Caslyn, 1996). For example, as of 1996, no studies on SMI had examined whether or not measures of social support predict the receipt of aftercare services (Klinkenberg & Caslyn, 1996). Without a sound theory in which to examine the variables affecting service engagement, healthcare practice and policy cannot be adequately modified to anticipate and accommodate disengagement from treatment. In fact, the absence of any theoretical framework precludes the empirical testing of treatment-seeking behavior (Vermeire et al., 2001). A framework is needed in which to understand how different healthcare behavioral models apply to persons with SMI and their subsequent care-seeking behavior.

Several healthcare behavioral models have been formulated and applied to the explanation of mental-health care service engagement, including the health belief model, or HBM (Rosenstock, 1966), the network episode model, or NEM (Pescosolido, 2006), and the demoralization framework model, or DFM, based on research by Clarke & Kissane (2002). The HBM has attempted to describe how an individual’s beliefs of the risks and benefits of a prescribed action lead to a particular set of healthcare behaviors (Vermeire et al., 2001). The NEM goes beyond the individual to incorporate the broader social influences on healthcare behaviors, and the DFM attempts to incorporate motivation and patient empowerment into the explanatory model. Despite the existence
of these frameworks, their constructs have not been sufficiently incorporated in the clinical setting in order to increase service engagement (Bhui & Bhugra, 2002).

Thus, in order to understand how and why individuals with SMI engage in service, or disengage from services, more research is needed. There is an especial need for examining healthcare behavior according to the framework of sociological and psychological models that incorporate patients’ subjective perceptions of the efficacy of medical-treatment engagement (Vermeire et al., 2001). Engagement is best accomplished by (a) eliciting the subjective views and perceptions of service engagement directly from the population with SMI, and (b) examining the variables affecting service engagement according to a theoretical framework.

**Literature Review**

**The impact of untreated SMI on the individual and society.** The cost of healthcare is arguably one of the greatest challenges in United States’ public policy (Insel, 2008). The costs of treating mental disorders substantially add to these expenditures, contributing 6.2% to the nation’s total spending on healthcare (Mark et al., 2007). The financial impact of this percentage was averaged to be $750 million per year between 1986 and 2005, and costs have only risen since then (United States Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, 2010). Direct costs, such as medication, office visits, and hospitalization, make up a large portion of mental-healthcare spending. However, the economic burden of untreated mental illness is harder to quantify, since both direct and indirect costs must be considered. Indirect costs are incurred through reduced labor supply, reduced educational
SERVICE ENGAGEMENT AND SERIOUS MENTAL ILLNESS

attainment, public income support payments, and costs associated with other consequences, such as incarceration and homelessness. Untreated SMI also contributes to the high rate of emergency room care and to early mortality (Insel, 2008).

The National Comorbidity Survey (NCS) is one of the largest cross-sectional, population-based, nationally represented epidemiological studies of mental disorders (Kessler et al., 2001). The purpose of the survey was to identify the number of people in the United States with untreated SMI and the reasons for their lack of treatment. SMI are a group of chronic disorders associated with complex needs, defined by Public Law 102-321 as any American Psychiatric Association Diagnostic and Statistical Manual (DSM) mental disorder that leads to “substantial interference” with “one or more major life activities” (Wang et al., 2002, p. 93). Life activities include basic skills, such as eating and bathing, social functioning, and vocational and educational engagement (Kessler et al., 2001). The mental disorders that meet Diagnostic and Statistical Manual of Mental Disorders, 4th edition, text revision (2000) criteria for SMI are schizophrenic spectrum disorder, major depressive disorder, depression not otherwise specified (NOS), psychosis NOS, bipolar disorder I, bipolar disorder II, and mood disorder NOS (American Psychiatric Association, 2000). Results from the NCS show that, of the 6.2% of respondents who met criteria for SMI in the 12 months prior to the interview, fewer than 40% received consistent treatment (Kessler et al., 2001). Of those receiving treatment, only 15.3% of respondents with SMI received minimally adequate treatment (Wang et al., 2002).
In 2008, the survey was repeated in the form of the National Comorbidity Survey Replication (NCS-R) in order to analyze the indirect costs of untreated SMI. Data showed that individuals with SMI had a mean reduction in earnings of $16,306. By extrapolating these results to the general population, researchers found that untreated SMI cost the nation an estimated annual loss of $193.2 billion in earnings in 2008 (Insel, 2008; Kessler et al., 2008). This figure does not include direct costs of untreated SMI, including Social Security Disability Insurance (SSDI), supplemental cash assistance, food stamps, and federally funded public housing. The findings from the NCS-R illustrate the evidence that impaired functioning associated with untreated SMI carries an enormous societal burden (Kessler et al., 2008; Wang et al., 2005).

**Noncontinuity of care in the population with SMI.** The negative impact of untreated SMI on the individual and society is clear. Unfortunately, this population is especially prone to treatment dropout. Unlike other mental disorders, SMI generally require ongoing maintenance to facilitate recovery. Continuous contact with the mental-health system decreases the likelihood of relapse and recurrences (Kreyenbuhl, Nossel, & Dixon, 2009). Long-term service engagement in the population with SMI is also known as *continuity of care*. Continuity of care has been defined as the orderly, uninterrupted movement of patients among the diverse elements of the health delivery system. It is care in which the patient remains in contact with service providers, there are no breaks in service delivery, and service users experience smooth and uninterrupted care (Crawford et al., 2003). Included in the concept of continuity of care is the importance of patients’
perceptions of treatment in their decision making regarding whether to remain engaged in care (Kreyenbuhl et al., 2009).

In a systematic review of studies published from 1980-2003, Nosé, Barbui, and Tansella (2003) measured the weighted mean of nonadherence to medication and outpatient appointments at 25.78%, but estimates have ranged from 22% to as high as 90% (Klinkenberg & Caslyn, 1996). Disengagement from mental-health services among individuals with SMI can be a significant problem with devastating consequences, such as exacerbation of symptoms, repeated hospitalizations, and relapse (Kreyenbuhl et al., 2009). Indeed, people with SMI who drop out of contact with services are often those with the greatest need (Crawford et al., 2003). According to O’Brien, Fahmy, and Singh (2009), commonly cited reasons for treatment dropout include dissatisfaction with services, unsympathetic providers, not being listened to, and not being able to actively participate in decision making.

Studies that have examined breaks in continuity of care in mental-health services have focused on the period between inpatient hospitalization and outpatient care, as this time is highly vulnerable for treatment dropout (Crawford et al., 2003; Kai & Crosland, 2001; Kessler et al., 2001; Kreyenbuhl et al., 2009), with failure to follow up after discharge estimated at 58% (Nosé Barbui, & Tansella, 2003). Qualitative studies consisting of interviews of mental-healthcare consumers suggest that they value continuity of care as well (Priebe et al., 2007). In a qualitative study examining treatment engagement from the consumers’ perspective, responders consistently highlighted the
importance of building a continuing relationship with one provider over time to facilitate recovery (Kai & Crosland, 2001).

**Compliance, adherence, and service engagement.** Treatment dropout has been referred to in the literature with varying terminology and definitions. Definitions of treatment dropout have also been inconsistent, sometimes referring to failure to enter a treatment program, premature termination of treatment, incomplete implementation of instructions, medication nonadherence, and failure to attend service appointments (Nosé, Barbui, Gray, & Tansella, 2003). These inconsistent terms and definitions have exacerbated the confusion in SMI treatment research.

Engagement in treatment was first referred to as *compliance*, then as *adherence*, and finally with the current term of *service engagement*. Compliance can be defined as the extent to which a person’s behavior coincides with medical or health advice (Vermeire et al., 2001). Inherent in the definition of compliance are the assumptions that medical advice is good for the patient and that rational behavior means precisely following medical advice. Noncompliance, therefore, is the failure or refusal to comply, and can imply disobedience. The term compliance is inherently negative as well, as it suggests yielding and submission to the prescriptions of a professional (Vermeire et al., 2001). Accordingly, the term compliance was replaced with the term adherence. Adherence is preferable to compliance as it incorporates the broader notions of concordance, cooperation, and partnership, thus facilitating a recovery orientation (Vermeire et al., 2001). However, adherence retained the same definition as compliance, that is, “the extent to which a person’s behavior coincides with the medical advice given”
SERVICE ENGAGEMENT AND SERIOUS MENTAL ILLNESS

(Nosé, Barbui, Gray, et al., 2003, p. 197). Included in the definition is the following of medication schedules, completion of treatment programs, and attendance at appointments (Nosé, Barbui, & Tansella, 2003). Previous adherence research has failed to quantify the concept. For instance, is adherence defined as 100% compliance or a certain percentage thereof? The term adherence has since fallen out of favor, as (similar to the term compliance) it implies a paternalistic model of treatment in which a provider prescribes a treatment plan for the patient to follow.

With the advent of the Recovery model, the favored term is service engagement, since this concept is a broader interpretation than adherence and considers the patient’s perspective (Kottsieper, 2011). Service disengagement in the population with SMI can be defined in many ways, including referral failures, missed appointments, and medication nonadherence (Kreyenbuhl et al., 2009). In this study, service disengagement is defined as failure to attend the first follow-up outpatient appointment following discharge from an inpatient setting. Studies have shown that this time period of treatment is the most critical for interruption of continuity of care because it is the most likely time for dropout to occur (Kessler et al., 2001). In fact, it is the most crucial time period for implementing strategies to facilitate long-term engagement in treatment (Kreyenbuhl et al., 2009).

**Service engagement/disengagement risk factors.** Comprehensive reviews of the SMI service disengagement literature reveal that previous research has delineated common categories of risk factors, which are also used for the purpose of this study (Compton, Rudisch, Craw, Thompson, & Owens, 2006; Klinkenberg & Caslyn, 1996; Kreyenbuhl et al., 2009). First, the characteristics of individuals who fail to engage in
mental-health treatment, also known as *predisposing factors*, have been examined. Predisposing factors include sociodemographic characteristics, such as age, gender, ethnicity, and social class, and clinical factors, such as diagnosis, onset, and severity of the illness. In addition to these predisposing factors, characteristics of the healthcare delivery system, known as *service factors*, function as influencing variables in treatment engagement. Service factors consist of systemic issues, such as appointment availability, accessibility of the treatment facility, affordability of the treatment, and public stigma.

The third category of variables is termed *provider factors*, which are the characteristics of the treatment provider, including communication style and theoretical orientation. For example, does the provider practice a shared decision-making model (SDM) of healthcare, or is the therapeutic relationship paternalistic? Is the doctor’s communication clear, and does it function to enhance the patient’s understanding of the treatment regimen? The fourth and final group of variables examined is *perceived need factors* (previously referred to in the research as *insight*), which is the extent to which individuals believe they have an illness that requires treatment.

Research has revealed some common predisposing factors that put an individual at greater risk for treatment disengagement (Klinkenberg & Caslyn, 1996; Kreyenbuhl et al., 2009). In terms of sociodemographic information, younger age, male gender, and ethnic minority background have been associated with treatment disengagement (Crawford et al., 2003; Kessler et al., 2001; Kreyenbuhl et al., 2009; Kruse, Rohland & Wu, 2002; Nosé, Barbui, & Tansella, 2003; O’Brien, et al., 2009; Stein, Kogan, Sorbero, Thompson, & Hutchinson, 2007). Additional individual social factors linked to treatment
SERVICE ENGAGEMENT AND SERIOUS MENTAL ILLNESS

dropout are low social status, low social functioning, social isolation, low social support, and unemployment (Becker & Maiman, 1975; Compton et al., 2006; Crawford et al., 2003; Kessler et al., 2001; Killaspy, Banerjee, King, & Lloyd, 2000; Kreyenbuhl et al., 2009; Kruse et al., 2002; Nosé, Barbui, & Tansella, 2003; O’Brien et al., 2009).

Specific clinical characteristics of different psychiatric illnesses have also been linked to service disengagement. These are severity of the psychopathology, first illness episode or hospitalization, and early-onset psychosis (Boyer, McAlpine, Pottick, & Olafson, 2000; Compton et al., 2006; Crawford et al., 2003; Killaspy et al., 2000; Kreyenbuhl et al., 2009; Kruse et al., 2002; Nosé, Barbui, & Tansella, 2003; O’Brien et al., 2009). Finally, a dual diagnosis of SMI and substance abuse (SA) greatly increases the risk of service disengagement (Kreyenbuhl et al., 2009; Nosé, Barbui, & Tansella, 2003, Phillips & Johnson, 2001). This risk factor is especially salient in the population with SMI, as epidemiological studies estimate the prevalence of comorbid SA at between 30 and 60%, with risk as high as 86% for some subgroups (Johnson, 2000). The Epidemiological Catchment Area Study revealed that in the United States, 47% of participants with schizophrenia or a schizophreniform disorder showed evidence of current or past SA, compared with a general population rate of 13.5% for alcohol and 6.1% for drugs (Regier et al., 1990).

Despite these common findings, there is no overall consensus as to which predisposing factors influence service engagement. For example, although much research suggests that social isolation predisposes one to treatment dropout, Klinkenberg and Caslyn (1996) found that lack of social support does not predict service disengagement.
The second major grouping of treatment engagement risk factors are service characteristics. These include, but are not limited to, lack of availability of appointments or providers (Compton et al., 2006; Kessler et al., 2001; Kreyenbuhl et al., 2009; Stefl & Prosperi, 1985), lack of access to transportation (Kreyenbuhl et al., 2009; Rossi et al., 2005; Stefl & Prosperi, 1985), confusion about where to seek help (Kessler et al., 2001; Kreyenbuhl et al., 2009), the nonaffordability of the treatment or insurance coverage (Henshaw & Freedman-Doan, 2009; Kessler et al., 2001; Kreyenbuhl et al., 2009; Kruse et al., 2002; Stefl & Prosperi, 1985), and the fear of public stigma (Henshaw & Freedman-Doan, 2009; Kai & Cosland, 2001; Kessler et al., 2001; Kreyenbuhl et al., 2009; Stefl & Prosperi, 1985). Sometimes service disengagement arises from such practical constraints as forgotten appointments (Killaspy et al., 2000; Kreyenbuhl et al., 2009, Rossi et al., 2005), having moved (Young & Ensing, 1999), and lack of time (Kessler et al., 2001; Young & Ensing, 1999).

Stefl and Prosperi (1985) analyzed data from community telephone surveys in order to delineate systemic barriers to mental health service utilization. The results were grouped into four categories, terms which are also used in this study. Barriers to service engagement were grouped as availability, accessibility, affordability, and acceptability. Availability refers to the availability of appointments for the patient; the availability of information, such as where treatment services are located; and the availability of treatment providers. Accessibility refers to the patient’s practical ability to reach treatment, including lack of transportation, the lack of a phone, and a lack of time. Affordability refers to such factors as the cost of treatment, the lack of insurance
coverage, and the ability to take time off from work to attend treatment. Finally, 
acceptability refers to whether or not the condition is seen in a positive light, both 
publicly and privately. Acceptability can be compared to the concept of stigma, the 
presence of which highly influences healthcare decision making (Corrigan, 2004; 
Henshaw & Freedman-Doan, 2009; Rusch, Angermeyer, & Corrigan, 2005). Stigma as a 
process involves negative labeling, stereotyping, and discrimination against an individual 
(Link & Phelan, 2006). Stigma can diminish self-esteem and lead to diminished 
opportunities and social isolation (Corrigan, 2004).

The final group of variables is what was formerly known as insight and is now 
referred to in the literature as need factors. While most literature still refers to “lack of 
insight” as a barrier to treatment, the term puts the burden of responsibility for service 
engagement solely on the patient. The term need is more accurate, as it implies a social 
transaction or interaction. A lack of insight into the consequences of the illness (or lack of 
perceived need for treatment) can result in the minimization of symptoms, minimization 
of the impact of the illness on social functioning, and/or a poor relationship with 
healthcare professionals (Kreyenbuhl et al., 2009; O’Brien et al., 2009; Priebe, Watts, 
Chase, & Matano, 2005; Tait, Birchwood, & Trower, 2002; Young & Ensing 1999). In 
treatment disengagement studies, commonly cited reasons for treatment disengagement 
resulting from lack of perceived need are as follows: the patient does not see a problem or 
does not think that treatment is necessary (Crawford et al., 2003; Kessler et al., 2001; 
Kreyenbuhl et al., 2009); the patient wants to solve the problem on his or her own 
(Crawford et al., 2003; Kessler et al., 2001; Kreyenbuhl et al., 2009; Priebe et al., 2005),
and the patient sought treatment in the past and was dissatisfied (Kessler et al., 2001; Kreyenbuhl et al., 2009; O’Brien et al., 2009; Young & Ensing, 1999).

Service engagement/disengagement protective factors. Mental-healthcare consumers want to be able to build a continuing relationship with one person over time and to express concerns about changes in physicians. In a qualitative study examining how people with SMI experience healthcare, patients reported noncontinuity of care as a salient reason for treatment disengagement (Kai & Crosland, 2001). Since problems with continuity of care are such a common occurrence, a number of linkage strategies have been suggested (Boyer et al., 2000; Craig et al., 2004; Crawford et al., 2003; Dixon et al., 2009; Rossotto, Wirshing, & Liberman, 2004; Susser et al., 1997). These strategies focus on both facilitating the therapeutic relationship and making adjustments to service delivery. In a systematic review and metaregression analysis of randomized, controlled trials and controlled clinical trials, Nosé, Barbui, Gray, et al. (2003) reviewed 24 studies on different community linkage interventions and found that after a median follow-up of 6 months, these interventions more than doubled the likelihood of service engagement, with both psychotropic medications as well as scheduled appointments. Thus, community linkage interventions have evidence-based efficacy as facilitators of service engagement in the population with SMI.

Boyer, et al. (2000) evaluated linkage strategies and identified three strategies that significantly increased the probability of patients’ attending their first outpatient appointments. These were (a) having the patient start an outpatient program prior to discharge, (b) clear communication about the discharge plan between inpatient staff and
outpatient clinicians, and (c) involving family in the treatment process. Studies show that allowing inpatients to meet the outpatient treatment team prior to discharge is associated with high rates of long-term service engagement (Nosé, Barbui, Gray, et al., 2003).

Rossotto, et al. (2004) evaluated a community reentry module aimed at enhancing treatment adherence in persons with schizophrenia by teaching relapse prevention skills; they found that participation in the module was associated with a rate of continuity that was twice as high as that observed in the control group. The brief critical time intervention model (B-CTI), an intervention promoting continuity of care in the population with SMI following psychiatric inpatient hospitalization, uses such strategies as a thorough assessment of patient needs and a high level of patient contact following discharge (Dixon et al., 2009; Susser et al., 1997). Results from a randomized, controlled trial indicated that B-CTI provided strengthened therapeutic ties, social integration, and emotional support (Dixon et al., 2009). Finally, an intensive linkage intervention known as the Lambeth Early Onset Team (LEO) provided assertive outreach strategies, such as cognitive-behavioral therapy (CBT), family counseling, vocational training, and social support for individuals with SMI with early psychosis. A randomized, controlled trial revealed the LEO to be superior to standard care, as the treatment group had lower rates of service disengagement and hospital readmission than did the control group (Craig et al., 2004).

Increased attention has been placed on building a positive therapeutic relationship between the patient and mental-healthcare professionals. A positive relationship that establishes continuity of care is based upon trust and effective communication (Kai &
Feldman-Stewart, Brundage, and Tishelman (2005) presented a provider communication framework and highlighted four key components of successful communication: (a) establishing communication goals, (b) adequate convergence and understanding of beliefs and values of each participant, (c) a clear communication process in which verbal and nonverbal messages are given and received, and (d) a suitable environment in which the communication occurs. A multinational, randomly controlled trial evaluating a patient-provider communication intervention revealed that giving the patient simple communication skills training can improve communication enough to meet patients’ needs and adjust their healthcare management (Van Os et al., 2004). Another randomized, controlled trial testing a computer-mediated intervention for patient-provider dialogue (DIALOG) revealed that structuring patient-clinician dialogue to focus on patients’ views positively influenced their treatment satisfaction (Priebe et al., 2007).

A strong relationship requires not just adequate communication, but trust and positive regard as well. Preliminary evidence shows that a healthcare model of SDM can foster this trust and strengthen the relationship (Charles, Gafni, & Whelan, 1997; Frosch & Kaplan, 1999; Joosten et al., 2008; Kasper, Mulley, & Wennberg, 1992; Schauer, Everett, & del Vecchio, 2007). Shared medical decision making is an interactive collaborative process by which patients and providers reach a healthcare decision based on mutual agreement (Schauer et al., 2007). SDM bolsters patient autonomy and gives clients an active role in their own healthcare and treatment, thus decreasing the chance for service disengagement. In a review of the literature, Stewart (1995) found that SDM
leads to improvements in the therapeutic relationship, as well as improvements in treatment adherence, treatment satisfaction, and health outcomes. Thus, the SDM model can be effective in promoting consumer treatment engagement and can even foster patient empowerment (Schauer et al., 2007). Another systematic review of the effects of SDM on patient satisfaction and treatment adherence revealed that SDM can be an effective and useful way of reaching a treatment agreement, especially when healthcare interventions involve long-term care (Joosten et al., 2008).

**Service engagement and health care decision behavioral models.** Theoretical frameworks and behavioral models are often used to explain and describe healthcare behavior. According to Vermeire et al. (2001), most of the published explanatory models are only partially satisfactory in predicting healthcare behavior because measurement methods were sparingly tested and therefore failed to gather valid information on the extent of patient engagement in service. Therefore, there is a need for applying various psychological research models as a framework for explaining real-world behavior. Existing models can be enhanced by incorporating patients’ attitudes and subjective perceptions, including their perceived efficacy of treatment suggestions, the balancing of risks and benefits, and management of the possible discrepancies between doctor’s and patient’s perceptions of risk.

The first framework, the health belief model, or HBM (Rosenstock, 1966), was developed in order to understand healthcare decision making for physical illness, but can also be applied to mental-healthcare treatment-seeking behavior. The second framework examined in this paper is the network episode model, or NEM (Pescosolido, 2006),
developed in response to the increased recognition of cultural and social forces guiding healthcare decision making. Finally, a suggested demoralization framework model (DFM) based on the proposed framework of Clarke and Kissane (2002) is presented in this study. Service engagement in mental-health services can be examined in light of all three frameworks. See Appendix A for the HBM, Appendix B for the NEM, and Appendix C for the DFM.

**Health Belief Model (HBM).** The HBM was one of the first theoretical models developed to investigate and explain public-healthcare behavior (Rosenstock, 1966). According to this model, a person’s behavior regarding healthcare is the result of a careful cost-benefit analysis. It conceptualizes healthcare consumers as rational, active choosers of healthcare behavior. The HBM grew out of a study originated by the United States Public Health Service in the late 1940s and early 1950s to investigate health behaviors in tuberculosis screening and treatment (Rosenstock & Hochbaum, 1961). The originators of the HBM were concerned with the failure of a free tuberculosis health-screening program and sought to explore a variety of healthcare behaviors, including service engagement and treatment adherence (Rosenstock, 1960). Derived from previous motivational research, the HBM was developed to explain and predict health behavior in terms of belief patterns and motivational factors. The model was formulated according to three basic principles: (a) a certain set of beliefs is required before action of a given kind will take place; (b) the individual’s motives and beliefs about various courses of action are often in conflict with each other, and behavior emerges as the resolution of such conflicts; and (c) health-related motives may not always give rise to health-related
behavior, and conversely, health-related behavior may not always be determined by health-related motives (Rosenstock, 1960).

Since the HBM grew out of previous motivational research, it is classified as a value-expectancy model. In such a model, behavior is predicted from the value an individual assigns to an outcome and from the individual’s expectation that a given action will result in that outcome (Becker & Maiman, 1975). Value-expectancy models include two classes of variables, which are (a) the psychological state of readiness to take specific action and (b) the extent to which a particular course of action is believed to be beneficial in reducing the threat. Thus, Rosenstock (1966) proposed five constructs influencing healthcare behavior: (a) perceived susceptibility, (b) perceived severity, (c) perceived benefits, (d) perceived barriers, and (e) cues to action. Subsequent research has demonstrated that the HBM constructs can be measured with a substantial amount of convergent validity (Cummings, Jette, & Rosenstock, 1978).

The construct of perceived susceptibility refers to an individual’s subjective belief of their risks of contracting a condition. Perceived severity concerns the individual’s subjective perception of the seriousness of a given health problem. The degree of seriousness is judged by both the degree of emotional arousal created by the thought of the condition as well as the perception of the amount of difficulty a health condition will create. Together, these two constructs describe an individual’s level of readiness to act and are influenced by clinical, as well as social, factors (Rosenstock, 1966).

The next two constructs, perceived benefits of taking action and perceived barriers to taking action, are sometimes conceptualized in combination to predict the
course of action taken (or not taken). The individual’s behavior will depend on how beneficial she or he thinks the action will be, considered in tandem with her or his belief about the availability and effectiveness of the various courses of action. If the perceived benefits are high and the negative aspects relatively weak, the action in question is likely to be taken. If, however, the perceived benefits are low and the potential negative aspects are strong, they may function as barriers to prevent action (Rosenstock, 1966).

The level of readiness (perceived susceptibility and perceived severity) provides the force to act, and the perception of benefits and barriers provides a preferred path of action. However, the combination of these factors may not be enough to prompt behavior without a subsequent cue to action. Cues to action constitute those variables that serve to trigger healthcare behaviors. These include interactions with healthcare providers, influences of one’s social network, and the impact of public-healthcare campaigns. The required intensity of the cue varies with differences in the level of readiness (Rosenstock, 1966).

The advent of social learning theory introduced the concept of self-efficacy as an influencing factor in explaining and predicting behavior (Bandura, 1977). Self-efficacy refers to expectations about one’s own competence to perform a behavior and to influence outcomes. The original HBM did not recognize efficacy expectations as accounting for variance in behavior, since it originated from tuberculosis screening research and predated the theory of self-efficacy. However, a growing body of literature showed that patients with chronic illnesses requiring long-term behavioral changes did indeed consider self-efficacy in initiating and maintaining behavioral change (Bandura,
1977). Thus, the HBM was revised to include self-efficacy as a separate dimension (Rosenstock, Strecher, & Becker, 1988). For a behavioral change to succeed according to the revised HBM, individuals must have an incentive to take action (perceived susceptibility and severity), believe the change will be beneficial (perceived benefits and barriers), and also believe themselves competent to implement that change (self-efficacy).

Janz and Becker (1984) provided substantial empirical support for the HBM. The validity of the HBM dimensions were consistent across type of healthcare utilization (general vs. specific) and across type of data (retrospective vs. prospective). Support for the HBM was also demonstrated for preventative behaviors, such as screening for risk factors. Finally, the constructs defining the HBM were supported regarding sick-role behaviors for a variety of medical conditions, including hypertension, diabetes, and end-stage renal disease (sick-role behavior was defined in the study as “actions taken after diagnosis of a medical problem in order to restore good health or to prevent further disease progress” [p. 3]).

The HBM has also been shown to explain and predict mental-healthcare utilization and service engagement (Adams & Scott, 2000; Henshaw & Freedman-Doan, 2009; Nageotte, Sullivan, Duan & Camp, 1997). In a study exploring medication usage in participants with SMI, Adams and Scott (2000) found that perceived severity of illness and perceived benefits of treatment explained 43% of the variance in medication-taking behavior. In a secondary analysis of data collected in the Mississippi public mental-health system, Nageotte et al. (1997) found the HBM to be a sound conceptual framework in explaining medication-taking behavior. Specifically, the belief that one had a mental
illness (perceived susceptibility) was significantly associated with higher levels of compliance.

Although the components of the HBM show empirical validation, there are limitations to the theory. For one, a basic underlying assumption of this model is that health is seen as a desirable goal, which may or may not be true for different individuals. In addition, the rational orientation of the model has been criticized for omitting the emotional components of some health behaviors (Henshaw & Freedman-Doan, 2009). Janz and Becker (1984) pointed out that other variables also influence healthcare behavior, such as environmental and social factors that may impact an individual’s preferred course of action.

**Network Episode Model (NEM).** As opposed to the HBM, which views individuals as rational decision makers, the NEM instead emphasizes the role social networks play in influencing healthcare decisions (Pescosolido, 1992). In the NEM, social networks are seen as structures of instrumental and emotional support, conveyers of information, and powerful coercive influences (Pescosolido, 2006). Networks are comprised of family, friends, the community, the doctor-patient relationship, the culture and climate of the health care organization, and social and financial systems affecting healthcare. This model suggests that healthcare behaviors develop over time and evolve into patterns of service usage. Furthermore, it specifically considers coercion as a variable in healthcare decision making, while the HBM has been criticized in that it cannot be applied to the numerous individuals coerced or ordered into treatment.
SERVICE ENGAGEMENT AND SERIOUS MENTAL ILLNESS

(Henshaw & Freedman-Doan, 2009). Therefore, the NEM may be a more comprehensive framework in which to analyze mental-healthcare behavior.

The NEM proposes that the interaction among persons and their social networks acts as the primary mechanism through which people recognize health problems, contact health facilities, and comply with medical advice (Pescosolido, Gardner, & Lubell, 1998). Rather than conceptualizing healthcare behaviors as isolated and independent choices, the NEM takes into account the entire illness “career” by incorporating individual decisions into overall patterns of healthcare behavior. This model attempts to conceptualize patterns of healthcare service use by assuming that (a) people in all societies consult both professionals and lay people for healthcare advice during an illness episode, (b) the decision process is dynamic in that individuals continuously combine series of decisions over stretches of time into patterns, (c) choices are not necessarily rational, and (d) the underlying mechanism at work is interaction in social networks (Pescosolido, Wright, Alegria, & Vera, 1998).

Pescosolido (2006) developed the NEM by combining existing rational models of healthcare decision making with the theoretical orientation of sociolegal literature that highlighted how people with mental illness are forced into treatment. She theorized that individuals enter psychiatric care by making a rational choice, by being forced into treatment (termed coercion), or by muddling through the system. Muddling through is defined as the phenomenon of neither actively resisting nor actively seeking treatment. When people muddle through, they “bounce around and off circumstances and others as
they attempt to deal with problems, engaging in successive, limited comparisons between alternatives” (Pescosolido, Gardner, et al., 1998, p. 275).

The NEM is a process-oriented model that focuses on the interaction of the larger cultural, economic, medical, and systemic factors affecting the individual’s use of mental health services. Social networks play an active role in both choice and coercion: choice, by incorporating the influence of community and family members on individual decisions, and coercion, by taking the decision out of the individual’s control and placing it with family members or the community, including police, physicians, and judges. Muddling through, by its very definition, implies the active influence of social networks on individual healthcare behavior.

Several studies support the validity of the NEM. The Indianapolis Network Mental Health Study (INMHS) demonstrated that the patient’s social network impacted health-related outcomes, such as trust in physicians, satisfaction with mental health services, and perception of the course of mental illness since onset (Perry & Pescosolido, 2010). Examination of data from the Mental Healthcare Utilization Among Puerto Ricans Study, an island-wide community survey, revealed that distinct patterns of service utilization were influenced by which social networks the individual consulted before seeking care (Pescosolido, Wright et al., 1998). For example, those who sought advice from a general medical provider or clinic behaved differently from those who sought advice from clergy or traditional healers.
SERVICE ENGAGEMENT AND SERIOUS MENTAL ILLNESS

Demoralization Framework Model (DFM). While the NEM improves on the HBM in that it incorporates a wider range of social influences on individual healthcare behavior, it is not a comprehensive framework for examining service disengagement among individuals with SMI. As recent research has emphasized existential concerns among the population with SMI that are not identified by the HBM or NEM, a more complete framework of healthcare behavior must incorporate these constructs of concern (Borg & Kristiansen, 2004; Folkman & Greer, 2000; Kai & Crosland, 2001). For example, people coping with SMI are likely to be concerned about how the illness affects their identity and place in society (Folkman & Greer, 2000). Research into mental-health stigma acknowledges that treatment outcomes are powerfully influenced by perceived public stigma, and internalized self-stigma contributes to demoralization with resultant diminished self-esteem and self-efficacy (Corrigan, 2000; Corrigan, Watson, & Barr, 2006; Dinos, Stevens, Serfaty, Weich, & King, 2004; Pescosolido, Martin, Lang, & Olafsdottir, 2008; Watson, Corrigan, Larson, & Sells, 2007). Clarke and Kissane (2002) addressed some of these existential meaning-related constructs in their proposed demoralization framework. Therefore, the research must consider another model of healthcare behavior based on the demoralization framework.

Clarke and Kissane (2002) developed their framework based on the concept of demoralization first described by Jerome Frank. That is, demoralization occurs when distress and subjective incompetence coexist in an individual, resultant from a stressful life event (Frank, 1974). Like Frank, they proposed that demoralization is the main reason that people seek and engage in psychiatric treatment, yet it is a concept largely
SERVCE ENGAGEMENT AND SERIOUS MENTAL ILLNESS

ignored in psychiatry (Clarke & Kissane, 2002). They posited that demoralization is an important construct influencing treatment engagement and adherence, and thus must be incorporated in the mental healthcare literature.

Demoralization as a process is hypothesized to occur as follows: In the event of a stressful situation or threat to an individual’s being, the individual is potentially put in the position to fight for survival. If the individual also does not know how to change the situation or extricate him or herself from it, the individual may feel an inability to cope with the situation. A persistent inability to cope induces helplessness. When an individual is helpless, he or she experiences feelings of incompetence, loss of control, and diminished self-esteem. In the event of helplessness, the construct of hope and its accompanying protective factors can buffer the individual from demoralization. However, if the individual feels helpless and hopeless, he or she can experience feelings of shame and social isolation, especially if the individual perceives that he or she has failed to meet personal or others’ expectations. These combined factors lead to a loss of meaning and purpose in life, further fueling helplessness, hopelessness, and the demoralization process. The resultant existential despair is the ultimate expression of demoralization.

Demoralization is therefore defined as a persistent inability to cope, which is influenced by self-formed constructs of hopelessness, helplessness, and lack of meaning in life. Individuals coping with SMI often report stories of victimization, social isolation, and disempowerment, which negatively impact recovery and contribute to demoralization of the individual (Kai & Crosland, 2001). The demoralization framework considers the
powerful influence of social and internalized stigma on healthcare decision making and service engagement.

The constructs of helplessness, hopelessness, and meaning-making are operationally defined as follows. The concept of helplessness is based on Seligman’s learned helplessness theory, the idea that uncontrollable aversive events often lead to the supposition that behavior no longer affects outcome (Seligman, 1971). Here, helplessness is conceptualized as subjective incompetence that leads to persistent feelings of an inability to cope. Hope is conceptualized based on Nunn, Lewin, Walton, and Carr’s definition (1996) that hope is “the construction of, and response to, the perceived future in which the desirable is subjectively assessed to be probable” (p. 531). It is future oriented and expectant, involving cognitive and affective aspects of longing for and believing in something that is not certain, but possible (Clarke & Kissane, 2002). In hope theory, the consequence of attaining or not attaining a goal produces emotional reactions that can lead to existential distress. The existence of hope in the face of a stressor thus acts as a buffer against demoralization.

The constructs of loss of meaning and sense of purpose in life as applied to psychotherapy originate from Frankl’s meaning-making theory (Frankl, 1946/2006). Meaning-making describes how people make narrative sense of the world around them (Bruner, 1990). Meaningfulness implies a sense of coherence of a person’s world, which is constructed through people’s narratives of their lives (Ville & Khlat, 2006).

Although demoralization is a mental experience, it has proved to be significantly comorbid with serious physical and mental illness (Angelino & Treisman, 2001; Clarke,
Kissane, Trauer, & Smith, 2005; Griffith & Gaby, 2005; Jacobsen, Maytal, & Stern, 2007; Parker, 2003; Rafanelli et al., 2005). In the palliative-care setting, demoralization is associated with chronic medical illness, disability, body disfigurement, fear of loss of dignity, and social isolation (Clarke & Kissane, 2002). Case vignettes of demoralization have been reported in patients with cancer (Angelino & Treisman, 2001; Clarke et al., 2005; Griffith & Gaby 2005; Jacobsen et al., 2007), acute coronary heart disease (Rafanelli et al., 2005), motor neuron disease (Clarke et al., 2005), and limb amputation (Griffith & Gaby, 2005). Furthermore, demoralization is commonly seen in medical and surgical patients who are referred for psychiatric consultation (Slavney, 1999).

Demoralization can result from both the illness itself, including traumatic injury and acute and chronic illnesses, and the treatment of the illness, such as pain, discomfort, and disfigurement resultant from chemotherapy or surgery (Jacobsen et al., 2007). In fact, some argue that demoralization is one of the most common reasons psychiatrists are consulted for medically ill patients (Griffith & Gaby, 2005). The constructs defining demoralization have also been extensively studied in the mental-health literature and found to correlate significantly with the experiences of the population with SMI.

**Purpose of the Study**

The majority of previous research has focused on risk factors as predictive variables in service disengagement. Although some weak associations have been found, sociodemographic variables and disease factors are inconsistently correlated with service engagement and are thus poor indicators of healthcare behavior. Approximately 200 different doctor, patient, and encounter-related variables have been studied, but none has
been consistently predictive of service engagement (Vermeire et al., 2001). Perhaps this inconsistency is because the majority of research focused on adherence to schedules and attended appointments, rather than took into account other facets of behavior, such as motivation and autonomy, which are harder to quantify (Crawford et al., 2003; Nosé Barbui, & Tansella, 2003).

In the current climate of healthcare policy change, Jacobson and Curtis (2000) proposed several questions that need to be examined to deepen the understanding of service engagement as an individual process, including, “What stimulates and sustains that process? What hinders or smothers it? What barriers stand in the way of implementing a recovery orientation? By what criteria should the system be judged?” (p. 10). In order to answer these questions, researchers and clinicians need an explanatory framework based on the subjective views of healthcare consumers. This study examines three frameworks in which to conceptualize service engagement behavior among individuals with SMI: the health belief model (HBM), the network episode model (NEM), and the demoralization framework model (DFM).

The HBM attempts to explain treatment seeking and adherence behavior based on social learning and cognitive theories. It conceptualizes healthcare consumers as individual, rational, active decision makers in their own care (Rosenstock, 1966). In contrast, the NEM examines individual healthcare behavior in the larger context of dynamic social systems (Pescosolido, 2006). Researchers have suggested that more empirical testing of the NEM is needed, as it might provide a better understanding of subtle variables affecting healthcare behavior (Klinkenberg & Caslyn, 1996; Kottsieper,
SERVICE ENGAGEMENT AND SERIOUS MENTAL ILLNESS

Finally, the DFM is conceptualized based on Clarke and Kissane’s demoralization framework (2002) and previous research on stigma (de Figueiredo, 1993; de Figueiredo, 2007; de Figueiredo & Frank, 1982; Frank, 1974; Phelan, Link, Stueve, & Pescosolido, 2000). This model was chosen because its defining constructs (hope, meaning, and purpose) are also key themes in the Recovery movement (Jacobson & Curtis, 2000). In the context of recovery, one must understand how individuals develop new meaning and purpose in life in order to hold onto hope, so that adequate treatment can be provided to facilitate overcoming the negative impact of SMI (Russinova, 1999).

In summation, untreated SMI carries enormous psychological and financial costs, for both the individual and society. Studies suggest that approximately 40% of individuals with SMI discharged from inpatient treatment fail to attend their first outpatient appointment (Kessler et al., 2001; Klinkenberg & Caslyn, 1996), and this disruption in continuity of care leads to exacerbation of the illness, increased rehospitalization rates, and increased costs for the mental-health system in general (Insel, 2008; Kessler et al., 2008; Wang et al., 2002). Previous research has examined risk factors for service disengagement and strategies to improve compliance; however, most of the variables examined have been inconsistently correlated with compliance behavior and thus cannot be used to adequately predict healthcare-seeking behavior in the population with SMI.

One of the cited reasons for the failure of previous explanatory models to predict service engagement is that they have failed to include the patients’ perspective and subjective attitudes towards a prescribed treatment (Vermeire et al., 2001). Thus, the goal
of this study was to elaborate on the meaning, understanding, and experience of mental-healthcare service engagement from the viewpoint of individuals with SMI, within the framework of three healthcare behavioral models. An explanatory framework of service engagement, based on the subjective views of mental-healthcare consumers, can be a starting point to guide policy and improve quality of care for this unique population. A qualitative methodology and semistructured interview for data collection, may allow the revelation of themes that can extend theory and guide future research (Klinkenberg & Caslyn, 1996).

**Research Questions**

This study aimed to answer the following research questions:

1. Why do consumers of mental healthcare choose to follow up with aftercare services following their discharge from an inpatient stay?
2. Why do consumers of mental healthcare choose NOT to follow up with aftercare services following their discharge from an inpatient stay?
3. How do the following health care models (the health belief model, the network episode model, and the demoralization framework model) contextualize what participants report with regard to aftercare service engagement or disengagement?

**Method**

**Overview**

The purpose of the present study was to explore, describe, and explain the individual and social constructs affecting service engagement in the population with SMI. This study utilized a qualitative research design based on grounded theory methodology.
A single interviewer collected data in the form of narratives. These narratives were analyzed using grounded theory methodology to derive conceptual categories in order to explore whether or not these categories meshed with the different healthcare decision-making models (HBM, NEM, and DFM). Of paramount concern in this research was to understand if the healthcare behavior of mental-healthcare consumers was consistent with the theoretical frameworks provided. For example, did these models adequately explain adherence or engagement behaviors as experienced by the consumers of mental healthcare? Did the sociodemographic and systemic risk factors found to influence service disengagement in this study fit into any of the three theoretical frameworks previously described? Were there any factors that facilitated service engagement, and could these factors be extrapolated to influence mental healthcare policy and practice?

The conceptual categories derived from the research were analyzed to determine which factors influenced service engagement and service disengagement. Which barriers may have been blocking access to mental healthcare, and how were these barriers overcome?

Finally, the ultimate concern of the data analysis was to determine the individual patient’s conceptualization of his or her illness and healthcare engagement process.

**Research Design and Design Justification**

Grounded theory methodology is appropriate for answering these questions. Grounded theory is rooted in the symbolic interactionist school, which focuses on meaning and the symbols people use to convey meaning. Meanings are shared through language, and these meanings are continually being revised in social interaction. Reality is therefore a dynamic process (Baker, Wuest, & Stern, 1992). The research method is
called grounded theory because it grounds a theory in reality. Grounded theory seeks to describe and explain a phenomenon of interest and has specific procedures for data collection and analysis. Data collection procedures involve interviews and observations, which are then analyzed as indicators of phenomena and are given conceptual labels. By comparing data and naming like phenomena with the same term, the researcher accumulates the basic units of theory. These concepts serve as the units of analysis.

In grounded theory, concepts are generated from the data and then systematically related. The categories must be well developed, have conceptual density, and have many conceptual linkages. The conditions affecting the phenomenon under study must be built into its explanation. Concepts that pertain to the same phenomenon are grouped to form categories, and analysis of the data makes use of constant comparisons. In this way, patterns and variations can be identified and accounted for. This procedure of data collection and analysis systematically and sequentially enables the research process to capture all potentially relevant aspects of the construct under study (Corbin & Strauss, 1990). By deriving conceptual categories from the data, these categories can be compared and contrasted to the theoretical categories in the HBM, NEM, and DFM.

Qualitative research seeks to understand human experience from the subject’s own frame of reference (Baker et al., 1992). It is an approach to the subject matter of human experience, focusing on narrative accounts, description, interpretation, context, and meaning (Kazdin, 2003). This type of research is an inductive process that provides rich and multilayered details of individual experience, adding to the body of literature by providing new insights, generating theory, and describing and interpreting phenomena of
interest. Qualitative research takes place in a naturalistic setting and reveals themes, such as human experience and subjective viewpoints, not covered in quantitative research. The qualitative researcher views social phenomena holistically, and thus is included in the interpretation of the data in light of his or her perspective. Introspection and personal reflection are integral parts of the process, as they help to shape the interpretation of the data (Creswell, 2003).

Validity is key in qualitative research, to ensure that the results are confirmable, credible, and trustworthy. **Confirmability** refers to the extent to which an independent reviewer could conduct a formal audit and re-evaluation of the procedures and generate the same findings. Confirmability reflects the replicability of the findings and depends on the accuracy with which the investigator follows the methodology stated in the study. **Credibility** is the believability of the results. To ensure credibility, the process of triangulation was used in analysis and interpretation of the data. Triangulation refers to using multiple raters and procedures to converge the data; the more convergent the information, the stronger the triangulation. Finally, **trustworthiness** reflects the extent to which the data have confirmability, credibility, and **transferability**, which is whether or not the data are context bound. In this sense, transferability is similar to the construct of external validity (Kazdin, 2003).

By using these constructs to define validity, qualitative research uses five types of validity in its methodology. **Descriptive validity** is the extent to which data are factually accurate. Descriptive validity was controlled by retaining raw materials, recording narrative interviews, and transcribing the narratives verbatim from the recordings.
Interpretive validity is the extent to which the meaning of the material is interpreted accurately and is not simply a reflection of the investigator’s perspective. To ensure interpretive validity, the investigator made explicit her own views and biases, and reflected upon these views throughout the interpretive process. Secondly, triangulation was used in analysis of the data in order to support emergent variables and themes by using multiple raters and procedures to converge the data. Theoretical validity is the extent to which interpretations and conclusions are tied to grounded theory, and not simply a summary of the data, and was controlled by carefully following grounded theory methodology. Internal validity measures the accuracy of the resultant data and was controlled by ensuring confirmability, credibility, and trustworthiness, as previously described. Finally, external validity is the extent to which the findings are generalizable to the population of interest. In qualitative research, analyses are assumed to have some generality as well as specificity, because while the phenomena under study are unique to the individual and thus nonreplicable, the experiences, understandings, and interpretative meanings of those experiences may very well resonate with others (Kazdin, 2003).

Grounded theory uses three types of coding in data analysis: open coding, axial coding, and selective coding. In this study, interviews were recorded and transcribed verbatim, then coded using all three types of coding. Three doctoral-level psychology students performed as coders. Open coding was used to analyze and conceptualize the data. To do so, each coder individually first read the interview transcripts; all three coders then compared for similarities and differences in information, with basic units being given conceptual labels. Conceptually similar information was grouped together to form
categories and subcategories. This process was done repeatedly until saturation was
reached through triangulation of the data. This researcher then used axial coding to relate
categories and subcategories and to test the relationship against the data. Subcategories
were related to categories through the interaction of phenomena. Later in the research
process, selective coding was used to tie all the concepts together around a unified “core”
category, the main analytic idea presented in the research. All three forms of coding
enhance internal validity and sharpen the theoretical framework. The theoretical
framework was then compared with existing literature to establish further validity.
Comparison with conflicting frameworks improved the construct definitions and
increased internal validity, while comparisons with similar frameworks established
generalizability, thus increasing external validity (Pandit, 1996).

Grounded theory is unique as compared to other forms of qualitative analysis in
that data collection and analysis occur concurrently and are based on a constant
comparative method. As more information is collected, codes are revised and the data
recoded. Ongoing analysis sharpens the focus of the study, as categories develop by
fitting codes together in an ever-increasing conceptual framework (Baker et al., 1992).
Thus, grounded theory was used in this study in order to capture the dynamic and ever-
changing nature of healthcare decision making in a valid, reliable context.

Participants

A total of 12 participants was included in the study, four of whom were deemed
engaged in service and eight of whom were disengaged from follow-up services. *Service
engagement* was defined as attending an initial outpatient appointment within 4 weeks
following discharge from an inpatient facility. *Service disengagement* was defined as failing to attend an initial outpatient appointment within 4 weeks following discharge from an inpatient facility, as this time period is the most vulnerable for treatment dropout (Kessler et al., 2001). This sample of convenience was recruited from the inpatient psychiatric unit of a major general hospital in New Jersey. The inpatient unit at this hospital is a 15-bed, voluntary, short-term facility. The participants entered treatment between August 2, 2012, and March 22, 2013, and were consented prior to discharge from the unit.

**Inclusion and Exclusion Criteria**

Patients were screened according to the following inclusion criteria: participants (a) were over the age of 18 years, (b) were fluent in English, (c) were residents of New Jersey, (d) had outpatient referrals made prior to discharge, and (e) met *Diagnostic and Statistical Manual of Mental Disorders, 4th edition, text revision (DSM-IV-TR)* criteria for serious mental illness, defined as a schizophrenic spectrum disorder, major depressive disorder, depression NOS, psychosis NOS, bipolar disorder I, bipolar disorder II, and mood disorder NOS (American Psychiatric Association, 2000). Patients were excluded from participation if they had a documented diagnosis of mental retardation, a pervasive developmental disorder, and/or organic brain damage. They were also excluded if they were represented by legal guardians or discharged to another inpatient or rehabilitation facility. Potential participants were screened for inclusion and exclusion criteria by examining their official medical chart, including intake paperwork and psychiatric diagnoses. This researcher also consulted with various inpatient staff, including the
attending psychiatrist, psychiatric residents, psychiatric nurses, and social workers, in order to ensure the accuracy of the inclusion and exclusion criteria.

**Recruitment**

Of hundreds of patients who were admitted to the inpatient unit during the data collection period, 37 met inclusion and exclusion criteria and also agreed to be consented by this researcher. Upon a patient’s admission to the inpatient unit, this researcher used the previously described procedures to determine if the patient met inclusion and exclusion criteria for the study. If eligible candidates were in the unit, this researcher then approached potential participants relatively close to their discharge date. The researcher explained the nature of the study, informed potential participants that they would be paid $10 at the conclusion of the study, and then consented those who agreed to participate. Participants also consented for the researcher to contact them 6 to 8 weeks after their discharge date for an interview. This time frame was chosen because most follow-up appointments are made to occur within 4 weeks of discharge of the patient from the inpatient unit utilized for recruitment in this study. The consent form included a section in which to provide a phone number, address, and other contact information to enable the researcher to locate the individual at the time of the research interview.

Six to 8 weeks following discharge, participants were contacted by phone and asked whether or not they attended their first outpatient appointment. Those participants who could be reached were asked if they were still interested in participating in the study. After potential participants were confirmed, the researcher completed a form documenting sociodemographic and clinical variables, which were obtained from the
patient before the commencement of the interview process. See Appendix D for the sociodemographic form.

Of 37 consented individuals, 12 agreed to participate in the study. One consented participant was excluded from the study because the person was subsequently discharged to an inpatient facility. Of the remaining consented individuals, 21 were unreachable or did not return phone messages left by the researcher. Of the 15 who were reached, three were deemed ineligible because the potential participant was incarcerated or in another inpatient unit at the time of follow-up. Therefore 12 individuals met inclusion and exclusion criteria and were still willing to participate in the study. These 12 individuals formed the participants of this research study. See Figure 1 for the flow-sheet of participant recruitment.

---

**Figure 1.**

- 37 potential participants consented
  - 36 attempted to call
    - 21 unreachable
      - 15 reached
        - 12 completed interviews
  - One not called because did not meet inclusion criteria: was discharged to an inpatient unit
  - 3 ineligible
Measures

This qualitative study used a semistructured interview designed by the researcher in order to gather data. The interviewer was a graduate doctoral-level student who had taken at least one course in qualitative methodology and data analysis. Answers were recorded verbatim with a “Voice Record” digital application. Information obtained from each interview was considered descriptive data and served as the basis for analysis. The interview questions were designed to elicit information regarding each participant’s perception of variables influencing the service engagement process (see Appendix E for interview questions). Analysis was conducted by looking for recurrent themes or key concepts that emerged from each narrative, identifying consistent patterns in the material, and linking variables to describe and interpret personal experience, as per standard grounded theory analysis procedure (Kazdin, 2003). Narratives were analyzed by three raters until saturation was reached, at an interrater reliability rate of 100%.

Procedure

Interviews were conducted at a public location in the community of the participant’s choice and comfort. Possible interview locations were suggested by the interviewer and chosen by the interviewee. Locations included private conference rooms at the hospital, fast-food restaurants, cafes, and conference rooms in the community. Confidentiality was maintained by ensuring that the chosen location was relatively empty and free from other patrons at the time of the interview and that voice volume was kept at a minimum level. This researcher conducted the interviews; therefore, the interviewer and interviewee recognized each other since both had met during the consent process. To
further ensure proper identification, this researcher also contacted the interviewee on the
day of the interview and described what she would be wearing to the interview.

Prior to questioning, the interviewer emphasized the voluntary nature of
participation and reviewed the consent form. The semistructured interview consisted of
13 questions that were held consistent for each participant, as well as prompts (when
needed) in order to elicit richer detail and content from the narrative. The interviewer sat
across a table from the interviewee and placed a digital device between them for
recording purposes. Interview times ranged from 30 minutes to 2 ½ hours, with an
approximate mean time of 1 hour. At the conclusion of the interview, each participant
was thanked for his or her time and given $10 cash compensation for participation.

Recordings were transcribed verbatim by the researcher at the conclusion of each
interview. Each transcript was read three times by the lead investigator and twice by each
subsequent rater. Transcripts were first individually coded for consistent themes using
open coding. Coders then met as a group and reviewed each transcript with open coding
until saturation was reached. This process of triangulation served to produce convergence
and support validity (Creswell, 2003). Following triangulation of open coding, the author
conducted axial coding by repetitively reviewing the open-coding results and forming
conceptual categories and linkages based on the emergent variables. This process of
continual comparison was repeated until core themes began to emerge, at which point
selective coding was used to link categories and subcategories of variables around a core
theme.
Biases

A personal journal was kept by all three coders in order to explore biases and perceptions of subject matter and research process. This researcher kept a personal journal with impressions of each participant, including observations and interpretations of appearance, body language, affect, and demeanor. The two additional coders also kept personal journals while reading each transcript in order to explore and document their own impressions and interpretations of the data. Journals were compared during coding in order to explore biases and perceptions of the participants, subject matter, and research process. This procedure was done to ensure validity and reliability in the data.

The author has a background and training in CBT and so naturally brings this viewpoint to the research. She also has extensive training in the recovery model of SMI throughout Master’s- and doctoral-level coursework and took an elective course entitled “Psychiatric Disabilities and the Recovery Model.” The author was a member of a research team at the Philadelphia College of Osteopathic Medicine (PCOM), as part of a study funded by the National Institutes of Health (NIH) that investigated the impact of hope and empowerment in the recovery model of treatment for those diagnosed with an SMI. The Hope and Empowerment Intervention Research Lab has developed a novel treatment adjunct to therapy in order to increase service engagement and decrease relapse rates in the population with SMI. This author has contributed to developing the treatment protocol and writing the treatment manual, specifically independently researching and authoring Module Four in the treatment manual and contributing to the research on the
remaining seven modules. The idea for this dissertation topic was inspired by her participation, research, and experience in this research lab.

Most importantly, this author has worked with the population with SMI in inpatient, outpatient, correctional, and forensic settings, and has witnessed their many struggles and triumphs throughout the course of treatment and recovery. Through witnessing the barriers these individuals face in treatment, as well as the positive effects of service engagement, advocacy for this population has become both a professional and personal goal. For full disclosure, the author wrote two invited articles, one entitled *Effective engagement of mental health services with the seriously mentally ill: The importance of the patient's perspective* (Friedman, 2013) and the other entitled *Mental health-care policy and the Recovery model: Improving service engagement and ending stigma* (Friedman, 2013). As an advocate for the population with SMI, this author has a personal investment in the research.

The two additional coders also have background and training in CBT, and so naturally bring this viewpoint to the research. Both coders also have doctoral-level training in the recovery model, a topic that is threaded throughout many didactic instructions and classes. Therefore, when discussing such issues as patients with SMI, they automatically tend to think from the viewpoint of the recovery model. One coder was a mental-health crisis counselor in a high school in Philadelphia, having helped connect students with mental-health and similar needs to the appropriate agencies in the community. At times, the coder was asked to help intervene and oversee crises, as well as coordinate care when a student and his or her family were transported to the crisis center.
SERVICE ENGAGEMENT AND SERIOUS MENTAL ILLNESS

This work included visiting students once they were admitted to inpatient units and helping inpatient staff with treatment planning. This coder had several students on her caseload who had been diagnosed with schizophrenia and were actively psychotic during psychotherapy sessions. In addition, this coder worked in the pharmaceutical industry, having the opportunity to work with psychiatric drugs in the rater assessments division. One of the assigned drug trials was a Phase III drug that was being studied for its efficacy on treating the negative symptoms of patients who had been diagnosed with schizophrenia.

The other coder also has extensive experience working with patients diagnosed with SMI. As a case manager for a community mental-health center in Philadelphia, this coder worked with underserved populations by making house calls and visiting inpatient units with patients diagnosed with SMI. The coder also worked as a Master’s-level practicum student twice per week at a community mental-health center, doing therapy and intakes with individuals with SMI. This coder had clients with SMI who were low income, many of whom were on public assistance, and many clients also had previous inpatient stays. In addition, the coder had a 1-year doctoral-level practicum placement at an acute inpatient hospital, working with actively psychotic/delusional clients and clients with a wide range of diagnoses. Finally, this coder participated in a 20-hour recovery training at her place of employment. This training discussed the recovery model and how it would translate into working with clients in outpatient community mental-health contexts. These background experiences naturally influenced the coder’s approach to analyzing the data in this research paper.
During the coding process, the coders found that their different backgrounds and roles in the research process affected their interpretation of their perceptions of the interviewed participants’ transcripts. The author approached the coding from the role of a direct observer of the participant, while the two additional coders had no knowledge of the participant’s age, ethnicity, race, gender, socioeconomic status, clinical diagnosis, or any other identifying information. Despite these differences, all three coders agreed on the data produced, as only triangulated data were considered valid for the purpose of this study.

**Results**

In this section, the first two research questions are answered: What barriers did clients face, and what facilitated treatment engagement? Findings regarding themes emerging from the data are elucidated and highlighted by individual narrative responses. Three core influencing factors for treatment engagement or disengagement emerged from the research: provider factors, including communication and treatment style, with the clarity of the discharge instructions emerging as a powerful influence on treatment engagement; systemic barriers; and perceived need factors. These themes are reported in this section, and tied to behavioral treatment models in the Discussion section. Please note that pseudonyms were used for the purpose of this paper, and careful attention was paid to include quotes that did not reveal identifying information.
Consumers Who Attended Follow-up Care

Systemic barriers and provider factors. This section will reveal themes of systemic and provider factors from narratives of consumers who attended follow-up care. Direct quotes are used to emphasize salient points in the narratives and illustrate the experience from the consumer’s perspective.

Franz’s story. Franz’s story encompasses a tale of systemic factors that worked to facilitate treatment, rather than to serve as barriers to treatment. Franz’s discharge instructions were clear, and a follow-up outpatient appointment was made for him by the inpatient unit prior to discharge. Franz not only attended the initial appointment, but also overcame great odds, such as being homeless and without a consistent provider prior to his inpatient stay. Franz’s narrative detailed how the entire treatment system, from inpatient to outpatient to continual follow-up, worked for him:

(The hospital) let me out to (name of outpatient placement), and then I was taken to a hotel down in (town in New Jersey). Uh, I spent three days in (town). Then they transferred me to a homeless shelter. . . . I spent 3 weeks there until I had secured an apartment, where I currently live by myself now.

Franz also experienced frequent and consistent contact with a person in the treatment system, which helped facilitate ongoing treatment after his initial follow-up:

Caroline was my case worker and she, um, she still to this day is very much in touch with me. . . . I think I'm doing very well, personally. . . . I kind of didn't believe that all this was going to happen. . . . and the next thing I know, it happened so fast. . . . Since I've left, it [life] has been wonderful.
Micah’s story. Micah’s narrative was semi-incoherent, but it came to light that although he did not understand his diagnosis or discharge, “They must have made an appointment on some paper and gave me a date. . . . They gave the paperwork to my brother.” This chain of events led to Micah’s attending follow-up outpatient treatment: “It was my brother. He said, ‘I'm going to get you to (name of outpatient program).’ He called them, and they came and got me.” Micah also revealed that he is engaged in outpatient treatment because of continuous contact with one provider: “I like (name of outpatient program). (Program name) helps. I like seeing Dr. (name redacted). I see her like every 2 or 3 weeks. It's helping.” Micah also revealed through his interview that other protective factors are in place, including his brother’s continuing support and the fact that his outpatient program provides transportation to and from appointments. One should note that Micah does not have a history of substance use or abuse; therefore, the nature of his disorganized speech and incoherent narrative at the time of the interview was not influenced by substance use, but rather more indicative of his general mental-health status.

James’s story. James reported that his discharge instructions were clearly delivered: “They gave me a piece of paper and told me to call the people up, call the groups up, and things like that.” He was instructed to “follow up, um, going to meetings, going to outpatient. . . . So now I'm in a 5-day program.” Although the provider style was paternalistic because James was told which outpatient program to attend, rather than included in a collaborative approach to placement, James seemed to take to this approach to treatment: “When somebody gives me advice, that's when I want to reach out and get
help. . . . So when people tell me the best thing, you know, to try to help me, I take it.”
This statement demonstrates that although the provider style was paternalistic, the therapeutic relationship was intact. An outpatient appointment was made for him prior to discharge from the inpatient unit, wait time to the appointment was minimal: “I've been going ever since I got out. The first day I got out, she signed me up for it, and I started that first day.” James revealed that the communication style of the hospital staff was helpful: “I could open up when I was at (name of inpatient unit).”

*Keith’s story.* Keith’s interview revealed themes of patient-centered treatment style and SDM, as well as systemic factors that facilitated his treatment and ultimate outpatient follow-up. First, Keith had already been in an outpatient program and stated that he would like to be returned to treatment there. The inpatient unit made an appointment for him prior to discharge: “The appointment was set, and the next day I was going.” Second, he reported that he has a consistent case worker whose treatment style he enjoys and with whom he can engage in treatment: “I go to Alisha. When you do start talking, she'll pull the rest out of you. To talk. To get it out. I like that.” Unlike some other participants, Keith stated that his discharge plans were clearly explained by multiple inpatient staff:

I saw this psychiatrist first, the doctor. She let me know what meds I was gonna be taking, what would stop it. Then, uh, one of the nurses went over all this stuff. And um, my fiancée had to come get me because that's who they released me to. They explained everything to her also. I also got a sheet of contact information, and everything I signed I have a copy of.
Keith’s story illustrates the multiple systems involved in healthcare decision making and how clear communication and patient-centered treatment that includes a member of the client’s social support system can facilitate a successful discharge. Keith ultimately attended his follow-up appointment.

**Perceived need factors.** James’s narrative also revealed themes of perceived need factors for treatment that clearly influenced his decision to attend outpatient treatment:

> My motivation for going was that I really needed help. Instead of going back in and out of the hospital. . . . I finally gave up and went there. My motivation was to get help…to get my life back on track. Cause, you know, I was living on the streets, things like that, so I think this hospital really helped me a lot. They gave me direction, where to go, how to get help. . . . Sometimes when I go there, I don't want to go home. I just want to stay. . . . I like outpatient treatment. . . . I just don't want to go back to the hospital.

**Consumers Who Did Not Attend Follow-up Care.**

**Systemic barriers and provider factors.** This section will reveal themes of systemic barriers and provider factors from narratives of consumers who did not attend follow-up care. Direct quotes are used to emphasize salient points in the narratives and illustrate the experience from the consumer’s perspective.

**Bernard’s story.** Bernard did not have his own physician, and although he was told by the inpatient psychiatrist that he needed to be on medication, no outpatient appointments were made for him by the inpatient unit. In his own words:
I had to go to (name of hospital redacted) in (city in another state). . . . I didn't have a doctor at the time, and it clicked that if I ran out of medication or ran into some kind of problem, to go there. . . . I didn't go to (name of hospital) because the intake coordinator, she looked at the medication, and it wasn't suitable for the program.

Bernard, therefore, faced the systemic factor of unavailability of a provider. He admitted that he felt he needed treatment: “I know I needed medication. And I wasn't using it. I follow up and continue to seek help, you know, treatment.” Bernard also faced a unique situation, as he had family support in New Jersey but was sent to another state for treatment by the inpatient unit. Although Bernard tried to find the help he needed, he was unable to find a provider. Bernard also was struggling with private stigma because he had to leave his family behind in order to get treatment:

That was so hard. And me leaving my family to, like, provide for themselves. . . . I just had to pack up and leave, and everybody was saying that ‘you're leaving for the best,’. . . . and that was some of the struggles for me, to go all the way to another state just to get help, and to leave my family.

**David’s story.** David’s story was a long and varied tale of recurrent depression following a physical ailment that left him disabled and in chronic pain. His narrative was rich with themes of loss of meaning in life, helplessness, hopelessness, and existential despair. These themes will be further elaborated upon in the Discussion section. David felt a perceived need for treatment and wanted to attend his appointment. However, he faced the systemic barrier of inaccessibility of transportation:
The first day that they were supposed to pick me up, I was up, I was ready, I was waiting, and, time went by, time went by, and nobody picked me up. So I called there after going from voicemail to voicemail. . . . I was waiting for someone to pick me up, nobody picked me up. . . . the lines of communication were just boggled. . . . The second day the same thing happened. . . I waited, and nobody showed up. And after that happened two or three times, I just gave up.

**Eduardo’s story.** Eduardo attempted to attend his outpatient appointment, but ran into several systemic barriers. The first barrier was accessibility of the appointment, specifically the accessibility of time: “I had to take off work, alright, because they wouldn't give me an evening hour.” Despite this first barrier, Eduardo attempted to attend his initial appointment. However, he then faced the systemic barrier of affordability:

> When I went there, they said they had my insurance information, and said, ‘You owe us $35,’ and I said, ‘I don't have $35’ and they said ‘Well you can't see the doctor unless you have it,' and I said, ‘Fine, I'll leave.’ . . . You're only as sick as the insurance company says you are.

Eduardo still attempted to attend his next appointment, but then faced the systemic barrier of availability of an appointment: “Three out of four appointments got canceled by them. So I just said, ‘Screw you, I ain't going.’” Eduardo also reported conflicts with his provider’s communication style: “Just that attitude. . . . one woman, a therapist. . . . I'm cracking jokes and stuff, and she was just as serious as a heart attack. And I'm like, this ain't gonna work.” He discussed that he felt the perceived need for treatment for his illness, but that the help would not come from the medical healthcare system:
I always thought, you know, psychology was, you know, like you see in the movies, where you sit down, you talk about issues and then they will give you a little something to help you along, but you need to think about this: The last two shrinks I went to, I walked in, and they were like, ‘what's your problem?’ and I tell them, and they say, ‘okay’ and just write out prescription pads. And they say, ‘okay, I'll see you in 2 weeks.’ That didn't help me at all. I thought I was there to talk about something.

**George’s story.** George reported that his discharge instructions were clear, verbally and in writing: “It was typed, with phone numbers and all the available information.” Despite this, George did not attend his prescribed outpatient treatment, as he faced two specific systemic barriers: affordability of treatment and accessibility of treatment as a result of time constraints: “My first appointment I canceled because I had to work.” George managed to make another appointment, and “I was refused treatment because my Medicare hasn't come through yet . . . and if you're not covered, you can't see the counselor.” George felt the perceived need that he had an illness and needed treatment for that illness. However, he also revealed that he thinks his illness will get better without professional therapy and wants to solve his problems on his own:

I’m basically a loner-type person, so all I think I can do things on my own, by myself…that I can control the situation. . . . Mentally, I think I’m doing better. . . . I have moments where I, I get a little bit depressed, but I get through them, and it's just temporary.
**Provider factors, perceived need, and stigma.** This section will reveal themes of provider factors, perceived need, and stigma from narratives of consumers who did not attend follow-up care. Direct quotes are used to emphasize salient points in the narratives and illustrate the experience from the consumer’s perspective.

*Alice’s story.* Alice did not go to her outpatient appointment, and the reasons she gave were related to provider and perceived need factors. In sum, she did not agree with her discharge instructions. Alice was given verbal and written instructions, and had a follow-up appointment made for her. She recounted that the discharge was clearly explained; however, she did not agree with the suggested living arrangements. Alice initially complied with her discharge, but soon found that it would not work out practically: “My niece wasn't to be able to have me stay with her. . . . if anybody would've found out I was living there, she could possibly get put out. So I knew that wasn't going to work.” Alice also had her own plans for after her discharge:

I decided I didn't want to go back to North Jersey, and I wanted to stay with the gentleman that I'm with. I decided I wanted to go back home, and that's what I did. . . . I was mentally and emotionally sane. I was myself again. So I didn't need to go into a day program. I needed to get back into my life.

While Alice acknowledged that she had an illness, she felt that outpatient follow-up would not be effective, and she would rather solve her problems on her own:
I don't need any, ah, follow-up treatment. I mean, been there done that. I know my triggers. I know myself pretty well. . . . I’m all about taking care of me. I want my mind to stay sane and stable. I don’t like hospitalizations. . . . I know that I made changes since I was in the hospital . . . so I really feel positive that it’s not going to be any more.

**Charlene’s story.** Charlene was given the name and contact information to make an appointment with a psychiatrist prior to discharge from inpatient hospitalization. However, it became apparent that Charlene did not feel as if she needed outpatient treatment: “I was gonna go, but I went to one of those programs before and it didn’t work. So I wasn't thinking this one was gonna work. So I just stayed home.” Therefore, she felt as if she would prefer to solve her problems on her own rather than attending psychiatric or psychological services, based on her past experiences within the mental-healthcare system.

**Harold’s story.** Harold disagreed with his discharge instructions and provider treatment style:

It was made quite clear to me what I was supposed to do. . . . everything was explained to me step-by-step along the way. . . . I wanted to listen, but I definitely did not want to do aftercare. . . . I didn't want to do it. An outpatient program where you go and you sit 5 hours a day, I mean, I don't have time for that. . . . it just seemed like a pain in my ass that I did not want to do. That's it. . . . I had been through outpatient appointments before and I don't have 5 hours a day to sit and listen to these nonsensical programs. Which is what it was to me.
Harold revealed an acknowledgment of an illness and perceived need for treatment, and had insight as to why aftercare was necessary: “They wanted me to stay on my medication and go to aftercare. I did not go to aftercare, which is why I ended up going to (another inpatient unit) probably a month and a half, 2 months later.” Despite Harold’s acknowledged need for treatment, he did not receive the treatment he craved, apparently because of conflicts with a paternalistic and authoritarian provider treatment style and nonshared decision making:

- They really wanted me to do aftercare. They explained all that to me. . . . I didn't want to deal with it. . . . You sit all day. . . . Groups aren't matched well. . . . I just didn't have time and didn't want to do it. . . . Anything but an outpatient program.

Interestingly, Harold’s interview revealed that the barrier of “acceptability,” that is, public stigma, may have been a factor in his disengagement with treatment:

- You have to watch what you say in that place. . . . you might end up institutionalized somewhere against your will. That was something that kind of really made me say not everything I wanted to say while I was there because I was afraid I wouldn't get out. . . . there were times when they asked me ‘How do you feel?’ and I didn't tell them everything and exactly how I felt because I knew, I'll be here another three days or another week, or they might even put me in front of a judge or something. . . . So it was kind of scary. I understand that it is a psych unit, but it was a little scary, you know.
**Lanora’s story.** The interview revealed that Lanora clearly understood her discharge instructions, and felt the perceived need for treatment:

I was down and depressed . . . And I felt overwhelmed. So I chose to, rather than act out on them, you know, act out on the voices, I chose to seek help to prevent it. . . . I knew it was because I had stopped taking my medication, I ran out of my medication. . . . so I came over to get some medication and to get myself back together.

However, she plainly stated that she disagreed with the “doctor’s diagnosis” and paternalistic/authoritarian treatment style:

I have a problem with authority figures, and somebody telling me what to do. . . . They have too many expectations for a person. . . . you have to do group sessions. I don't like doing group sessions. I like doing one-on-one in the beginning, and then work my way into group sessions. . . . I have real trust issues, serious trust issues with people. Since I've been discharged. . . . I've just been taking my medication and, you know, I'm feeling fine.

Although Lanora did not attend outpatient services at the placement recommended by the inpatient unit, she felt the need for treatment:

In initial I was gonna go, but now I’m seeking other places on my own. . . . You know, I seeked out my own treatment plan . . . By doing research and finding a program that I thought I needed, rather than what the doctors were telling me to do. . . . I found somewhere where I will be able to express my personal, and like be myself. I don’t have to worry about walking around on eggshells.
Lanora’s narrative revealed strong themes of perceived public stigma, resulting from past experiences with outpatient treatment:

Because of other programs that I have been at, you know, the business was like, took out of, out of like the, the confidentiality was broken, and my business was took on the outside. . . . there's people that I know at (name of prescribed outpatient program). . . . And you know, they're the type, that, uh, when they get upset, they'll throw your business and your personal, and your psyche, your mental psyche, they'll throw it out. Like, they'll put it on the streets or whatever. . . . So I'd rather go somewhere, I don't know too many people that go to.

Summary of Findings

**Outpatient follow-up.** Of the 12 study participants, four attended outpatient appointments following their inpatient stay and eight did not attend any follow-up outpatient appointment. The disengagement rate of 67% for this sample mirrors previous research, such as the NCS, which showed that fewer than 40% of respondents received consistent treatment (Kessler et al., 2001), as well as other studies reporting national disengagement rates ranging from 22% to as high as 90% (Compton et al., 2006; Klinkenberg & Caslyn, 1996).

**Individual/predisposing factors.** The following section summarizes the individual/predisposing factors of each participant in the study. Individual factors include sociodemographic information, clinical factors, and perceived need of each participant.
Sociodemographic factors. Of the 12 interviewees, three were women and nine were men. Race varied from African American, to Caucasian, to biracial. Ages of the participants ranged from the 30s to the 60s. Although patients of all ages were approached and/or consented for the study, interestingly no patients under the age of 30 years agreed to participate in the final interview. Therefore, the possible risk factor of a young age or early onset of psychosis, as identified by several studies in the literature review, could not be commented on in this study (see Boyer et al., 2000; Compton et al., 2006; Crawford et al., 2003; Kessler et al., 2001; Killaspy et al., 2000; Kreyenbuhl et al., 2009; Kruse et al., 2002; Nosé Barbui, & Tansella, 2003; O’Brien et al., 2009).

Interviewees were diverse in other identified socio-demographic factors, as reported in Table 1.

Clinical factors. Clinical diagnoses were obtained from each participant’s official medical chart. Of the 12 interviewed, diagnoses included bipolar disorder, major depressive disorder (recurrent) with psychosis, major depressive disorder (recurrent) without psychosis, and schizophrenia, paranoid type. Participants were also asked during their interview to state their diagnosis, in order to ascertain their perceptions of their illness and treatment. Of note, some participants were able to identify their official diagnosis, while others either did not know or identified nonclinical terms such as “stress,” “hopeless,” “suicide attempt,” and “from all my pills” as reasons for their stay at the inpatient unit.
### Table 1

**Sociodemographic Factors**

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</tr>
<tr>
<td>Own</td>
<td>2</td>
</tr>
<tr>
<td>Rent</td>
<td>7</td>
</tr>
<tr>
<td>Shelter/ group home</td>
<td>1</td>
</tr>
<tr>
<td>Living with parent, sibling, etc.</td>
<td>2</td>
</tr>
<tr>
<td>Number of people in household</td>
<td></td>
</tr>
<tr>
<td>1 to 3</td>
<td>5</td>
</tr>
<tr>
<td>3 to 5</td>
<td>6</td>
</tr>
<tr>
<td>5+</td>
<td>1</td>
</tr>
</tbody>
</table>
As part of the preinterview survey, participants were also asked how long they had been receiving psychiatric care, how many inpatient hospitalizations they had experienced (both voluntary and involuntary), and if they took their medications as prescribed. Years of receiving psychiatric care ranged from 1 year to more than 30 years, and one participant could not remember. Number of hospitalizations ranged from one to more than 20, with three participants responding that they were hospitalized so many times that they lost track or could not remember the exact number. Of the 12 participants, 10 took their medication as prescribed.

As predicted by the research, a dual diagnosis of SMI and SA was especially salient in the population under study, confirming epidemiological studies that estimate the prevalence of comorbid SA at between 30 and 60% (Johnson, 2000). A majority of the participants reported comorbid SA. See Table 2 for a summary of clinical factors.

**Perceived need factors.** Of the 12 interviewees, all 12 revealed the perception that they did have an illness. However, of those 12, four felt that they did not need any type of outpatient treatment. Cited reasons for lack of need for treatment included (a) the participant believed that his or her problem would resolve without treatment, (b) the participant felt that treatment would not be effective, (c) the participant wanted to solve the problem on his or her own, and (d) the participant did not want to attend outpatient treatment because of perceived public stigma. Data collected from interviews, conducted as part of the Epidemiological Catchment Area Study at Yale University, indicated that need factors may have the strongest relationship with service utilization and that
Table 2

Clinical Factors

<table>
<thead>
<tr>
<th>Factor</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical diagnosis</td>
<td></td>
</tr>
<tr>
<td>Bipolar disorder with psychosis</td>
<td>4</td>
</tr>
<tr>
<td>Bipolar disorder without psychosis</td>
<td>2</td>
</tr>
<tr>
<td>Major depressive disorder, recurrent, with psychosis</td>
<td>2</td>
</tr>
<tr>
<td>Major depressive disorder, recurrent, without psychosis</td>
<td>3</td>
</tr>
<tr>
<td>Schizophrenia, paranoid type</td>
<td>1</td>
</tr>
<tr>
<td>Number of years receiving psychiatric care</td>
<td></td>
</tr>
<tr>
<td>0 to 4</td>
<td>7</td>
</tr>
<tr>
<td>5 to 10</td>
<td>0</td>
</tr>
<tr>
<td>11 to 20</td>
<td>2</td>
</tr>
<tr>
<td>21 to 30</td>
<td>2</td>
</tr>
<tr>
<td>Numerous/ can’t remember</td>
<td>1</td>
</tr>
<tr>
<td>Number of psychiatric hospitalizations</td>
<td></td>
</tr>
<tr>
<td>1 to 4</td>
<td>5</td>
</tr>
<tr>
<td>5 to 10</td>
<td>2</td>
</tr>
<tr>
<td>11 to 20</td>
<td>2</td>
</tr>
<tr>
<td>21 to 30</td>
<td>0</td>
</tr>
<tr>
<td>Numerous/ can’t remember</td>
<td>3</td>
</tr>
<tr>
<td>Takes medication as prescribed?</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>10</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
</tr>
</tbody>
</table>

predisposing and enabling factors are contingent upon the presence of need (Leaf et al., 1988). The data from this study revealed the results in Table 3.
Table 3

Perceived Need Factors

<table>
<thead>
<tr>
<th>Group</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant admitted he or she had an illness</td>
<td>12</td>
</tr>
<tr>
<td>Participant admitted he or she needed treatment</td>
<td>7</td>
</tr>
<tr>
<td>Perceived reasons for lack of need a:</td>
<td></td>
</tr>
<tr>
<td>1. Participant felt that the problem would get better without treatment</td>
<td>1</td>
</tr>
<tr>
<td>2. Participant felt that the treatment would be ineffective</td>
<td>4</td>
</tr>
<tr>
<td>3. Participant wanted to solve the problem on his or her own</td>
<td>5</td>
</tr>
<tr>
<td>4. Participant did not attend treatment because of perceived stigma</td>
<td>2</td>
</tr>
</tbody>
</table>

*aSome interviewees had more than one reason for lack of perceived need.

Service factors. The following section summarizes the service factors that affected participants in the study. Service factors included systemic issues, such as availability, affordability, accessibility, and acceptability of treatment, and provider factors, including therapeutic relationship, treatment style, and communication style.

Systemic issues. The narratives revealed themes of all systemic barriers cited in the literature (availability, affordability, accessibility, and acceptability). Of the eight interviewees who did not attend outpatient appointments, myriad reasons were given, and some interviewees had more than one reason for non-attendance. Of the 12 interviewees,
one had no treatment provider and two could not make or find any available appointments. Two reported being denied treatment because they did not have insurance, including Medicare and/or Medicaid. Two participants reported having an appointment, but no accessibility to transportation to reach those appointments. Four were unable to make their scheduled appointment because the outpatient provider was not flexible with appointment scheduling and/or could not take the participant’s needs into consideration. For example, some participants reported that they could not take off from work for an appointment, and the outpatient provider was unwilling to accommodate their schedule. Finally, three of the participants reported feeling perceived public stigma, and one reported feeling private stigma because he had to “leave his family behind” in order to attend treatment. See Table 4 for a summary of systemic factors acting as barriers that affected treatment engagement.
Table 4

Systemic Barriers

<table>
<thead>
<tr>
<th>Barrier</th>
<th>n</th>
<th>Reason(^a)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Availability</td>
<td>1</td>
<td>No provider</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>No appointment</td>
</tr>
<tr>
<td>Affordability</td>
<td>2</td>
<td>Denied service because of lack of insurance</td>
</tr>
<tr>
<td>Accessibility</td>
<td>2</td>
<td>No transportation</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Lack of time (had to work or option of flexible</td>
</tr>
<tr>
<td></td>
<td></td>
<td>appointment timing was not available)</td>
</tr>
<tr>
<td>Acceptability</td>
<td>2</td>
<td>Felt public stigma</td>
</tr>
</tbody>
</table>

\(^a\)Some interviewees had more than one systemic barrier to treatment attendance.

**Provider factors.** Many themes of provider factors emerged, both positive and negative, emerged from an analysis of the research. In sum, authoritarian treatment style was a running theme throughout many narratives, with such phrases being used as, “I was told to”, “they told me to”, “they gave me papers”, “they said this is the place that…we got in touch with them and they’re gonna pick you up.” Certain interviewees actively disagreed with their prescribed discharge plans. A paternalistic therapeutic relationship
was also a salient theme, along with an authoritarian treatment style. However, three of
the 12 participants did report a patient-centered treatment style in tandem with SDM.

The theme of communication style of the treatment provider emerged as one
influencing factor in outpatient follow-up. Of the 12 participants, eight perceived that
they “felt listened to” by their treatment provider, and 10 felt that at least one of their
providers (either inpatient or outpatient) was a “sympathetic provider.”

Perceived clarity of discharge instructions varied. Nine reported that the
instructions were clear, although some disagreed with the prescribed treatments and/or
facilities. One did not understand the instructions, one reported not remembering the
instructions, and one was very unclear in the narrative as to whether or not the
instructions were understood.

One salient example of a disengaged patient was Eduardo, who was dissatisfied
with the services he received due to failed expectations. Specifically, he was referred to a
psychiatrist who provided medication treatment but not talk therapy. According to
Eduardo, “that didn’t help me at all. I thought I was there to talk about something.”
Eduardo also experienced an unsympathetic provider, as revealed by his colorful
description of the “sour-faced” therapist who would not respond to his jokes. This may
seem like a minor miscommunication, but the mismatch between Eduardo’s personality
and the provider’s engagement style directly led to him terminating treatment: “she was
just as serious as a heart attack, and I’m like, this ain’t gonna work.” See Table 5 for a
summary of provider factors that served to influence treatment engagement.
Table 5

*Provider Factors*

<table>
<thead>
<tr>
<th>Factor</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Therapeutic relationship</td>
<td></td>
</tr>
<tr>
<td>Patient-centered</td>
<td>4</td>
</tr>
<tr>
<td>Paternalistic</td>
<td>8</td>
</tr>
<tr>
<td>Treatment style</td>
<td></td>
</tr>
<tr>
<td>Shared decision making</td>
<td>4</td>
</tr>
<tr>
<td>Authoritarian</td>
<td>8</td>
</tr>
<tr>
<td>Communication style</td>
<td></td>
</tr>
<tr>
<td>Patient felt listened to?</td>
<td>8</td>
</tr>
<tr>
<td>Sympathetic provider?</td>
<td>10</td>
</tr>
<tr>
<td>Discharge clearly explained?</td>
<td>9</td>
</tr>
</tbody>
</table>

**Discussion and Analysis of Results**

The purpose of this study was to elaborate on the meaning, understanding, and experience of mental-healthcare service engagement from the viewpoint of individuals with SMI, within the framework of three healthcare behavioral models. This study was exploratory, designed to discover what mental-healthcare consumers had to say about their treatment experience. Interview questions focused on several themes, including the following: What factors make one more or less likely to disengage from treatment? What boundaries stand in the way of quality mental healthcare, and did participants in this
study overcome these barriers? If so, how was this overcoming achieved? Furthermore, what was each individual’s perception of his or her overall treatment experience from inpatient stay, to discharge, to follow-up? Data collection in the form of interviews allowed the researcher to assess mental healthcare consumers as whole persons, by reporting the meaning of their experiences through narratives. In this section, the results are interpreted in light of clinical implications of service engagement and disengagement behaviors. A discussion of additional themes revealed by the research follows. Finally, the data are explained through the lens of several behavioral healthcare models, with suggestions for future research and directions.

Theoretical and Clinical Implications of the Research Findings

Provider communication and treatment style. Previous studies examining systemic barriers and service factors have often focused on problems associated with providing continuity of care in the critical time period between inpatient hospitalization and outpatient treatment following discharge, as this time is highly vulnerable for treatment dropout (Crawford et al., 2003). In a qualitative study examining how people with SMI experience healthcare, patients reported noncontinuity of care as a salient reason for treatment disengagement (Kai & Crosland, 2001). Mental-healthcare consumers want to be able to build a continuing relationship with one person over time and express concerns about changes in physicians.

Previous research revealed that a strong influence on mental-healthcare engagement is the nature of the provider relationship and the degree to which patients are active participants in their treatment plan (Borg & Kristiansen, 2004; Charles et al., 1997;
A strong therapeutic relationship is key to service engagement (Becker & Maiman, 1975; O’Brien et al., 2009; Priebe et al., 2005; Vermeire et al., 2001; Young & Ensing, 1999). Kai and Crosland (2001) asserted that a positive relationship that establish continuity of care is based upon trust and effective communication. Keith illustrates the importance of trust and effective communication with a single provider with his assertion that “When you do start talking, she'll pull the rest out of you. To talk. To get it out. I like that.” Keith’s trust in his provider, coupled with her effective communication style, facilitated his ongoing treatment.

In order to assess whether or not participants were able to clearly understand what their inpatient provider communicated regarding outpatient treatment planning, two explicit interview questions were the following: “What was your specific discharge treatment plan? How was this information delivered to you?” All 12 participants gave varying answers, suggesting that no uniform method of discharge treatment planning was followed at this facility. All reported that they were given a discharge packet, consisting of the following information: addresses and phone numbers of community health services, psychiatric day programs, outpatient mental-health counseling centers, drug and alcohol treatment centers, and crisis hotlines. However, Charlene, David, Micah, and Lanora were simply given the information packets and told the name of the outpatient referral program. Only Micah attended his outpatient appointment, but apparently
because of the support and insistence of his brother rather than of the effectiveness of the discharge instructions. The other eight participants were given their discharge packet, but in addition had their discharge instructions verbally explained by the staff. Eduardo reported that the team “clearly went through” the information packet, although he ultimately did not attend his follow-up appointment because of other factors. Bernard and James reported that they were also given the information packet and had their discharge instructions explained verbally, but neither attended his outpatient appointment because of disagreements over the treatment team’s recommendations. However, they were not given a choice of treatment options. Perhaps if there had been a uniform way of communicating treatment needs to the consumers identified in this study, they would have been more likely to attend treatment.

As previously mentioned, no uniform discharge process was followed at this particular treatment facility. Data gathered from the narratives support the suggestion that provider communication was unclear in certain cases. For example, Alice reported that she was not sure whether or not she was supposed to call her outpatient provider, or if the outpatient provider was supposed to contact her. Eduardo described walking out of an appointment because the treatment provider did not match his communication style. Finally, Micah stated several times that “nobody talked to me,” and he clearly did not understand his treatment instructions. Although research exists that specifies the importance of provider communication (Becker & Maiman, 1975; O’Brien et al., 2009; Priebe et al., 2005; Vermeire et al., 2001; Young & Ensing, 1999), results from this study showed a lack of clear communication between provider and consumer.
Although provider communication frameworks exist (see Feldman-Stewart et al., 2005), no such frameworks were followed at the inpatient facility in question, perhaps explaining the confusion of several of the participants. A clear communication process in which verbal and nonverbal messages are given and received is especially relevant, considering that some patients were given only written discharge instructions and others were given discharge instructions both verbally and in writing. Priebe et al. (2007) developed a computer-mediated intervention for patient-provider dialogue (DIALOG) and revealed that structuring patient-clinician dialogue to focus on patients’ views positively influenced their treatment satisfaction. A future study could assess the effectiveness of DIALOG in facilitating continuity of treatment.

**Shared decision making (SDM).** SDM is a collaborative process in which consumers and providers work together to exchange information and clarify values in order to achieve consensus on healthcare decisions (Adams & Drake, 2006; Adams, Drake, & Wolford, 2007; Kreyenbuhl et al., 2009). Several participants did report that multidisciplinary treatment teams explained their discharge options in a mutual setting. This patient-centered model of SDM is supported by the literature as a facilitator to better treatment outcomes (Adams & Drake, 2006; Adams et al., 2007; Kreyenbuhl et al., 2009; Schauer et al., 2007). The literature on the health outcomes of patient-centered treatment reveals that SDM has a positive impact on treatment engagement.

The strength of the therapeutic relationship and the nature of the decision-making process are both influenced by provider communication style (Feldman-Stewart et al., 2005; O'Brien et al., 2009; Priebe et al., 2007; Van Os et al., 2004). Harold reported that
the entire treatment team handed him his discharge packet, explained the instructions, and even went over his medications and dosages: “They went over my medications with me and the prescriptions that they gave me, told me when I should take it, and how much I should take . . . they really wanted me to do aftercare and they explained it all to me.”

Studies show that the quality of clinical communication is related to positive health outcomes, perhaps because clear communication style and teaching strategies can overcome patient misunderstanding of a treatment strategy or its effectiveness (Vermeire et al., 2001). Perhaps this theme of clear communication is what Keith meant when he stated, “I don’t understand medical talk.”

In this study, SDM was endorsed as an important trait by most of the participants, although it did not directly lead to outpatient engagement. This result may be because those who endorsed SDM were still unable to overcome systemic barriers, such as Franz (who agreed with his discharge plan but could not overcome the systemic barrier of accessibility of transportation) and Bernard (who also agreed to discharge instructions but could not overcome the systemic barrier of availability of provider). Franz, Keith, and James all expressed themes of SDM throughout their narratives, and all three ultimately attended follow-up treatment. Interestingly, Alice, Charlene, Harold, and Lanora endorsed an authoritarian and paternalistic style of provider decision making, and not one attended outpatient follow-up. This variable is correlational, but cannot be said to be causal, partly because of the nature of the study design and partly because other factors were influencing the noncontinuity of treatment for each participant. For example, Alice
and Charlene also reported systemic barriers, as well as a lack of perceived need, and Lanora expressed a fear of public stigma serving as a barrier to treatment engagement.

**Systemic linkage strategies.** Previous research revealed that allowing inpatients to meet the outpatient treatment team prior to discharge is associated with high rates of long-term service engagement (Nosé, Barbui, Gray, et al., 2003). The facility at which this research was conducted did not practice this linkage strategy. However, two participants, James and Keith, revealed that they had been in outpatient treatment programs prior to their inpatient stay and asked to be returned to those treatment programs. Both James and Keith told the treatment team that they preferred their established outpatient facilities, in which they already knew their caseworkers and had an established support system. According to James, “I’ve been going ever since I got out…the first day I got out she signed me up for it, and I started that first day.” This statement also supports claims that a minimal wait time to the first outpatient appointment facilitates continuity of care (Compton et al., 2006; Crawford et al., 2003).

Results of this study suggest that Boyer et al.’s (2000) three identified linkage strategies may increase the probability of patients’ attending their first outpatient appointments. These strategies are: (a) having the patient start an outpatient program prior to discharge; (b) clear communication about the discharge plan between inpatient staff and outpatient clinicians; and (c) involving family in the treatment process. This particular facility did not follow the first linkage strategy of having the patient start an outpatient program prior to discharge. However, as previously noted, clear communication about the discharge plan between inpatient staff, consumers, and
outpatient clinicians facilitated treatment in several cases. Also, involving family in the treatment process proved to facilitate treatment engagement for Keith and Micah. The treatment team explained Keith’s discharge plan to his fiancée, and he credits her with treatment engagement, explaining that she monitors his medication, researches his mental illness, and helps him with activities of daily living. Micah’s brother brought him to the inpatient unit, as well as facilitated his transfer to outpatient treatment, providing transportation and emotional support.

As previously mentioned, other linkage strategies exist, but none was implemented at this facility. Perhaps implementation of the brief critical time intervention model (Dixon et al., 2009; Susser et al., 1997) or strategies gleaned from the Lambeth Early Onset Team (LEO) would reduce relapse rates in the population studied. For example, the LEO revealed that assertive outreach strategies, CBT, family counseling, vocational training, and social support for individuals with SMI were associated with lower rates of service disengagement and hospital readmission (Craig et al., 2004). Although the LEO strategies were implemented in an outpatient setting, perhaps initiation of these strategies by an inpatient unit would decrease relapse rates during the critical time period between discharge and outpatient treatment. As reported in the Results section, data gathered from the narratives revealed the importance of social support, including family and continued employment. No participants reported being provided with any of these services from the inpatient unit.
Facilitating perceived need. All 12 of the interviewees revealed the perception that they did have an illness. However, of those 12, four felt that they did not need any type of outpatient treatment. Although previous research would identify this behavior as “noncompliance,” a recovery orientation assumes that the consumer is an equal partner in the decision-making process, and that consumers may have personal, subjective reasons for not attending outpatient treatment. Reasons revealed in this research were factors tied to self-efficacy and/ or non-SDM. For example, Alice, Charlene, Eduardo, George, and Harold all stated either that they had been to outpatient treatment in the past and it did not help them or that they felt they would prefer to turn to family members and other means of social support, rather than the medical system, in times of crisis. For some participants, their decisions were effective in preventing relapse at the time of the interview. For example, Alice, Charlene, and Eduardo reported being happy with their decision not to attend outpatient treatment. Alice credited self-efficacy and family support for her emotional well-being, Charlene credited her relapse prevention to self-efficacy (“I just stayed home and stayed off the drugs”), and Eduardo emphasized the importance of continued employment to his emotional stability.

George and Harold reported perceived need for treatment, but not for outpatient follow-up care. Unlike for Alice, Charlene, and Eduardo, this decision turned out to have detrimental consequences for George and Harold. Harold stated that he did not agree with the treatment team’s decision to recommend outpatient care, which he had tried in the past and did not find enjoyable. However, he realized that his decision not to attend treatment led to a relapse and additional treatment in an inpatient unit, stating, “I did not
go to aftercare, which is why I ended up going to (another inpatient unit) probably a month and a half, 2 months later." George also did not attend outpatient treatment, but expressed during the interview that he was still experiencing symptoms of his mental illness. He indicated that he was willing to try other avenues, such as electroconvulsive therapy (ECT), stating, “I received six ECT treatments . . . and I think they helped a lot. . . . I need to make an appointment for that. I'll make one today.”

Therefore, providers should keep in mind that although some patients may be able to identify their treatment needs, others may require additional education as to the nature of their illness, symptom identification, relapse prevention, and education about different modes of mental-health treatment efficacy. Woolf et al. (2005) suggested that clinicians and their staff should undergo informed-choice training, emphasizing communication and negotiation skills when collaborating with patients on treatment planning. This research supports the SDM model of medical care and the importance of provider communication, and fits with the information reported by the participants in this study.

**Additional Variables Revealed by the Research**

**Meaning-making, sense of identity, and a return to “ordinary life.”** Previous studies have found significant correlations between meaning-/purpose-in-life assessments and hopelessness, well-being, quality of life, and mental health (Zika & Chamberlain, 1992). Existential meaning is an important theme in the lives of individuals with SMI, as purpose in life correlates positively with quality of life, as well as with service engagement (Stolovy, Lev-Wiesel, Adiel, & Gelkopf, 2009). Murphy (2000) interviewed eight individuals with SMI and psychotic symptoms and found that they often attached
meaning to the hallucinogenic content of their psychotic episode. Additionally, many had existential crises following their psychotic episodes, because the experience led them to question whether there was any meaning or purpose to their existence. Theories of service disengagement are therefore incomplete without considering the meaning that patients assign to their illness and their experience of that illness (Vermeire et al., 2001).

David’s story is a prime example of loss of meaning in life and a search to reclaim that meaning. He described himself as an “active person” who found meaning in his work, which was of a physical nature. Following a devastating injury, he was unable to return to his job: “When I got in an accident... all that just came to a crashing halt... and I’ve never seemed to be able to fully recover.” He described a daily struggle with the reminder that “[I am] not the person I used to be...I enjoyed my work, I enjoyed interacting with people...and when it’s all stripped from you...it just tears you up inside.” David’s struggle can be best summarized by his statement that he wants his “former life back.” He is currently searching for other sources of “self-enjoyment” and “self-pride.” As of the time of the interview, he was not attending outpatient treatment.

Like David, Eduardo experienced depression and what he described as “hopelessness.” He made meaning from his illness by “not dwelling on the past” and deciding that “it’s over and done with, and what happened is what happened...the only thing you have right now is the moment you are in.” Although he also did not attend outpatient treatment, he reported that his “days are full.” He makes meaning and finds hope through relationships with his family. For example, he recently found out that he will be a grandfather soon, giving his life meaning and purpose beyond his illness.
Owing to systemic factors reported earlier, George was unable to attend his follow-up outpatient appointment. However, he also craves meaning and a return to a “normal” life. His goal is to have “victory” over depression instead of succumbing to it. James and Keith revealed similar sentiments. James stated several times that he wanted to “get his life back on track” and to “get direction” on how to live a productive life. Keith reported that certain dates serve as triggers for his depression or psychosis as a result of tragedies he experienced on those dates. At the time of the interview, both James and Keith were in active treatment and trying to make sense of their lives and symptoms of suffering. Alice was not in active treatment, but she made the decision that a return to ordinary life was more important: “I didn’t need to go into a day program….I needed to get back into my life.” According to Lanora, she did not attend treatment, but found meaning. She said, “[I] went back to my marriage, and my happy life.”

The ability to sustain psychological well-being during episodes of SMI is necessary for recovery. The process of setting goals and building meaning engenders a sense of purpose, a perception of personal control, and goal-directed coping for the person with SMI (Folkman & Greer, 2000). Previous qualitative research clearly shows that individuals coping with SMI want to develop meaning in their lives and that hope for a better life is necessary in recovery (Borg & Kristiansen, 2004; Folkman & Greer, 2000; Kai & Crosland, 2001). In an editorial written by an individual hospitalized for SMI, the author recounts that “It seemed that there should be more to life. . . . One pleasant aspect of being in the hospital was that it gave me a chance to think about what I really wanted to do with my life” (Herrig, 1995). Interestingly, Keith repeated a similar sentiment when
he said, “It’s usually when you get the most out of it, when you’re on bad days. Because you’re more focused to listen.” In keeping with the recovery theme, time spent in treatment can be meaningful in and of itself.

**Hope, empowerment, and self-efficacy.** The data gathered through narratives in this study revealed messages of hope and empowerment. Alice disclosed, “dealing with my sickness . . . was very positive in my growth. . . . that’s going to help me come up out of this rut. . . . so I feel really positive that it’s not going to be any more.” Although Alice did not attend outpatient treatment, she is clearly expressing a message of hope for her future. Perhaps this hope is the result of self-empowerment; Alice did not agree with discharge recommendations and decided to take treatment into her own hands. Now that she had decided to return to her husband and home, she stated that “things are going well…it’s been wonderful.” Alice presented as a woman with a positive outlook who focused on her own goals instead of the treatment team’s decision. These goals included reuniting with her husband, forming closer bonds with estranged family members, and participating in pleasurable activities with her family. She now describes herself as “joyous.” This statement seems to demonstrate the healing power of hope and self-empowerment.

Other participants revealed similar themes. Eduardo disclosed that pending discharge he was “hopeless” but now finds hope and empowerment in his employment, “Thank God they saved my job because I was able to come right back. . . . Mostly I’m pretty good . . . all my goals now are realistic.” Franz originally had “no plans whatsoever” following his discharge, but as described earlier in this paper, systemic and
provider factors worked to facilitate treatment engagement. However, he specified that facilitating treatment was, “a combo of the unit, the counselors, the people, and my own free will. I decided . . . that I’d had enough. . . . So as far as I’m concerned, I’m done. As far as I’m concerned, I beat it.” Keith finds his strength through self-empowerment: “You gotta do research on yourself sometimes. . . . Being outside calms me down. Listening to the radio. . . . I feel good.” Finally, Charlene reported that although she did not attend her follow-up appointment because she “went to one of those programs before and it didn’t work,” life has been “great. Just living day to day. Doing it on my own.”

Russinova (1999) suggested that the empowering potential of hope can intervene to enhance the process of recovery from SMI. During a stressful situation or threatening event, hope can preserve the meaning of life. Alternatively, hopelessness can foster existential despair. In the face of loss, individuals high in hope can cope with the situation by developing strategies for overcoming adversity and bolstering subjective competence (Shorey, Snyder, Rand, Hockemeyer, & Feldman, 2002). Indeed, hope is closely related to meaning and purpose, in that a breakdown in hope leads to loss of meaning in life (Clarke & Kissane, 2002). Evidence has been accumulating on the empowering potential of hope in the process of recovery from SMI (Russinova, 1999). Hope is considered a positive factor in the lives of persons living with schizophrenia, their significant others, and their healthcare providers, and hope intervention programs have been shown to enhance quality of life (Herth 2000; Herth 2001). Feldman and Snyder (2005) proposed that hope is a construct similar to meaning-making theory, since goal-directed thinking is correlated with life meaning.
Social networks and rebuilding a sense of community. Pescosolido (2006) provided a framework for assessing the influence of social networks on healthcare decision making in the NEM, the validity of which has been shown in several different cultures (Pescosolido, Gardner et al., 1998; Pescosolido, Wright et al., 1998; Olafsdottir & Pescosolido, 2009). Individuals are not raised in a vacuum, and different social networks clearly contribute varying healthcare attitudes and beliefs to the decision-making process. In light of the responsibility the field of psychology has towards acknowledging multiculturalism, the concepts comprising this framework must be investigated in deeper detail. For example, how exactly and in what ways do different social networks influence different types of individuals?

This study revealed the importance of social networks in influencing treatment engagement. Lanora chose not to attend her outpatient treatment precisely because a family member who she believed “has my best interests in mind” advised her not to go to the program. She also reported reaching out to a Hispanic treatment center, even though she does not categorize herself as of Hispanic ethnicity: “A lot of people are under the impression that it’s just for the Hispanic culture, when it’s not.” As previously reported, Alice did not attend outpatient treatment because she preferred to live with her husband; however, she also revealed the importance of living close to other family members: “That’s a joy. Sometimes when you get close to losing your life, you become more serious about your loved ones.” Although Bernard did not receive treatment because of systemic barriers, he revealed that having a “closer bond to his family” drove his decision to leave the state and attempt to engage in treatment; he also reported, “my motivation
was me being a grandfather. . . . My support group is my family.” Keith described how his fiancée monitors his medications, researches the side effects of such, and encourages Keith to attend treatment. Finally, when Micah was asked of his perceived benefits of attending treatment, he reported that “it was my brother.” Essentially, Micah’s brother encouraged him to attend treatment and even provided him with transportation to his initial appointment.

Research shows that persons less integrated in their social groups report more distress than those more integrated, even when the former have fewer stressful life events than the latter (de Figueiredo & Frank, 1982). Social bonds are involved in preventing distress and subjective incompetence from occurring together, which is the hallmark of demoralization (de Figueiredo & Frank, 1982). When persons feel subjective distress, they are more likely to withdraw socially, and this social withdrawal reinforces their feelings of shame, hopelessness, and helplessness (Clarke & Kissane, 2002). This process is exactly what happened to David, who had a job and family before his accident. Following his accident and subsequent loss of meaning in life, he developed feelings of incompetence and helplessness caused by a failure to live up to expectations. These feelings led to hopelessness and social withdrawal, including the loss of his social support system, with resultant feelings of shame and existential despair, the ultimate expression of demoralization. When social bonds are inadequate, the distress of a threatening life event can be overwhelming. Relationships with family members, friends, clinical staff, medical team, the hospital, and/or institution are factors that can either prevent or prolong demoralization (Kissane, Clarke, & Street, 2001).
SERVICE ENGAGEMENT AND SERIOUS MENTAL ILLNESS

**Stigma.** Stigma is a proven significant contributor to demoralization syndrome and a salient barrier to treatment engagement in the lives of individuals with SMI (Corrigan & Watson, 2002; Corrigan, Markowitz, & Watson, 2004; Martin, Pescosolido, & Tuch, 2000; Phelan et al., 2000). Research on stigma experience and its outcomes reveals that individuals with SMI, their families, and their providers all report continuous experiences of stigma and discrimination (Pescosolido et al., 2008). Many consumers in the mental-health system fear being looked down upon and worry about what their friends, relatives, coworkers, and community may think about treatment engagement (Stefl & Prosperi, 1985). The negative consequences of stigma, especially hindrances to service engagement, have been well documented (Corrigan, 1998, 2002, & 2004; Hayward & Bright, 1997; Link & Phelan, 2006; Link, Phelan, Bresnahan, Stueve, & Pescosolido, 1999; Rusch et al., 2005).

Studies suggest that a majority of Americans report an unwillingness to work alongside or have intimate connections with persons with mental illness (Pescosolido et al., 2008, Phelan et al., 2000). Research supports the negative impact of discrimination on the lives of individuals with SMI, as well as on their families and healthcare providers; in fact, stigma may occupy a central place in explanations of low service use, inadequate treatment infrastructures, and hindered process towards recovery from mental illness (Pescosolido et al., 2008).

Lanora described the concept of stigma precisely with her description of previous treatment experiences:
Because of other programs that I have been at. . . . The confidentiality was broken, and my business was took on the outside. . . . When they get upset, they'll throw your business and your personal, and your psyche, your mental psyche, they'll throw it out. Like, they'll put it on the streets or whatever.

Harold experienced perceived stigma as well:

You have to watch what you say in that place. . . . You might end up institutionalized somewhere against your will. That was something that kind of really made me say not everything I wanted to say while I was there because I was afraid I wouldn't get out.

Like Lanora, Harold’s fear of perceived stigma hindered his treatment engagement. In contrast, Eduardo did not experience stigma, which may have led to an increase in hope for the future. Eduardo expected to lose his job, a personal source of meaning and purpose, and the lack of stigma from his boss bolstered his hope for the future: “Thank God they saved my job because I was able to come right back. And I told my boss. . . . and he’s very sympathetic.” Eduardo is, therefore, not just financially stable, but emotionally bolstered by a lack of public stigma in this particular situation.

**Implications for Behavioral Models of Healthcare Engagement**

Several healthcare behavioral models have been formulated and applied to the explanation of mental-healthcare service engagement, including the health belief model (HBM), the network episode model (NEM), and the demoralization framework model (DFM). The HBM has attempted to describe how an individual’s beliefs of the risks and benefits of a prescribed action lead to a particular set of healthcare behaviors.
et al., 2001). The NEM goes beyond the individual to incorporate the broader social influences on healthcare behaviors, and the DFM attempts to incorporate stigma, motivation, hope, and patient empowerment into the explanatory model.

**Health belief model (HBM).** For a behavioral change to succeed, according to the revised HBM, an individual must have an incentive to take action (perceived susceptibility and severity), believe the change will be beneficial (perceived benefits and barriers), and also believe themselves competent to implement that change (self-efficacy). Although the basic components of the HBM show empirical validation, there are limitations to the theory. For one, a basic underlying assumption of this model is that health is seen as a desirable goal, which may or may not be true for different individuals. They do not necessarily see themselves as “unhealthy” or perceive “health” as the goal of treatment. Charlene admitted to committing violent acts and to SA, but did not perceive that she had an “illness” that required the intervention of the mental-healthcare system. David indicated that he desired to be rid of symptoms of psychosis, but revealed a distrust of the healthcare system and medical providers, indicating that doctors cannot be trusted to provide adequate treatment. Eduardo was coerced into treatment, as described in the next section; he did not actively choose “healthcare” as a desired goal. Harold explicitly stated, “I did not want to do aftercare.”

In addition, the rational orientation of the model has been criticized for omitting the emotional components of some health behaviors (Henshaw & Freedman-Doan, 2009). Participants interviewed for this study revealed emotional, and not necessarily rational, approaches to their healthcare decision-making behavior. George described himself as a
“loner” who preferred to solve his problems on his own because of his interpersonal style. Harold reported that treatment was a “pain in [his] ass that [he] did not want to do” and revealed that a benefit of not attending treatment was “less hassles. . . . I didn’t want to deal with it.”

Janz and Becker (1984) pointed out that other variables, such as environmental and social factors that may impact an individual’s preferred course of action, also influence health care behavior. For these reasons, the NEM is a better fit to explain the healthcare-seeking behavior in the population with SMI examined in this study.

**Network episode model (NEM).** The NEM is a more valuable predictor of healthcare behavior than the HBM, as the NEM focuses on broader social issues and takes into account the interaction among social networks, patient beliefs, and doctor-patient relationship, variables that were also thematic throughout this research. This model is also powerful in that it suggests that healthcare behaviors develop over time and evolve into patterns of service usage. The NEM proposes that the interaction between persons and their social networks acts as the primary mechanism through which people recognize health problems, contact health facilities, and comply with medical advice (Pescosolido, Gardner, et al., 1998). Rather than conceptualizing healthcare behaviors as isolated and independent choices, the NEM takes into account the entire illness “career” by incorporating individual decisions into overall patterns of healthcare behavior. This model attempts to conceptualize patterns of healthcare service use by assuming that (a) people in all societies consult both professionals and lay people for healthcare advice during an illness episode, (b) the decision process is dynamic in that individuals...
continuously combine series of decisions over stretches of time into patterns, (c) choices are not necessarily rational, and (d) the underlying mechanism at work is interaction in social networks (Pescosolido, Wright, et al., 1998).

According to data collected from the narratives, themes emerged of underlying social networks driving healthcare behavior. Alice, Bernard, Eduardo, Keith, and Lanora all reported consulting lay people, specifically friends and family members, in addition to professionals when seeking treatment advice. Keith repeatedly referred to his family as his “support team.” James told an interesting tale of a stranger intervening in a suicide attempt, advising him to seek treatment instead: “This guy, he stopped me and told me to go to (name of hospital redacted) and get some help, so I came here.”

The various narratives also made evident that healthcare decisions were dynamic and evolved from patterns of service usage over time. Alice did not attend treatment, specifically reporting, “been there done that.” Charlene stated, “I was gonna go, but I went to one of those programs before and it didn’t work.” Harold had also attended outpatient programs in the past: “I had been through outpatient programs before, and I don’t have 5 hours a day to sit and listen to these nonsensical programs.” His past experiences seemed to be influencing his current healthcare engagement behaviors. Keith was one of the few participants who did attend follow-up outpatient treatment, perhaps because he was discharged to a facility that he had previously attended and in which he received good care. Finally, Lanora chose not to attend outpatient treatment in part because of her past experiences with participants of other outpatient programs “breaking
confidentiality” and in part because a family member advised her not to attend her referred outpatient treatment program.

Furthermore, the NEM specifically considers coercion and “muddling through the system” as variables in healthcare decision making, as opposed to the HBM, which considers treatment engagement an active, rational choice. Although seven participants indicated that they went into treatment by choice, themes of coercion and “muddling through the system” were also exposed through the data.

**Coercion.** Eduardo experienced coercion by the legal system to attend treatment. According to Eduardo, when he awoke in the emergency room, “They had me handcuffed to a gurney. They said either you go upstairs [to the inpatient unit] or we call the cops and you go to jail.” Therefore, even though the inpatient facility was voluntary, the legal system was a factor in Eduardo attending treatment. Eduardo’s account supports Pescosolido’s (1992) suggestion that people with mental illness are sometimes forced into treatment by the legal system.

Micah also experienced coercion into treatment. According to official hospital records, Micah entered the inpatient unit after his brother called the facility to inform them that Micah refused to take his evening medications, because Micah believed the medications would “blow him up.” According to Micah: "They said I was dead. They said I was dead. . . . I think they called my son. See, I was there, and they made an appointment for me to come here. . . . They didn't even talk to me. Nobody talked to me." Micah did not understand how he got into treatment, or even why he was there. While the service providers may have had Micah’s best interest in mind when consulting with his
brother, they ultimately failed to bring Micah into the dialogue. Although he did attend outpatient treatment, his decision could hardly be called a “choice” if Micah could not even explain why he was in treatment.

*Muddling through.* Pescosolido defined “muddling through” the system as the phenomenon of neither actively resisting nor actively seeking treatment. When people muddle through, they “bounce around and off circumstances and others as they attempt to deal with problems, engaging in successive, limited comparisons between alternatives” (Pescosolido, Gardner, et al., 1998, p. 275). Themes of “muddling through” the system were revealed in this research. Franz stated the following:

I woke up 3 days later, didn't realize, didn't even know how I got to the hospital. Um, didn't understand what happened. . . . then they left me there for 5 days. Then they put me in the crisis unit. . . . I don't remember any of this. This is what I was told by other people. My father, my daughter, my son, and as far as I know, I still don't know the whole story. . . . I, uh, went, not knowing what it was about, so, they mentioned taking me up to the crisis unit. . . . I didn't know if they would be giving me, like, sedated, or giving me group therapy. They didn't explain it. I just went up there.

George also revealed through his narrative that he actively agreed to go to the inpatient unit. However, his story is categorized as “muddling through” rather than “choice” because of the circumstances he faced of limited alternatives to psychiatric commitment:
I was brought into the hospital by ambulance, and I first went to the trauma unit, and then . . . They might have asked me later on, after my operation and everything, and after anesthesia, did I want to go to the psychiatric unit for help? And at that time I said "yes."

**Demoralization framework model (DFM).** The construct of demoralization was first proposed by Jerome Frank (1974), who suggested that the primary function of all psychotherapies is to combat demoralization. He based this premise on a growing body of treatment engagement research that consistently showed that those who sought psychiatric treatment experienced greater social isolation, helplessness, and sense of failure than those who did not seek treatment. Frank posited that these constructs are all symptoms of demoralization. He defined demoralization as distress combined with subjective incompetence resulting from a persistent inability to cope with stressors (de Figueiredo & Frank, 1982). Subjective incompetence was defined as “a state of self-perceived incapacity to act at some minimal level according to some internalized standard in a specific stressful situation” (p. 353).

Clarke and Kissane (2002) described demoralization as a clearly defined syndrome of existential distress occurring in persons suffering from a mental or physical illness that threatens life or integrity of being. Constructs important to its understanding are helplessness, hopelessness, meaning, and purpose, as they are the expression of existential despair. Clarke and Kissane argued that a stressful situation that includes a severe threat in which an individual does not know the solution, can activate feelings of helplessness that, if not buffered by hope, can further lead to a loss of meaning and
purpose in life. As part of the demoralization process, helplessness, hopelessness, and loss of meaning create feelings of existential despair, which can lead to further social isolation, internalized stigma, and loss of self-esteem. This perception further fuels the demoralization process by reinforcing feelings of hopelessness and helplessness.

David’s story was an especially salient example of the demoralization process. Like many other participants, he experienced a stressful situation (a disabling physical accident). However, in David’s case, he was unable to resolve the situation, which led to feelings of helplessness (as revealed by repeated statements that basic activities of daily living are a “struggle,” “I never planned on this. . . . I never wanted this to happen,” “I’m not in control,” and “I just gave up”). He then experienced hopelessness (“If this is the way my life is going to be, then, you know what, I’d rather not be”). He reported that he lost his meaning and purpose in life, which were his job and his family. He therefore perceived that he had failed to meet his own and others’ expectations. As his feelings of shame and failure persisted, hopelessness led to existential despair through the loss of meaning and significance in life derived from personal competence and interpersonal ties. David’s narrative included numerous perseverations of words and phrases indicative of hopelessness, helplessness, and existential despair, such as “life’s a struggle,” “it’s all been stripped from me,” “self-pity,” “it tears you up inside,” “frustration,” “stuck,” “no sense of direction,” “I don’t know where to turn,” and “I just gave up.” He repeatedly stated that he does not understand why he does not “get a second chance to go back” and “I’m just trying to live life as best I can.” David’s affect and presentation suggested a demoralized figure, as he kept his head down, avoided eye contact, and was tearful.
throughout the interview process. This description fits the DFM, specifically “symptom expression of demoralization,” which specifies that the demoralized person experiences withdrawal, social isolation, and despair (Clarke & Kissane, 2002).

Preliminary data support the reliability and validity of the Demoralization Scale, which was developed by Clarke and Kissane to assess demoralization using constructs based on their model (Kissane et al., 2004). Demoralization can occur in communities, such as hospitals or institutions, when fragmentation, loss of leadership, rigidity, and polarization set up a vicious cycle of personal and professional conflicts (Hinshelwood, 1988). Demoralization among consumers of mental healthcare is linked to dissatisfaction with services and service providers, as well as to decline in the quality of care.

According to phenomenological research on demoralization, just as persons experiencing demoralization can be helped by a clinician with hope-enhancing and other therapies, their treatment can also be hindered by the withholding of help. According to Clarke and Kissane (2002), clinicians can make demoralization worse by “inadequate symptom relief, tactless communication of progress, inadequate listening to concerns, a dismissive attitude that devalues the patient as a person, or an inability to converse on matters of importance” (p. 738). Several participants in this study revealed such themes through their narratives, the details of which were reported in the Results section.

Finally, interventions that acknowledge constructs based in the DFM have been found to be highly effective (Dickerson, 1998; Lenert, 2009), especially in the population with SMI (Borras et al., 2009; Lecomte et al., 1999). Specifically, the empowerment model of intervention is particularly useful in combating demoralization. The
empowerment intervention is based on the principle that consumers of mental-health services can gain control over their lives by increasing self-determination, social engagement, and a sense of personal competence (Dickerson, 1998). Self-determination, social engagement, and subjective personal competence are fostered by emphasizing the patient’s strengths and competencies and by promoting consumer involvement in service planning and delivery. Implicit in the concept of empowerment is personal control, social engagement, goal setting, and appropriate coping strategies (Lecomte et al., 1999). Findings from empowerment intervention studies show that empowered patients are more than twice as likely to engage in treatment and more than three times as likely than comparison groups to have scheduled at least one follow-up visit (Alegria et al., 2008).

Note that not every participant in this study reported symptoms of demoralization. Therefore, one must use clinical judgment in conjunction with objective screening tools, such as the Demoralization Scale, in order to assess which patients may be in need of services to combat demoralization syndrome.

**Behavioral implications.** In light of the results of narrative data, behavioral healthcare models that emphasize process-oriented behaviors in consideration within a broader social structure are better predictors of healthcare engagement than are rational, value-expectancy models. Although neither the HBM, NEM, nor DFM adequately explained the healthcare behavior of all participants involved in this study, themes from each of these models were revealed in the narratives, as will be explained in the following pages. It is proposed that a behavioral healthcare model that incorporates constructs from
the NEM and DFM would be a more efficient predictor of healthcare behavior than either individual model in the population studied.

As reported, the HBM did not explain the behavior of all 12 participants, because of its previously listed limitations. First, individual factors (known as modifying factors in the HBM), such as demographic and psychosocial variables, have not been shown to correlate with healthcare decision making (Kessler et al., 2001; Klinkenberg & Caslyn, 1996). Second, information gathered from this study revealed that while all 12 participants experienced perceived susceptibility to their illness, not all experienced perceived severity, thus biasing the HBM category of individual perceptions, which links the two variables. Furthermore, participants in this study did not all perform the expected HBM cost-benefit analysis of perceived benefits of preventative action minus perceived barriers to preventative action. For example, while some participants, such as Alice and Lanora, weighed the costs and benefits of perceived avenues of treatment engagement, others did not (e.g., James, who, as reported, was planning to jump off of a bridge but was interrupted by a stranger and told to go to the hospital instead). According to James, he took the stranger’s advice based on a gut reaction, not a cost-benefit analysis of perceived barriers and benefits to treatment.

The most salient aspect of the HBM leading to the likelihood of taking recommended preventative health action may be cues to action, which in the original HBM included such concepts as mass media campaigns, advice from others, reminders from the physician, the illness of a family member or friend, and newspaper/magazine articles. The results from this study suggest that the specific cues to action that come
from one’s primary social support network were most influential on the healthcare
engagement behaviors of the participants involved, lending further support that the NEM
is a better predictor than the HBM to explain healthcare decision making in the
participants involved in this study.

The NEM is a process-oriented model that considers the individual’s healthcare
behavior within a broader social context (Pescosolido, 2006). The NEM proposes an
interaction amongst an individual’s sociodemographic and clinical factors, contents of his
or her social support system, patterns of behavior that have emerged over the entire
“illness career,” and various components of the treatment system. Results of the current
study revealed that participants’ healthcare behavior was influenced mainly by provider
communication and treatment style, SDM models vs. authoritarian treatment style, the
presence or lack of systemic linkage strategies, and the salience of perceived need
factors. The NEM takes all of these factors into consideration. Indeed, Pescosolido
proposed that more research is needed to fully flesh out the model and identify which
factors are more or less influential in treatment decision making (Pescosolido &
Olafsdottir, 2010).

The DFM is another important model to consider when treating those with SMI.
Although only one participant’s narrative followed the full trajectory of the DFM,
existential meaning-related constructs that compose this model were found as influential
themes throughout many of the narratives. As mentioned, themes of meaning-making, a
sense of identity, and a return to “ordinary life” were revealed throughout the narratives.
The importance of hope, and of instilling hopefulness in the patient, was found to be an
SERVICE ENGAGEMENT AND SERIOUS MENTAL ILLNESS

influencing factor in treatment engagement. Self-empowerment and self-efficacy were also revealed throughout several narratives as important constructs to mental health care consumers.

Although themes from the NEM and DFM were found throughout the narratives, neither model comprehensively explained healthcare-seeking behavior. A model that combines themes from both frameworks may be a more appropriate model to explain healthcare-seeking behavior in the SMI population. For example, the Framework Integrating Normative Influences on Stigma (FINIS) is a model developed by Pescosolido that incorporates themes from the NEM and includes the saliency of public and private stigma as a factor in service engagement and disengagement (Pescosolido et al., 2008). The FINIS focuses on the theory that different levels of social life interact to set the normative expectations influencing stigmatization, including micropsychological and sociocultural factors, social networks and organizational factors, and macrosocietal expectations. Considering the importance of stigma and its influence on service engagement, the FINIS may be a very appropriate framework in which to examine health behavior in future studies, especially in the population with SMI.

Multicultural and Diversity Considerations

Multicultural competency is a necessary skill when treating the population with SMI. When one approaches case conceptualization with multicultural values in mind, a wealth of additional information is available to the competent clinician. Considering that the purpose of the current study was to deepen the understanding of service engagement
as an individual process, a discussion of results is incomplete without taking into consideration the multicultural factors of the involved participants.

First, the population under study was recruited from a large urban hospital in the northeast section of the United States. As such, the sample of convenience was not representative of all individuals with SMI. A majority of the participants lived in the same urban area, parts of which are economically depressed. Therefore, they were of a low socioeconomic status and did not have access to resources that those from a middle- or upper-class background may have. This factor in turn, made systemic barriers, such as affordability and availability of appointments and providers, that much more salient. In fact, several participants self-described as homeless before hospitalization and identified lack of stable housing as a treatment barrier.

Second, the sample was recruited from a well-known, regionally recognized urban facility. This institution has access to numerous resources that a facility in a rural area may not have access to. Some participants who experienced successful discharges credited the skill and efficiency of the inpatient linkage to outpatient services. In the northeast region of the United States, especially in urban areas, access to outpatient resources may be more timely than in other parts of the country.

Third, the sample was somewhat diverse in sociodemographic and clinical characteristics. Although previous studies have not shown these to be consistently correlated with treatment engagement, they still must be taken into consideration when examining the results of the study. As previously mentioned, all participants were over the age of 30 years. This factor could create a cohort effect when examining the meaning
that participants ascribe to their illness. Perhaps individuals under the age of 30 years would attribute their illness characteristics or needs to factors that could not be examined in this study. Gender differences must be noted as well, as a majority of the participants (75%) were men. Men and women may create meaning from their experiences in different ways. In fact, gender studies show that men and women do indeed perceive physical and mental illnesses differently, especially according to their phase in life (Macintyre, Hunt, & Sweeting, 1996). Finally, this sample was not representative of all races, ethnicities, and genders. Meaning-making arises from experiences throughout one’s lifetime and is heavily influenced by cultural factors, including race, ethnicity, and gender.

Limitations of the Current Study

This study has several limitations. First, the nature of the participant pool may have led to biased results. Participants in the two groups were not matched for sociodemographic characteristics or clinical features. A study utilizing the same design and methodology, with the exception of matching service-engaged and service-disengaged individuals on sociodemographic information, may reveal subtle themes that could not be discovered by the current design. Additionally, a follow-up study with a larger participant pool may increase reliability. Participants were contacted by phone, thus excluding anyone without a home or a telephone. Participants were recruited from a voluntary unit, thus potentially biasing the sample. Finally, eight of the 12 participants were diagnosed with comorbid SA, which could potentially bias treatment engagement and discharge planning. The existence of comorbid SA is fairly common in the
represented population in this study, as evidenced by epidemiological research estimating
the prevalence of comorbid SA at between 30 and 60% (Johnson, 2000). This researcher
had no practical way of assessing if the participant was actively using a substance at the
time of the interview.

Second, the methodology and research design may limit reliability and validity of
results. Data collection was in the form of an interview and, thus, used self-reported
information. Standardized measures would improve the reliability of the data by
corroborating results. Many objective measures can be employed to assess the variables
examined in this study. For example, service engagement can be measured using the
Service Engagement Scale, recovery style by the Recovery Style Questionnaire, and
insight by the Insight Scale. The Structured Clinical Interview for the Positive and
Negative Syndrome Scale (SCI-PANSS) assesses the positive and negative symptoms of
psychosis and, thus, is a good objective measure for severity of illness. Many objective
measures are available for the clarity of patient and provider communication, one being
the Two-Way Communication Checklist. Finally, scales exist to measure the dimensions
of demoralization, including the Demoralization Scale and the Hope Scale. Stigma,
revealed to be an important theme in service disengagement, can be objectively
measured. One such measurement is the Self-Stigma of Mental Illness Scale.

This research was a qualitative study, the purpose of which was to reveal possible
themes of service disengagement risk factors. Future research should utilize the themes
revealed in this research to design a quantitative study to measure possible mediators and
moderators to service engagement in the population with SMI. Such a research design
would allow one to assess objectively the influence of different interventions on the
direction and amount of change in service engagement behaviors. As has been shown in
the research, psychoeducation as to the nature of the illness and the importance of service
engagement enhances adherence behavior (Nosé, Barbui, Gray et al., 2003). A study
comparing the efficacy of different types and structures of psychoeducation could add to
the understanding of service engagement. Researchers and psychologists have also
suggested that Motivational Interviewing may be an important intervention for increasing
service engagement (Kottsieper, 2006). Finally, several types of simple systemic
interventions exist that providers can use to possibly enhance service engagement in their
patients, and these could be objectively measured. Examples include service prompts in
the form of phone calls or reminder cards, marketing campaigns, and the recruitment of
family members to aid in the recovery process (Nosé, Barbui, Gray et al., 2003).

Suggestions for Future Work

Loss of autonomy and the therapeutic relationship. In a qualitative study
examining service engagement, Priebe et al. (2005) elucidated some nonquantifiable risk
factors by conducting indepth interviews with 40 individuals with SMI. Results indicated
that disengagement was often the result of a struggle against loss of autonomy and
identity as the result of mental illness and emphasized the importance of the therapeutic
relationship in facilitating treatment. In fact, researchers have proposed that qualitative
research on recovery from SMI would benefit by shifting the emphasis from the illness to
the person, in order to reveal subtle themes of disengagement (Sells et al., 2004).
The current study analyzed service engagement from the point of view of the patient, and groups were divided into the categories of service engaged and service disengaged accordingly. However, as systemic and provider factors seem to be more influential on service engagement than are sociodemographic factors, quantitatively designed follow-up studies could investigate the impact of qualities of the service provider and statistically compare different groups of provider characteristics. For example, one could compare providers who subscribe to the recovery movement with providers who follow the more traditional medical model of symptom reduction. Comparison groups could also be in the form of providers who engage in SDM versus providers who have a more paternalistic style. Does the provider follow a patient-centered approach, and if so, how much of an impact does this approach have on service engagement? Russinova (1999) proposed that a practitioner’s ability to inspire and maintain hope in clients with psychiatric disabilities plays a central role in providing the motivational resources necessary for the recovery process to occur. Finding out if patients tend to engage more in service when their healthcare attitudes and beliefs match those of their service provider would be interesting.

**Hope interventions.** This study gathered qualitative information through narratives, which revealed messages of hope and empowerment. A quantitative study assessing the efficacy of interventions intended to provide messages of hope can greatly contribute to the research. Multiple measures would improve the reliability and validity of the data by corroborating results.
Several hope intervention frameworks have been suggested in the research (Herth 2001; Larsen, Edey, & Lemay, 2007; Snyder et al., 2000). Herth (2000) developed a Hope Process Framework, defining hope as “a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving good, which, to the hoping person, is realistically possible and personally significant” (p. 1432). Hope theory has been studied extensively in both the medical and psychological literature, and hope is recognized as a healing force in the face of acute, chronic, and terminal illness (Feldman & Snyder, 2005; Herth 2000; Herth 2001; Hillbrand & Young, 2008; Houghton, 2007; Klyma, Juvakka, Nikkonen, Korhonen, & Isohanni, 2006; Larsen et al., 2007; Shorey et al., 2002). In fact, Herth (2000) designed a “hope intervention” for patients with cancer, and results suggest that helping the patient to search for hope, connect with others, and build a hopeful veneer is positively correlated with treatment outcome and quality of life.

**Spirituality and meaning-making.** The American Psychological Association (APA) has recognized the increasing research showing that spiritual and religious concerns indeed arise in psychotherapy. In a resolution adopted by APA Council of Representatives, they acknowledge that “evidence exists that religious and spiritual factors are under-examined in psychological research both in terms of their prevalence within various research populations and in terms of their possible relevance as influential variables,” specifically their influence on conducting culturally sensitive research, psychological assessment, and treatment (APA, 2007, p. 2-3).

Results from this study support the notion that some patients use their religious or spiritual beliefs to make meaning out of their suffering. Bernard reported that he managed
his daily stressors and symptoms of mental illness through dependence on his “higher power,” support from his church community, “faith,” and reliance on the “grace of God” as a support mechanism. He also specified that reliance on his faith is helping him. Franz specifically stated that he was “blessed that God didn’t take me.”

Based on the literature, Pargament, Murray-Swank, and Tarakeshwar (2005) offered an empirically based rationale for integrating spirituality into psychotherapy. They concluded that (a) spirituality can be a part of the solution to psychological problems, (b) spirituality can be a source of problems in and of itself, (c) people want spiritually sensitive therapy, and (d) spirituality cannot be separated from psychotherapy. Indeed, whether religion and spirituality are part of the solution or part of the problem is an important and legitimate assessment question for psychotherapists.

Following these arguments, attempts have been made to integrate spirituality, religion, and psychotherapy. One such modality, Spiritually Augmented Cognitive Behavioral Therapy (SACBT), was developed at the University of Sydney and tested in randomized, controlled trials in patients with depression and/or demoralization. SACBT augments regular CBT by using the principles of CBT with an added focus on existential issues. It differs from traditional CBT in that the focus is on meaning, purpose, and connectedness in the context of the patient’s belief system. SACBT also incorporates behavioral techniques, such as meditation, prayer, and ritual exercises. Controlled studies have demonstrated that 16-session SACBT is beneficial in extinguishing hopelessness and despair, improving treatment collaboration, reducing relapse rates, and enhancing functional recovery (D’Souza & Rodrigo, 2004).
Summary and Conclusions

The construct of recovery is comprised of a set of principles that has all been identified as important in the treatment of SMI, being implemented in the current policies and practices of mental-health systems across the country. The concept of stigma is tightly entwined with the reality of mental illness, and the public’s perception and level of knowledge influence mental-health policy. Mental-healthcare practitioners have a duty to alert others to the reality of SMI, inform the public and correct misunderstandings, and advocate for mental-healthcare parity and policy change. Research must be dedicated towards uncovering the attitudes and beliefs of the patient with SMI about the mental-healthcare system and healthcare service engagement. The goal of this research would be to elaborate on the meaning, understanding, and experience of mental-healthcare service engagement from the viewpoint of individual consumers. Having a recovery orientation implies designing health-care systems that meet peoples’ unique needs, in order to provide quality systemic care that people are willing and able to use.

Recovery research in particular is needed to examine healthcare behavior according to the framework of sociological and psychological models that incorporate patients’ subjective perceptions of the efficacy of medical treatment engagement. An explanatory framework of service engagement, based on the subjective views of mental-healthcare consumers, can be a starting point to guide policy and improve quality of care for this unique population. The patient’s view of the world and his or her illness within that world gives rise to a better understanding of the illness, including its personal meaning to the patient and the expected recovery process. This process is influenced by
the patient’s beliefs, histories, psychosocial resources, and expectations regarding the future. By relying on subjective, personal accounts of service engagement, the relationship between disengagement factors and healthcare-seeking behaviors can be elucidated. Only then can an explanatory model of healthcare behavior in the population with SMI be applied to the clinical setting to influence mental-healthcare practice.

Given the high potential for treatment disengagement and the negative consequences disengagement may have for some consumers, mental-health treatment systems must develop and implement strategies to increase engagement. Despite the existing research into disengagement risk factors, general consensus is lacking on which factors are most critical for service disengagement and treatment dropout. As previously mentioned, the results of studies examining predisposing factors remain inconsistent. Additionally, research suggests that systemic factors and provider factors are most critical for predicting service engagement (Compton et al., 2006; Klinkenberg & Caslyn, 1996; Kreyenbuhl et al., 2009). Therefore, a majority of the research literature centers around strategies to improve service factors, including overcoming systemic barriers and improving the provider-patient relationship (Boyer et al., 2000; Kreyenbuhl et al., 2009; Stefl & Prosperi, 1985). As the patient’s right to autonomy and self-determination is acknowledged and the mental-healthcare system moves away from the paternalistic model of healthcare, the doctor-patient relationship is being revised and refined (Vermeire et al., 2001). The proposed suggestions are intended for mental-healthcare providers and systems, with the aim of improving communication between providers and patients, as well as of suggesting adjustments in service delivery.
At the current time, practitioners and scholars of the mental-health system understand more than ever before about how and why some patients engage in service and some do not. However, they still have a long way to go and a lot of avenues to explore, as the findings of the current study illuminated. Going directly to the population of interest and eliciting their personal understanding of service engagement is an important start. This study is a jumping-off point for future research in the area of mental-health recovery.
References


SERVICE ENGAGEMENT AND SERIOUS MENTAL ILLNESS


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Appendix A

The Health Belief Model (Rosenstock, 1966)

Individual Perceptions

- **Perceived Susceptibility** to Disease X
- **Perceived Severity** of Disease X

Modifying Factors

- **Demographic Variables**
  - age, sex, race, ethnicity, gender, etc.
- **Psychosocial Variables**
  - employment status, social isolation, etc.

Likelihood of Action

- **Perceived Benefits** of preventative action minus **Perceived Barriers** to preventative action

Perceived Threat of Disease X

Cues to Action

- Mass media campaigns
- Advice from others
- Reminder from physician
- Illness of family member
- Illness of friend
- Newspaper article

Likelihood of taking recommended health action
Appendix B

The Network Episode Model (Pescosolido, 2006)

**SOCIAL CONTENT**

or

**EPISODE BASE**

**FOR THE INDIVIDUAL**

Social and Geographical Location
- Gender
- Age
- Education
- Work Status
- Marital Status
- Income
- Occupation

Personal Health Background
- Prior history of illness
- Coping style
- Medical insurance

Nature of the Event
Illness characteristics
- Severity
- Visibility
- Duration
- Acute/Chronic

Organizational constraints
- Organization of care
- Accessibility of care
- Financing of care

**SOCIAL SUPPORT SYSTEM**

<table>
<thead>
<tr>
<th>Network Structure</th>
<th>Network Content</th>
<th>Network Functions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Size</td>
<td>Beliefs and</td>
<td>Information</td>
</tr>
<tr>
<td>Density</td>
<td>attitudes toward</td>
<td>Advice</td>
</tr>
<tr>
<td>Duration</td>
<td>health, professional</td>
<td>Regulation</td>
</tr>
<tr>
<td>Reciprocity</td>
<td>medical care (e.g.,</td>
<td>Support</td>
</tr>
<tr>
<td>Strength of tie</td>
<td>perceived efficacy</td>
<td></td>
</tr>
<tr>
<td>Multiplexity</td>
<td></td>
<td>Support</td>
</tr>
</tbody>
</table>

**THE ILLNESS CAREER**

Key Entrances | Key exit | Key Timing |
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sick role</td>
<td>From sick role</td>
<td>Health advisors</td>
</tr>
<tr>
<td>Patient role</td>
<td>Termination of care</td>
<td>Consultations</td>
</tr>
<tr>
<td>Chronic role</td>
<td>Recovery</td>
<td>Degree of</td>
</tr>
<tr>
<td>Disabled Role</td>
<td>Death</td>
<td>compliance</td>
</tr>
<tr>
<td>Dying career</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**THE TREATMENT SYSTEM**

<table>
<thead>
<tr>
<th>Treatment network structure</th>
<th>Treatment network content</th>
<th>Treatment network functions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Size</td>
<td>Treatment efficacy</td>
<td>Information, Advice, Regulation</td>
</tr>
<tr>
<td>Density</td>
<td>Diagnostic capacity</td>
<td>Emotional support</td>
</tr>
<tr>
<td>Duration</td>
<td>Modalities</td>
<td>Material support</td>
</tr>
<tr>
<td>Reciprocity</td>
<td>Staff attitudes and culture</td>
<td></td>
</tr>
<tr>
<td>Strength of tie</td>
<td>towards health, clients,</td>
<td></td>
</tr>
<tr>
<td>Multiplexity</td>
<td>community, &amp; treatment</td>
<td></td>
</tr>
</tbody>
</table>
**Appendix C**

Demoralization Framework Model (Clarke & Kissane, 2002)

<table>
<thead>
<tr>
<th>Process of Demoralization</th>
<th>Symptom expression of demoralization</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assumptive World</td>
<td></td>
</tr>
<tr>
<td>• Specific meaning</td>
<td></td>
</tr>
<tr>
<td>• Particularized hope</td>
<td></td>
</tr>
<tr>
<td>• Sense of explicit role</td>
<td></td>
</tr>
<tr>
<td>Stressful situation or event:</td>
<td>(The situation puts the person in a position where their future, in significant ways of functioning or survival, feels uncertain or unknowable)</td>
</tr>
<tr>
<td>Person does not know how to:</td>
<td></td>
</tr>
<tr>
<td>• Change the situation</td>
<td>Helplessness</td>
</tr>
<tr>
<td>• Extricate themselves from the situation</td>
<td></td>
</tr>
<tr>
<td>Unable to resolve the situation themselves</td>
<td></td>
</tr>
<tr>
<td>May seek help:</td>
<td></td>
</tr>
<tr>
<td>• If help is unavailable, insufficient, untimely, or the person feels unable to ask for help.</td>
<td></td>
</tr>
<tr>
<td>• To the extent that the person perceives they have failed to meet their own and others’ expectations</td>
<td></td>
</tr>
<tr>
<td>• To the extent that the meaning and significance of life is derived from the competence, interpersonal ties and other areas of loss</td>
<td></td>
</tr>
<tr>
<td>Feelings of apprehension, panic, threat</td>
<td></td>
</tr>
<tr>
<td>Helplessness</td>
<td></td>
</tr>
<tr>
<td>Feelings of incompetence, impotence</td>
<td></td>
</tr>
<tr>
<td>Loss of sense of mastery and control over life</td>
<td></td>
</tr>
<tr>
<td>Diminished esteem</td>
<td></td>
</tr>
<tr>
<td>Hopelessness</td>
<td></td>
</tr>
<tr>
<td>Feelings of shame, aloneness, isolation: person withdraws</td>
<td></td>
</tr>
<tr>
<td>Existential despair, meaninglessness</td>
<td></td>
</tr>
</tbody>
</table>
### Sociodemographic Survey

**Appendix D**

Client ID # ___________________ Survey date ______________

1. What is your gender?  M / F / Other / Refuse to answer

2. What is your date of birth? _____ / _____ / __________

3. What race or ethnicity do you consider yourself to be?
   - White
   - Biracial
   - Native Hawaiian/ Pacific Islander
   - Black
   - Multiracial
   - Latino/a or Hispanic
   - Other: _______________
   - Asian
   - Native American

4. What is your current marital status?
   - Single/ Never married
   - Widowed
   - Married
   - Partnered
   - Separated
   - Other: _______________
   - Divorced

5. Do you have children?  Y / N
   - If so, how many?   _______
   - What are their ages?  _______
   - Do any live with you?  _______

6. How many people live in your household?  _______

7. What is your highest level of education?
   - Less than 9 years of school
   - 9-12 years, not graduated
   - High school graduate or GED
   - Some college, vocational, trade, or business school
   - Associate degree or vocational graduate
   - College degree
   - Some graduate school
   - Master’s degree
   - Doctoral degree or beyond

8. What is your current job status?
   - Full-time
   - Unemployed/ not looking for work
   - Part-time
   - Unemployed/ looking for work
   - Irregular schedule (work on & off)
   - Unemployed/ full-time student
   - Disabled
   - Other: _______________
9. What is your current living situation?
   Own
   Rent
   Homeless (street/car/empty building/etc.)
   Shelter
   Group home
   Transitional housing
   Assisted living
   Living with someone else (specify): ____________
   Other (specify): ____________

Clinical Information

10. How long was your stay on the unit (South 5)? __________

11. What is your diagnosis? _______________________

12. How long have you been receiving any type of psychiatric care? _______

13. How many times have you been hospitalized (voluntarily and involuntary)?
    __________

14. Do you have a problem with addiction?  Y  /  N
    a. If so, what is your substance(s) of choice?
       ____________________________

15. Do you currently take medication?  Y  /  N
    a. What medications?
       ____________________________
    b. Do you take your medicine as prescribed?  Y  /  N
    c. Were any of these prescribed for the first time in the past 4 weeks?  Y  /  N
    d. If so, which ones?
       ____________________________
Appendix E

Interview Questions

1. What were you in inpatient treatment for? (to assess whether or not the participant understands his/her diagnosis).
2. Did you choose to go to treatment? (to see if there was coercion involved).
3. What was your specific discharge treatment plan? How was this information delivered to you?
4. What were your plans for after you were discharged?
5. What has life been like since then?
6. If you did attend outpatient treatment, what was that experience like?
7. What was your motivation for attending outpatient treatment? (if they did attend).
8. Where were any barriers/challenges to attending your outpatient appointment? (for who attended). What were the barriers to attending your outpatient appointment? (for those who did not attend).
9. How did you overcome these barriers and challenges? (for those who did attend).
10. What were the benefits of attending? (for those who did attend).
11. What were the benefits of not attending? (for those who did not attend).
12. What would have made you more likely to attend treatment? What would have made you go to treatment? (for those who did not attend).
13. Is there anything I left out or anything else that you want to tell me?