

July 2018

Perspectives of older Blacks and Whites living with serious mental illness about outpatient mental health services

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Perspectives of older Blacks and Whites living with serious mental illness
about outpatient mental health services

by

Rosalyn Roker

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
School of Aging Studies
College of Behavioral and Community Sciences
University of South Florida

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Date of Approval:
July 9, 2018

Key Words: bipolar disorder, health belief model, mental health, older adults,
qualitative research, schizophrenia

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DEDICATION

To my son, Marvin DeRossi Keyon Jackson, who is living with schizophrenia. I am inspired by your courage. To my mother, Vernell Roker, a caregiver of a person living with mental illness. My strength and perseverance are a reflection of you.

ACKNOWLEDGMENTS

I must first thank God for His faithfulness and giving me enough light for each step that I took along this journey. I thank Him for giving me the courage and wisdom to trust Him even when things did not make sense to me. *“For I know the plans I have for you,” declares the Lord, “Plans to prosper you and not to harm you, plans to give you hope and a future.” [Jeremiah 29:11]* I am richly blessed, and will continue to trust God to direct my paths and provide every need as I walk into my next season.

Thanks and appreciation are extended to the University of South Florida’s College of Behavioral and Social Sciences, School of Aging Studies, for providing me with graduate assistantships that enabled me to attend the PhD program full-time. I must also thank Florida Agricultural and Mechanical University (FAMU), College of Pharmacy and Pharmaceutical Sciences, Center for Research and Education and Training Enhancement (CREATE) program, funded by the National Institutes of Health NIGMS’ Innovative Programs to Enhance Research Training (IPERT) and Sisters of the Academy (SOTA) for the mentorship and training opportunities. Heartfelt thanks to my sorority, Alpha Kappa Alpha Sorority, Inc. Educational Advancement Foundation for the scholarship.

Many thanks are extended to my dissertation committee members, Drs. Tamara Baker and Victor Molinari (co-major advisors), and Drs. Kyaien Conner, Debra Dobbs, William Haley, and Dinorah Martinez-Tyson who provided support and guidance during this process. A special thanks to my co-major advisors, Dr. Baker for taking a chance

and extending an opportunity to me as her graduate research assistant, and for embracing my vision for a research project related mental health service utilization among older Blacks living with serious mental illness, and Dr. Victor Molinari for adopting me as a student and assisting me through this process. Thanks are also extended to Dr. Iraida Carrion, my dissertation committee chairperson, for her support during my program.

I also extend thanks to the School of Aging Studies faculty and staff who provided support and guidance during my tenure in the graduate program. Gratitude and appreciation are extended to Dr. Brianne Stanback, who was a catalyst for my pursuit of the Ph.D., and Dr. Cathy McEvoy who found a way to make it happen. I can't thank you enough!

I'll forever be grateful to my study participants for their courage and willingness to share their personal experiences with mental illness; they were the life of this research project. Also, to the management personnel at the recruitment sites, and Dr. Roxann McNeish, who provided support and shared their knowledge about outpatient mental health services, please accept my deepest thanks. Thanks are extended to Eraldine Shakespeare-Williams for her kindness and assistance with coding the interview data.

Thanks are extended to my Ph.D. colleagues, Drs. Tiffany Young and Marianne Chanti-Ketterl who extended support along the way. Marianne has been like a sister to me; through thick and thin, in and out of school, she has listened, encouraged and been a dependable source of support. Marianne, I cannot thank you enough!

My support network outside of academia was amazing. I cannot thank my family enough for the many sacrifices, support, encouragement and love as I pursued my

dream. My son, Marvin, was my greatest inspiration and he made this journey worthwhile. Because of his experiences living with schizophrenia, I was motivated to do this type of research with the hopes that my work will one day make a difference in the lives of others who have similar experiences. My parents, Willington Roker (deceased) and Vernell Roker, taught me that hard work, integrity, and humility would take me far in life. My older sisters Beverly, Vicki (deceased), Denise, Delphine, Wilma, Cheryl, and Juliette (deceased) have always had my back and encouraged me to not only dream big, but to “have my party”. I love each of you and hope that I’ve made you proud! #Rokegirlmagic Oh, and I can’t forget Raina and Isabella “Izzy”, my two cats, who were adopted during my PhD studies and kept me company as I burned the midnight oil doing school work.

Dolliver Iverson, my “church” mom, listened, encouraged, and prayed for me as I shared my desires to learn more about serious mental illness and caring for older adults in the community. Brenda Jackson-Lee, Pamela Ravenel and Monique Warren knew where to find me on campus and literally brought me food, clothes or whatever they thought I needed to make sure I was okay. My Ladies of Literature book club members and my Gamma Theta Omega chapter of Alpha Kappa Alpha Sorority, Inc. sorors who demonstrated the meaning of “we help each other because we know there is no other like our sisterhood”. Fred and Marlina McClure, Dr. Mikki Chambers, Charnell Williams, LaShon Green, Sandra Fletcher, and Dianne Hart I cannot thank you enough. I am grateful for other family, friends and strangers for all they did by words, prayer, and deeds to help me accomplish this goal.

“If I can help somebody as I pass along, if I can cheer somebody with a word or song, if I can show somebody he’s traveling wrong, then my living will not be in vain.”

Dr. Martin Luther King, Jr.

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ABSTRACT

In the United States, over three million adults, age 50 and older, reported a diagnosis of serious mental illness (SMI) in the past year. Most of them live in community-settings and are less likely than younger adults to utilize mental health treatment. Lack of and insufficient treatment for SMI places them at increased risk of morbidity, earlier mortality, cognitive decline, and diminished quality of life. The current study aimed to: (1) examine the factors that influence Black and White older adults, who live with SMI, to seek and engage in outpatient mental health treatment; (2) identify the perspectives of Black and White older adults, who live with SMI, on the issues of accessibility, affordability, appropriateness, and availability of outpatient mental health services; and (3) determine whether the perspectives of Blacks and Whites are different on the issues of accessibility, affordability, appropriateness, and availability of outpatient mental health services.

I developed a qualitative, interview-based study using the health belief model (HBM) as the theoretical framework. Individual semi-structured interviews were conducted with 19 participants, between the ages of 50-70 years (mean age 58.9), who had a clinical diagnosis of bipolar disorder, schizoaffective disorder, and schizophrenia. The interviews were audiotaped, transcribed verbatim, coded and analyzed using thematic analysis.

Data themes related to factors that influenced outpatient mental health treatment and services were identified and organized based on the six HBM constructs.

Perceived barriers to mental health treatment engagement included lack of knowledge about available treatment and services in the community, poor mental health literacy, and stigma. Improved sense of well-being and increased socialization were perceived benefits of mental health treatment engagement. Risk of homelessness emerged from the data as the main influence for Black and White older adults, who live with SMI, to seek and engage in outpatient mental health treatment. For all participants, access to and availability of mental health services were not current issues. All except one participant had some type of medical coverage for their treatment and most of them felt that their current treatment was appropriate. There were no differences between Black and White older adults on the issues of accessibility, affordability, appropriateness, and availability of outpatient mental health services. In addition, Black participants did not feel a need for mental health services to be specifically tailored to Black older adults, and instead indicated they saw no differences in Blacks and Whites related to mental health services. These findings are contrary to existing research and may be indicative of the gravity of mental illness-related stigma, compared to racial stigma.

Better promotion of available mental health services in the community, mental health outreach, and community education about mental illness may be helpful for earlier identification of symptoms related to mental illness, earlier treatment and intervention, stigma reduction, and improved health and quality of life for community-residing older adults who live with SMI.

CHAPTER ONE: INTRODUCTION

The number of older adults living with serious mental illness (SMI) in America is growing. Results of the National Survey on Drug and Health, 2016, indicate that approximately three million adults age 50 and older, which includes approximately 2.7 million Whites and 212,000 Blacks, reported a diagnosis of SMI in the past year (Substance Abuse and Mental Health Services Administration, 2016). This number includes who were at least 50 years old. With increased life expectancy and continued health care advances, these numbers are anticipated to greatly increase over the next few decades. In fact, some researchers estimate that the number of older adults living with SMI in America will reach five million in 2030 (Bartels, 2003; Jeste, Alexopoulos, Bartels, & et al., 1999). With an estimated 85% of older adults with SMI living in the community (Cummings & Kropf, 2011), the expansion of this population is a growing public health concern.

Overview of Serious Mental Illness (SMI)

Serious mental illness (SMI) is defined as a *diagnosable mental, behavioral, or emotional disorder* of sufficient duration to meet criteria specified in the American Psychiatric Association Diagnostic and Statistical Manual (DSM) of Mental Disorders (currently DSM-5) that has resulted in functional impairment (excluding substance use and developmental disorders) which substantially interferes with or limits one or more major life activities (Federal Register, 1993; Substance Abuse and Mental Health Services Administration, 2015). SMIs include bipolar disorder, major depressive

disorder, schizoaffective disorder, and schizophrenia. SMI affect people of all ages, racial and ethnic backgrounds, and varying social status.

Several terms, including severe mental illness, severe and persistent mental illness, chronic mental illness, and serious mental disorder are used interchangeably with SMI in the literature. Mental illness refers to the collection of all diagnosable mental disorders (U.S. Department of Health and Human Services, 1999). In its most recent edition of the DSM, DSM-5, the American Psychiatric Association (2013) defines mental disorder as *“a syndrome characterized by clinically significant disturbance in an individual’s cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress or disability in social, occupational, or other important activities”*. The DSM-5 includes severity specifiers (e.g., mild, moderate, severe, extreme) in the diagnostic criteria for some mental disorders to assist clinicians with rating the intensity, frequency, duration, symptom count, or other severity indicator of the disorder. Bipolar disorder and major depressive disorder are included among the mental disorders with severity specifiers. Not all mental disorders in the DSM-5 have severity specifiers or meet the criteria for SMI.

Bipolar Disorder, Schizoaffective Disorder and Schizophrenia

Bipolar disorder and schizophrenia are among the top 10 leading causes of disability in the world (World Health Organization, 2001). The onset of bipolar disorder is often in the late teens or early adult years, with at least half of all cases starting before age 25 (Kessler et al., 2005). Schizoaffective disorder affects individuals throughout their lives (Malaspina et al., 2013), with psychotic symptoms (e.g., thought disorder, delusions,

hallucinations) and affective symptoms presenting simultaneously (Malhi, Green, Fagiolini, Peselow, & Kumari, 2008). The prevalence of schizoaffective disorder in the general population is estimated to be less than 1% (0.5-0.8%) (Malhi et al., 2008), and the age of onset is similar to bipolar disorder (Nardi et al., 2005). Schizophrenia affects people throughout their lives, and the initial onset of the illness for most people occurs between the ages of 16 and 30 (Wetherell & Jeste, 2004). Only 15%-20% of people with schizophrenia have their initial onset of the illness between the ages of 40 and 65. Schizophrenia is the most disabling psychotic disorder (Harvey, 2005), affecting approximately 1% of the American population (Harvey, 2005). The number is much lower for older adults (65+ years old), with the estimated community prevalence ranging from 0.1%-0.5% (Broadway & Mintzer, 2007).

People with bipolar disorder and schizophrenia (Bertolote & Fleischmann, 2002) and schizoaffective disorder (Nardi et al., 2005) are at increased risk of substance abuse (alcohol and illicit drugs) and suicide. On average, people with these disorders have higher rates of chronic illnesses (e.g., cardiovascular disease, hypertension, diabetes, emphysema), are at increased risk of disability, morbidity, and early and excess mortality (shorter life span estimates range from 13-30 years) than the general population (De Hert et al., 2011; Laursen, 2011; Parks, Svendsen, Singer, Foti, & Mauer, 2006; Rössler, Salize, van Os, & Riecher-Rössler, 2005; Simpson & Tsuang, 1996). Many of the risk factors contributing to the excess morbidity and mortality among this population are modifiable (Parks et al., 2006).

Importance of Studying Older Adults with Bipolar Disorder, Schizoaffective Disorder, and Schizophrenia

The current study focuses on community-residing Black and White older adults who have a clinical diagnosis of bipolar disorder, schizophrenia, and schizoaffective disorder. These disorders have a significant negative impact on people's social functioning, employment and educational opportunities, family life, and health across the lifespan (George, Duran, & Norris, 2013). The early age of onset, chronic and recurrent psychosis, functional impairment, social functioning deficits, negative impact on ability to maintain substantial employment, increased risks of comorbid medical illnesses, and poor long-term outcomes among people with these disorders places them at a significant disadvantage as they age.

Data show that community-residing older adults with psychiatric disorders, especially Blacks, underutilize available mental health services in the U.S. (American Psychological Association, 2015; Bartels, 2002; Wang et al., 2005). When they do engage in mental health treatment, Blacks receive poorer quality of care compared to Whites (U.S. Department of Health and Human Services, 1999, 2001a). Undertreated and untreated SMI (Black, Rabins, German, McGuire, & Roca, 1997; U.S. Department of Health and Human Services, 1999) and medical comorbidity (Fullerton, McGuire, Feng, Mor, & Grabowski, 2009; Miller & Rosenheck, 2006) are risk factors for nursing home placement among older adults with SMI.

Compared to Whites, Blacks tend to have more persistent mental health problems and their needs are more likely to go unmet (Carson, Vesper, Chen, & Le Cook, 2014; Jimenez, Cook, Bartels, & Alegría, 2013; Snowden, 2001; U.S. Department

of Health and Human Services [HHS], 2001). There is evidence to support that Blacks are disproportionately diagnosed with schizophrenia as opposed to affective disorders even when presentation of symptoms are similar to Whites (Neighbors, Jackson, Campbell, & Williams, 1989; Snowden, 2001), disproportionately hospitalized for mental health treatment (Snowden & Cheung, 1990), and disproportionately use psychiatric emergency services (Snowden, Catalano, & Shumway, 2009) compared to Whites.

Many older Blacks are uninformed about available mental health services, and the services that they do know about are not affordable and neither designed nor culturally tailored to older Blacks (Morrell, Echt, & Caramagno, 2008). Discrimination and lack of cultural competence (Whitfield & Baker, 2014), distrust of health care providers (related to historical racism, discrimination, misdiagnosis) (Atdjian & Vega, 2005; Corbie-Smith, Thomas, & St. George, 2002; Whaley, 2001), and racial bias among treatment providers (e.g., mental health, medical, public health, human services) (Burgess, van Ryn, Dovidio, & Saha, 2007; Snowden, 2003; van Ryn & Fu, 2003) are also unique challenges for older Blacks with SMI (Dana, 2002; U.S. Department of Health and Human Services [HHS], 2001).

The negative health outcomes of older adults with SMI, particularly schizophrenia, in nursing homes and the sheer expense of nursing home care versus community-based care, call attention for research to examine hindrances to outpatient mental health care for this population. It is also important that research focus on the examination of factors that influence the decision-making of community-residing older adults to seek and engage in outpatient mental health services. The identification of these factors may be helpful in enhancing mental health engagement among non-

treatment seeking individuals, leading to a reduction in mental health treatment disparities and improved quality of life and overall health among this vulnerable group. The current study will be among the first to examine outpatient mental health treatment seeking and engagement by older Black and White adults, who live with SMI, using the HBM as a theoretical framework.

CHAPTER TWO: LITERATURE REVIEW

Chapter 2 provides an overview of research studies related to older adults and SMI, challenges for older adults with SMI, older Blacks and mental illness, residency and care of older adults with SMI, community support needs for older adults with SMI, and evidence-based interventions for older adults with SMI.

Research Studies on Bipolar Disorder, Schizoaffective Disorder and Schizophrenia

A study using data from San Diego County's Adult and Older-Adult Mental Health Services database to examine the prevalence, clinical features, and service use patterns of persons with bipolar disorder found that older adults (≥ 60 years) were more likely than younger and middle aged adults to have lower functional scores and more cognitive impairment (Depp et al., 2005). The sample included 2,903 people age 18 years old and older who were diagnosed with bipolar disorder. In this study, younger adults were more likely to have substance use disorders and use acute psychological services than older adults. In a different study, older adults with bipolar disorder reported higher medical comorbidity but lower psychiatric comorbidity than younger adults (Lala & Sajatovic, 2012).

Another group of researchers used data from the Department of Veteran's Affairs (VA) National Psychosis Registry to evaluate differences in clinical presentation, health service use, and psychotropic medication use between younger and older veterans (≥ 60 years) with bipolar disorder (M. Sajatovic, Blow, Ignacio, & Kales, 2004). The sample

included 65,556 veterans with bipolar disorder who used inpatient or outpatient VA services during FY 2001. For comparison purposes, three age cohorts were identified (under 30 years old, ages 30 to 59, and 60 or older). The authors found that although substance abuse disorder was higher among middle-aged veterans (30-59 years), the older group used more VA resources. No significant differences were found between age groups in the number of hospitalizations for mania or depression. Bipolar disorder was highest among veterans between the ages of 50 and 59. VA health care resource use increases among veterans with bipolar disorder as they age, with health care resource needs among this population extending past the age of 70.

Research has shown that with adequate medical and psychosocial treatment some people with schizophrenia can have improvement in psychotic symptoms as they get older. In a study that examined the relationship of age to clinical features, psychopathology, quality of well-being and everyday functioning among community-dwelling older adults (40-85 years) with early onset schizophrenia, Jeste and colleagues (2003) found that older age was associated with less severe general psychopathology and lower daily antipsychotic medication dosages. In addition, the authors found that although aging is associated with increased medical comorbidity, psychiatric symptoms, quality of life and everyday functioning is not negatively impacted by age. According to Depp and colleagues (2010), positive symptoms and frequency of illicit drug use decline as people with schizophrenia age, and they show improvement in mental health.

A different group of researchers found that as some people with schizophrenia age, negative symptoms become more prevalent (Kaplan & Sadock, 1988) and declines are seen in violent behaviors (Rodriguez-Ferrera & Vassilas, 1998). Because negative

symptoms are less likely than psychotic symptoms to be noticed by family members or others in the person's social network, mental health professionals oftentimes do not deem them as problematic (Kaplan & Sadock, 1988). Unfortunately, the negative symptoms are often interpreted as a "normal" part of aging and results in older adults not receiving needed mental health treatment.

A literature review related to studies that included only older adults who had a diagnosis of schizoaffective disorder indicates that little is known. Researchers often include schizoaffective disorder with schizophrenia as a combined category for the sample population. Researchers have indicated that schizoaffective disorder is a controversial diagnosis (Benabarre et al., 2001; Malaspina et al., 2013; Malhi et al., 2008) because of its excessive application in practice, low diagnostic stability, poor reliability, and weak validity (Malaspina et al., 2013). Patterson and colleagues (2001) examined social functioning (e.g., social appropriateness, grooming) among two groups of adults, one group had a diagnosis of schizophrenia or schizoaffective disorder (mean age 57.4) and were receiving outpatient mental health services, and a control group (mean age 59.4) without the disorders, using the Social Skills Performance Assessment, a performance-based task with role-plays. They found significantly more disability in all aspects of social functioning, including cognitive deficits and negative symptoms, among individuals with schizophrenia and schizoaffective disorder compared to the control group. In a different study, researchers evaluated quality of life, using the Quality of Life Index (QLI), among two groups of community-residing multiracial older adults in New York City, one group had a diagnosis of schizophrenia and schizoaffective disorder (mean age 61.4) and were receiving outpatient mental

health services, and a control group (mean age 63) without the disorders (Bankole et al., 2007). QLI scores were significantly lower in the group with schizophrenia and schizoaffective disorder compared to the control group. Individuals with schizophrenia and schizoaffective disorder reported greater IADL impairments, more financial strain, more acute stressors, more medication side effects, and greater positive and negative depressive symptoms.

Challenges for Older Adults with SMI

In general, people with SMI face many challenges as a direct result of their illnesses. They are vulnerable to stress, many are excessively dependent on others, have deficits in coping skills (e.g., grooming, shopping, budgeting, meal preparation, making and keeping appointments, using public transportation) (Grinker Sr & Harrow, 1987), experience difficulty forming and maintaining close, reciprocal relationships, and experience difficulty finding and maintaining steady, competitive employment (Gerhart, 1990). Older adults with SMI face unique challenges including stigma (Conner et al., 2010; Rüsçh, Angermeyer, & Corrigan, 2005), ageism, lack of financial resources (Bartels, 2004), frailty, and more severe cognitive and functional impairments. The noted challenges are hindrances to seeking and engaging in mental health services and adhering to recommended treatment. Some older adults equate having a mental disorder with personal failure, are embarrassed by the disorders and fear that by acknowledging they have a mental illness they will lose their independence (Substance Abuse and Mental Health Services Administration, 2005).

Lower socioeconomic status, combined with the negative effects associated with comorbid mental and physical disorders, are risk factors for social isolation among this

population. Comorbid mental and physical disorders are associated with increased likelihood of functional impairment and disability, both precursors to loss of mobility and subsequently resulting in people becoming homebound. Although they may experience more challenges, older adults are less likely than younger adults to seek help for mental disorders (Depp et al., 2005; Mackenzie, Gekoski, & Knox, 2006; Robb, Haley, Becker, Polivka, & Chwa, 2003).

Older Blacks and Mental Illness

The “triple jeopardy” of being old, Black, and mentally ill places this disadvantaged group at increased risk of disability and mortality. People in this group are among the most stigmatized and discriminated-against in society. They are victims of layers of discrimination and stigma which interferes with their receiving needed mental and health care treatment. Poverty, high medical comorbidity, and disparities in both medical (Kennedy, 2013; Nelson, 2002) and mental health service use (Atdjian & Vega, 2005; Cook et al., 2014; Jimenez et al., 2013; Neighbors et al., 2007; Neighbors et al., 2008; Snowden, 2012; U.S. Department of Health and Human Services [HHS], 2001) plague this marginalized group.

Strong cultural beliefs related to mental illness and mental health treatment are unique challenges for older Blacks with SMI. The perception of relatives, close friends, religious leaders, and community gatekeepers play a major role in the decision of Blacks to seek mental health treatment (Hines-Martin, Malone, Kim, & Brown-Piper, 2003). Because of this, depending on the beliefs of people in their circle, older Blacks may or may not engage in mental health treatment and/or adhere to prescribed treatment regimens. Racial minorities tend to be less likely than Whites to consider the

health care system as an avenue for mental health treatment (Corrigan, 2004). In particular, Blacks commonly use informal support systems, including family, friends, and church clergy (Young, Griffith, & Williams, 2014) instead of seeking help from professionals. Black focus group participants viewed asking for help as a sign of weakness and noted the historical expectation that life would be difficult and Blacks as a cultural group could and would cope with all diversity (Thompson-Sanders, Bazile, & Akbar, 2004). These culturally-based practices have been handed down through generations and are common among older Blacks. They may, however, be an impediment to older Blacks accessing and engaging in mental and physical health treatment.

Residency and Care of Older Adults Living with SMI

Some older adults with SMI reside in institutional settings (e.g., psychiatric hospitals, nursing homes, long-stay in-patient hospitalization, prisons); however, the majority reside in community settings with living arrangements varying from alone, at home with family, group homes and assisted care settings (Cohen et al., 2000; Gerhart, 1990; Jeste et al., 2003). Approximately one-third to one-half reside with family members (Cummings & Kropf, 2009; Lefley, 1987). Similar to care recipients in general, most older adults with SMI who live alone or with family members and are unable to adequately care for themselves receive care assistance from family members including spouses, adult children (Bartels, Mueser, & Miles, 1997), and siblings (Cummings & MacNeil, 2008). Daughters provide the vast amount of caregiving for those who are unable to adequately care for themselves (Cummings & MacNeil, 2008; Goldstein, 1988).

Nursing home care. A disproportionate number of older adults with SMI reside in nursing homes (Bartels & Van Citters, 2005), with reported admission rates three times that of people their same age without SMI (Bartels & Smyer, 2002). Older adults with schizophrenia, in particular, often lack family and social support and are at risk of nursing home placement (Harvey, 2005; Salokangas, Honkonen, & Saarinen, 2003) where they do not fare well (Harvey, 2005). They tend to have greater cognitive and functional decline and increased mortality, which is thought to be due to improper medication doses, use of older medications, staff not giving patients prescribed antipsychotic medications, and inexperienced and unmotivated staff servicing this population.

A study that examined the risk of nursing home placement among community-dwelling Medicaid recipients with schizophrenia found that middle-aged persons (40-64 years) with schizophrenia were four times more likely to be placed in a nursing home compared to their age-matched peers with no mental illness (Andrews, Bartels, Xie, & Peacock, 2009). The median age of admission is considerably lower 65 years old, compared to 80 years old for people who do not have schizophrenia (Andrews et al., 2009).

Most older adults with SMI who reside in nursing homes receive inadequate mental health care (Nardi et al., 2005; Salokangas et al., 2003). Although nursing homes are not the preferred place for older adults with SMI to live (Bartels, Miles, Dums, & Levine, 2003), at a minimum they provide a stable living environment, food, assistance with daily living activities and access to skilled nursing care to attend to patients' medical needs. Nursing home residency lessens certain barriers to care (e.g.,

transportation, medication adherence, treatment adherence), which are associated with poor health outcomes, that socially isolated older adults encounter.

Although home and community-based alternatives are less expensive, most Medicaid spending for long-term care is for nursing home care (Meesters et al., 2013). In general, White older adults are more likely than Black older adults to be placed in a nursing home (Akamigbo & Wolinsky, 2007). Blacks are more likely than Whites to be admitted to nursing homes that have a higher number of government-cited deficiencies for poor quality (Grabowski, 2004).

Consistent with the faster pace of population growth of older racial and ethnic minorities in the U.S., compared to Whites, there has been a similar rate in the increased use of nursing homes by older racial and ethnic minority groups, in general (Meesters et al., 2013). Notwithstanding the description of the population for the current study, Black and White older adults (50-70 years old), who live with SMI, data that follows is more general and based on available demographic information obtained from the Centers for Medicare & Medicaid Services (CMS), Nursing Home Data Compendium 2015 Edition. The total U.S. nursing home facility residents in 2014 was 1,406,220 million, a decrease from the 1,431,730 reported in 2011. In 2014, White residents comprised 77.9% of the total nursing home population, a decrease from 78.9% reported in 2011. Meanwhile, in 2014, Black residents comprised 14.2% of the total nursing home population, an increase from 13.8% reported in 2011. In 2014, 15% of nursing home residents were between the ages of 31-64 years old, an increase from 14.4% in 2011. Those between the ages of 65-74 years old comprised 16.5% of the nursing home population, an increase from 14.6% in 2011.

Community Support Needs for Older Adults with SMI

With adequate support, many older adults with SMI can thrive in community settings. Peer support (Solomon, 2004), accessible mental and physical health programs, medication management programs (Bedard, Gibbons, & Dubois, 2007), meal programs (e.g., Meals on Wheels), transportation services, individual and group therapy programs, adequate and affordable housing (Carling, 1993; O'Hara, 2007), face-to-face home and community-based services for mental health, and outreach programs (Bartels & Van Citters, 2005; Substance Abuse and Mental Health Services Administration, 2004; U.S. Department of Health and Human Services, 2001b) are among the community-based supports that can help older adults with SMI remain asymptomatic and enjoy a good quality of life.

Evidence-based Interventions for Older Adults with SMI

Past research confirmed that older adults with SMI can be engaged and retained in skills training, and some interventions show promise for improving skills and symptoms related to mental disorders and social functioning among this population (Mueser et al., 2010). The Functional Adaptation and Skills Training (FAST) program was designed to improve the functional and social skills in community-dwelling adults, age 40 and older (mean age 51.2), with schizophrenia and schizoaffective disorder. Two hundred forty, mostly White males, residing in board-and-care facilities in San Diego, CA were randomized to the FAST intervention or attention control group. FAST targeted six areas of everyday functioning, including medication management, social skills, communication skills, organization and planning, transportation and financial management. Participants randomized to the intervention met once weekly for 2 hours

over the course of 24 weeks where they practiced behavioral modeling, role playing and reinforcement. The attention control group received their usual medications and participated in 24 weekly, two hour group sessions with a therapist where they were able to discuss their personal issues in a supportive environment. Participants assigned to the intervention showed greater improvement in everyday living and social skills, but not medication management, than the control group (Patterson et al., 2006).

Druss and colleagues (2010) developed the Health and Recovery Peer (HARP) program, a peer-led intervention that helped people with SMI better manage their chronic medical illnesses. Most of the 80 participants (mean age 48 years) were lower income Black women with a primary diagnosis of schizophrenia or bipolar disorder. Participants were randomized to either the HARP intervention or usual care. Participants assigned to the intervention attended a maximum six group sessions that covered topics related to chronic disease management. A six-month follow-up showed the participants assigned to the intervention had increased patient activation and engagement with primary health care, spent more time participating in moderate/vigorous exercise, and had better medication adherence compared to the usual care group. The positive results of the HARP intervention show promise of the effectiveness of these types of programs for socially and medically disadvantaged populations.

Granholm and colleagues (2005) developed the Cognitive Behavioral Social Skills Training (CBSST), a psychosocial rehabilitation intervention for middle-aged and older adults with a primary diagnosis of schizophrenia or schizoaffective disorder. CBSST integrates cognitive behavioral therapy (CBT) and social skills training (SST) to

assist people achieve functioning goals related to living, learning, working, and socializing in the community of their choice. Seventy-six patients (mean age of 53.6 years) were randomized to either the CBSST intervention or treatment as usual (TAU). Participants assigned to the intervention received 24 weekly 2-hour group therapy sessions. At the conclusion of the program, participants assigned to the intervention performed social functioning activities significantly more frequently and showed significantly greater cognitive insight than the TAU patients. No significant difference was found in the general skill at performing specific everyday functioning activities after treatment. At the one-year follow-up, the significantly greater skill acquisition and self-reported performance of living skills were maintained but the greater cognitive insight was lost (Granholm et al., 2007).

Purpose of Study

The purpose of the current study is to explore how community-residing Black and White older adults (ages 50-70 years) living with SMI (i.e., bipolar disorder, schizophrenia, or schizoaffective disorder), who are recipients of outpatient mental health services, seek and engage in mental health treatment. Specifically, this study will address the following aims:

Aim 1: To explore factors that contribute to outpatient mental health treatment-seeking and engagement by community-residing Black and White older adults (ages 50-70 years) living with SMI.

Aim 2: To examine their perspectives on the issues of accessibility, affordability, appropriateness, and availability of outpatient mental health services.

Aim 3: To determine whether the perspectives of community-residing Black and White older adults living with SMI on issues of accessibility, affordability, appropriateness, and availability of outpatient mental health services are different.

CHAPTER 3: THEORETICAL FRAMEWORK

Several different theories and models were considered as guiding frameworks for the current study. This chapter provides summaries, strengths and weaknesses of three of them, the health belief model (HBM) (Janz & Becker, 1984; Rosenstock, 1974), theory of planned behavior (TPB) (Ajzen, 1985), and behavioral model for vulnerable populations (BMVP) (Gelberg, Andersen, & Leake, 2000), which have previously been used to guide health care utilization and mental health utilization research. The current study was guided by the HBM, which has previously been found to be a good model for addressing non-compliance/non-adherence of treatment regimens.

Health Belief Model (HBM)

The HBM (Janz & Becker, 1984; Rosenstock, 1974) is a commonly used social-cognitive theory, which emerged in the 1950s as one of the first theories of health behavior. It was developed by a group of U.S. social psychologists to explain the low rates of participation in mostly free or very low cost programs or screening tests (e.g., tuberculosis, cervical cancer, dental disease, rheumatic fever, polio, influenza) to prevent and detect asymptomatic disease. The original characteristics of the HBM were centered around the premise that to avoid a disease, people must first believe that (1) they are personally susceptible to it, (2) getting or having the disease would have at least an effect of moderate severity in some aspect of their life, and (3) they would gain a benefit (e.g., reduce susceptibility to illness/condition, reduce severity of condition),

and, in doing so, it would not require them to overcome important psychological barriers (e.g., costs, convenience, pain, embarrassment) (Rosenstock, 1974).

The HBM has been expanded over the years and currently includes six key constructs, perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action and self-efficacy, thought to influence people's decision to take action to prevent, screen for, and control illness (Janz, Champion, & Strecher, 2002; National Cancer Institute, 2005).

Perceived susceptibility refers to a person's belief of the risk of getting a condition. In cases of a pre-established medical (mental or physical) condition, the dimension includes acceptance of the diagnosis, if the person believes the condition will re-occur or they will have symptoms, and personal susceptibility to the condition in general. Perceived severity relates to a person's feeling about the seriousness of getting an illness, failure to get treatment for the illness, and the potential social consequences of having the illness. Perceived susceptibility plus perceived severity is labeled as perceived threat. Perceived benefits refer to a person's belief that the course of action recommended to minimize the risk of the illness threat or severity of the impact of the illness will be effective. Perceived barriers refer to what the person believes it will cost them (tangible and psychological) to take action in order to gain the benefit. Cues to action involve strategies to get the person ready to take action.

Self-efficacy was the last construct added to the HBM. Bandura (1995) described perceived self-efficacy as beliefs in one's capabilities to successfully organize and execute the courses of action required to manage prospective situations and produce

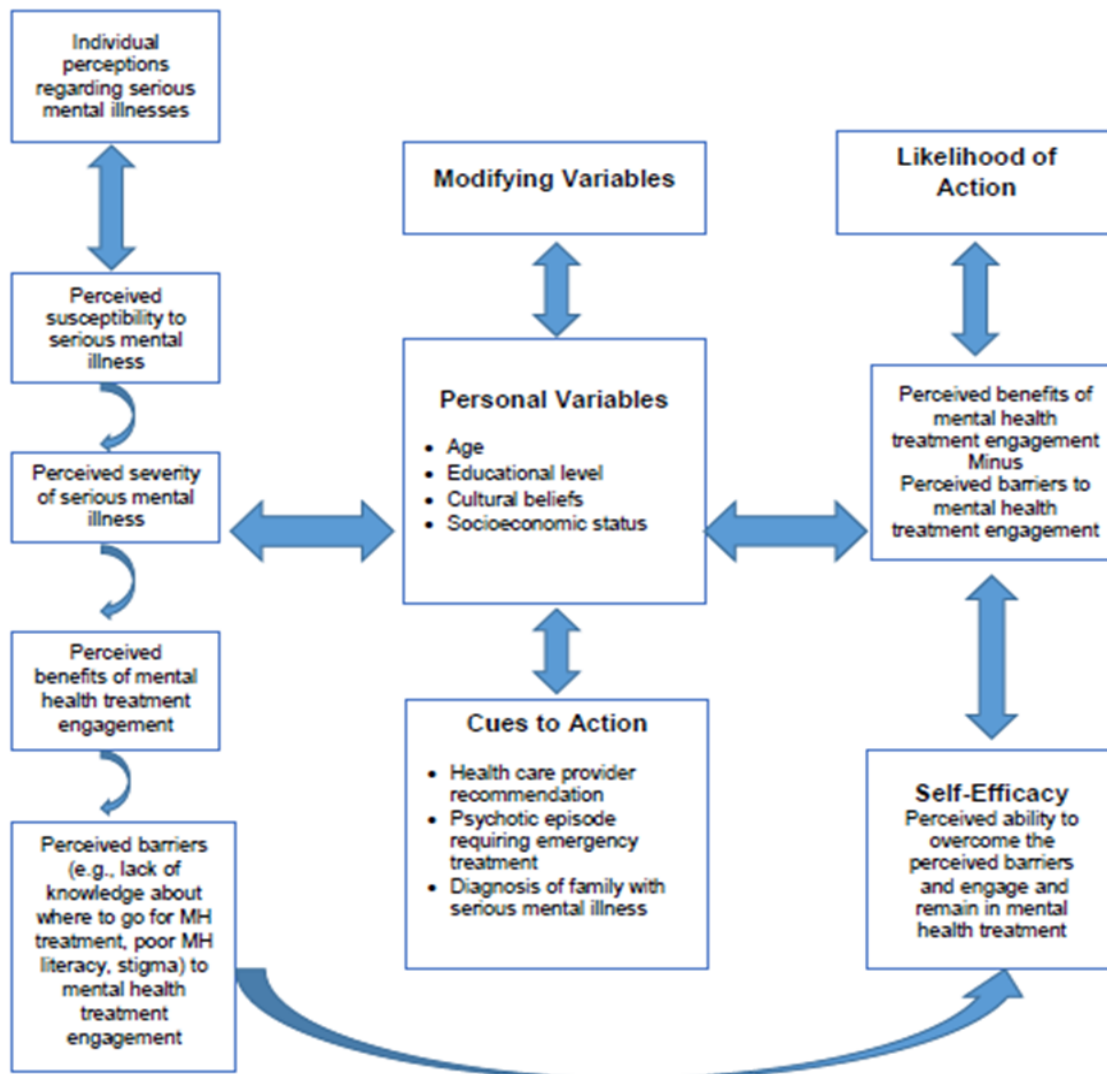
positive outcomes. The way people think, feel, motivate themselves, and act are all influenced by their efficacy beliefs.

According to HBM, people with SMI are more likely to engage and remain in mental health treatment if they perceive themselves as susceptible to the disorder or if they accept that they have the disorder, they perceive the serious consequences for failure to engage and remain in treatment for the disorder, and that the benefits of prolonged engagement in mental health treatment outweigh any perceived barriers to treatment engagement (see Figure 1). Copyright approval for Figure 1 is included as Appendix A.

Application of HBM – Serious Mental Illness and Disparities

Perceived susceptibility to Serious Mental Illness.

Knowledge of illness. Education about mental disorders, how they affect individuals and their families, available treatment options, and a clear understanding of the possible treatment outcomes plays a role in mental health treatment seeking, utilization, and adherence (Gary, 2005; Jorm et al., 1997). Compared to their White counterparts, older Black adults have a history of lower education and economic resources, which places them at a disadvantage when seeking and understanding the health system, particularly identifying and accessing mental health services. Research has shown that people with less education are more likely to have a lifetime mental disorder and are less likely to initiate and/or understand treatment options (Jimenez et al., 2013).



Original Source:
 Champion, V. L., & Skinner, C. S. (2008). The Health Belief Model. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health behavior and health education : Theory, research, and practice* (4th ed., pp. 45-65). San Francisco, CA: Jossey-Bass.

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Figure 1. Health Belief Model modified for SMI

Acceptance of SMI diagnosis. Embracing a label of what most Americans view as triple negatives, old, Black, and mentally ill, is unfavorable to individuals or their family members. Compared to non-Hispanic White peers, older Blacks may hold more negative attitudes toward mental illness (Snowden, 2001). Researchers found that older Blacks were less open to acknowledging mental health problems and seeking treatment than their younger counterparts (Diala et al., 2001). Older Blacks have a stronger tendency to view mental illness as a personal weakness and fail to report psychiatric symptoms. Blacks are more likely to turn to their churches and religious leaders (Blank, Mahmood, Fox, & Guterbock, 2002; Levin, 1984; Young et al., 2014) and extended family networks to help them deal with emotional and mental health problems (Blank et al., 2002).

Perceived seriousness of SMI (severity of the problem) and perceived benefits of mental health treatment engagement. Perceived seriousness of SMI and benefits of mental health treatment engagement have mixed results in the literature. In a study that examined differences between Blacks and Whites in their beliefs about the severity and natural course of mental illness, Anglin and colleagues (2008) found that Blacks were more likely than Whites to feel their mental conditions would improve on their own without professional mental health assistance.

Studies have shown that Blacks are more likely than Whites to believe mental health treatment (e.g., administered by psychiatrists, psychologists, social workers) is effective and can help people with their problems (Anglin et al., 2008; Schnittker, Pescosolido, & Croghan, 2005). Diala and colleagues (2001) found that Blacks with severe psychiatric problems had more positive attitudes towards seeking professional

help for mental illness than Whites. In another study, researchers found that Blacks were somewhat open to seeking mental health treatment (Ward, Clark, & Heidrich, 2009). The findings of positive treatment-seeking attitudes in the studies above contrast with other studies indicating negative mental health treatment-seeking attitudes of African Americans (Gary, 2005; Thompson-Sanders et al., 2004; U.S. Department of Health and Human Services, 2001a). Although some studies show favorable attitudes among Blacks toward mental health treatment-seeking, for some reason there is a disconnection between desire to seek treatment and maintain consistent treatment engagement by Blacks. Positive treatment-seeking attitudes tend to diminish after engagement with mental health professionals (Diala et al., 2000; Ward et al., 2009). Some researchers speculate that a lack of cultural competence among mental health practitioners may be responsible. Even when Blacks do seek treatment, many fail to complete treatment, while others do not comply with the prescribed regimen (Gary, 2005; Snowden, 2001).

Perceived barriers to mental health treatment engagement. Research has shown that compared to Whites, Blacks have more barriers to seeking mental health treatment (Snowden, 2001; U.S. Department of Health and Human Services, 2001a; Ward et al., 2009; Williams et al., 2007). The barriers may be compartmentalized into physical or environmental (e.g., geographical distance, finding a specialist, long waits), psychological (e.g., personal and family stigma, perceived prejudice and discrimination), systemic (e.g., lack of or inadequate insurance coverage, disjointed services, clinical bias, lack of cultural competence and/or insensitivity among mental health professionals) (Gary, 2005; Hines-Martin et al., 2003; Snowden, 2001; U.S. Department

of Health and Human Services, 2001a), sociocultural barriers (e.g., fear, cultural mistrust) (Henshaw & Freedman-Doan, 2009), economic barriers (e.g., lack of personal financial resources, lack of or inadequate health insurance coverage), individual barriers (e.g., stigma, denial, perceived vulnerability to mental disorders), and misunderstandings of mental health problems (Choi & Gonzalez, 2005).

Accessibility and affordability of treatment. Of all the noted barriers to mental health care utilization, lack of access to care in general is the greatest cause of disparities (Le Cook, Manning, & Alegria, 2013), especially among people with SMI. It is important to note that for Blacks, adequate insurance coverage alone does not result in similar rates of treatment-seeking as Whites (Padgett, Patrick, Burns, & Schlesinger, 1994; U.S. Department of Health and Human Services, 2001a). One study found a direct relationship between location of residence, race/ethnicity and access and use of mental healthcare (Chow, Jaffee, & Snowden, 2003). Older adults, especially older Blacks who live in rural areas are less likely to seek healthcare overall than those living in more urban or metropolitan areas (Abraham et al., 1993). It might possibly be due to limited treatment providers and the distance that some people in rural areas have to travel for services.

Stigmatization. Evidence shows that stigma negatively impacts mental health treatment seeking and adherence (Alvidrez, Snowden, & Patel, 2010; Conner et al., 2010; Corrigan, 2004; Sirey et al., 2001). Stigma related to mental illness is a significant contributor to disparities in overall well-being (physical and mental health) and life opportunities (e.g., job opportunities, personal relationships), compared to the general population (U.S. Department of Health and Human Services, 1999). The stigma

is double for Blacks and other ethnic minorities with mental illness (Gary, 2005). While Le Cook and colleagues (2013) have identified lack of access to care to be the greatest cause of mental health care disparities among people with SMI, other researchers have identified stigma as the most significant barrier to Blacks seeking mental health services (Thompson-Sanders et al., 2004; U.S. Department of Health and Human Services [HHS], 2001). Blacks are more likely than Whites to hold stigmatizing attitudes towards people with mental illness (Gary, 2005).

Stigma and racism were identified by Black focus group participants as major barriers to seeking mental health information and/or services (Mishra, Lucksted, Gioia, Barnett, & Baquet, 2009). They indicated that fear of being stigmatized and racism potentially lead to people denying their illness and avoiding mental health services. Some people have even recommended using the emergency room for mental health treatment instead of community-based to avoid being identified as having mental illness (Thompson-Sanders et al., 2004).

Self-efficacy. Diminished self-esteem and self-efficacy are directly related to mental illness (Corrigan & Watson, 2002). Ethnic and racial disparities specifically related to self-efficacy and SMI were not identified in the literature. Schmutte and colleagues (2009) used focus groups to explore how people with SMI perceived themselves and their experiences with medical care in relation to how they actively self-managed their physical health. They found that the majority of the focus group participants had limited knowledge and low self-efficacy regarding active self-management of their physical health. Additionally, due to a variety of expressed

barriers, the participants did not feel they had the power to effectively improve their physical health.

Adherence to provider recommendation. When people adhere to treatment, they are three times more likely to have a favorable health outcome than those who are non-adherent (DiMatteo, Giordani, Lepper, & Croghan, 2002). Family support and cohabitation significantly increase treatment adherence (DiMatteo, 2004). Several studies that examined adherence with antipsychotic medication use among people with bipolar disorder (M. Sajatovic, Valenstein, Blow, Ganoczy, & Ignacio, 2006, 2007) and schizophrenia (Gilmer et al., 2004; Opolka, Rascati, Brown, & Gibson, 2003; Robinson et al., 2002; Rosenheck et al., 2000; Valenstein et al., 2002) found that Blacks were significantly less likely than Whites to adhere to treatment.

Related studies using HBM

Previous studies have used the HBM as an organizing framework to examine the relationship between health beliefs and medication compliance among people with SMI. Kelly, Mamon, and Scott (1987) found that psychiatric outpatients (majority diagnosed with schizophrenia) at two Veterans Affairs (VA) clinics who were receiving antipsychotic drug regimens held identifiable beliefs about their treatment. Acceptability of illness was high among this study population, all participants identified with being severely mentally ill, and half of them believed they were susceptible to re-hospitalization as a result of their illness. Over 70% of the patients felt the anti-psychotic medication helped them. Five measures of health belief (susceptibility, severity, perceived benefits, perceived barriers, and cue to action) together accounted

for 20% of the variance in self-reported medication compliance, an indication that health beliefs affect the health behavior among this population.

Nageotte and colleagues (1997) conducted a secondary analysis of data collected in the Mississippi public mental health system (inpatient and outpatient) to examine factors associated with medication compliance in 202, primarily Black males with schizophrenia. Using the HBM as a conceptual framework in this study, the authors found that participants' belief that they had mental illness was positively associated with medication compliance. The majority (64%) of patients who believed they were mentally ill were medication compliant. Patients who disengaged from outpatient mental health services, and those who received no mental health treatment (outpatient or inpatient) for at least three months were less likely to be medication compliant.

Justification for using HBM framework

As illustrated in the studies above, the HBM is a good model for addressing non-compliance/non-adherence of treatment regimens which are likely to lead to poor health outcomes (mental/physical) and increased inpatient service use. Although participants in the current study were already in treatment, previous evidence has shown that individuals living with SMI in the community often disengage from mental health treatment leading to devastating consequences (Fischer et al., 2008; Killaspy, Banerjee, King, & Lloyd, 2000; Kreyenbuhl, Nossel, & Dixon, 2009).

No published research has been identified that exclusively examined the HBM in the context of exploring factors that influence the decision-making of community-residing older adults with SMI to seek and engage in outpatient mental health treatment.

Behavioral Model for Vulnerable Populations (BMVP)

The BMVP is a revision of the behavioral model of health services use, also known as the Andersen health behavioral model. Andersen developed the original model in the 1960s to assist in understanding the use of formal health services by families, the development of policies to promote equitable access to health care, and to define and measure equitable access to health care (Andersen, 1995). The original Andersen model looked at the family as a unit of analysis and suggested that people's use of health services and personal health practices are a function of their *predisposition* to use health services, factors that *enable* or impede health service use, and their *need* for health care (Andersen, 1995). Some of the changes over the years have included the individual as the unit of analysis, the addition of the health care system (policy, resources, organization, and customer satisfaction (convenience, availability, financing, provider characteristics, quality), and the inclusion of health status outcomes (perceived health status, evaluated health status, consumer satisfaction).

Even with the changes over the years, Gelberg et al. (2000) recognized a need to further expand the Andersen model, particularly the predisposing, enabling, and need components which predict personal health practices and the use of health services, to look at how health service utilization impacts health outcomes in vulnerable populations. The BMVP was needed to consider some of the unique challenges members of vulnerable populations encounter which possibly impact their health status and use of health services (Aday, 1994). Aday (1994) defines vulnerable populations as those at risk of poor physical, psychological, and/or social health, including the mentally ill, minorities, elderly, chronically ill, undocumented immigrants, children and adolescents,

high risk mothers, people with AIDS, substance abusers, the impoverished and homeless. Vulnerable populations have high levels of unmet mental health needs (Wang et al., 2005).

The BMVP can be divided into traditional domains (predisposing traditional, enabling traditional, need traditional) and vulnerable domains (predisposing vulnerable, enabling vulnerable, need vulnerable), which focus on structure and enabling resources (Gelberg et al., 2000). The characteristics of the traditional and vulnerable domains are vastly different. The characteristics of the traditional domains are the same as those for the Andersen model. In the vulnerable domain, the predisposing characteristics include social structure characteristics (acculturation, immigration status, literacy), childhood characteristics (foster care, group home placement, abuse and neglect history, parental illness), residential history (housing or homeless), living conditions (running water, sewers, heat/air conditioning, electricity, lead paint, unsafe structures), mobility (moves between communities and dwellings), criminal behavior and prison history, victimization, mental illness, psychological resources (mastery, coping, self-esteem, cognitive ability, developmental delay), and substance abuse. The enabling domain is comprised of different personal/family resources (receipt of public benefits, competing needs, availability and use of information sources) and community resources (community crime rates, availability of social services). Included in the need domain are perceptions and evaluated need regarding conditions of special relevance to vulnerable populations (mental health service use prediction, tuberculosis, sexually transmitted diseases, premature and low-birthweight infants, AIDS). The vulnerable domain also includes personal health practices such as food sources, hygiene, and risky sexual behaviors.

Perceived and evaluated health status are included as outcomes in both the traditional and vulnerable domains.

Some categories in the vulnerable domains need to be tailored to fit the specific vulnerable population being studied. Vulnerable people have higher probability of being subjected to experiences that are more detrimental to their physical and mental health, leading to higher incidences of disability, morbidity and mortality. Therefore, it is imperative that issues specific to this population be considered and addressed in order to improve health outcomes among this group.

Related studies using BMVP

Gelberg and colleagues (2000) first used the BMVP as a framework to determine predictors of health service utilization and physical health outcomes among 363 homeless adults in the Los Angeles area. The researchers were particularly interested in the effects of mental health, substance abuse, residential history, competing needs and victimization on the use of medical services. Having mental health and/or substance abuse issues were not deterrents to receiving care, but merely using available care did not affect health care outcomes. Instead, one of the major factors to better health outcome was access to a regular source of care (community clinic or private physician). The findings suggest that members of vulnerable populations (homeless persons) are willing to engage in medical treatment provided they find it important. The use of health services and health outcomes by members of vulnerable populations were found to be impacted by mental health, substance abuse, competing needs, history of victimization, and residential history. This study showed support for

the additional categories to the BMVP in studies examining the health of vulnerable populations.

The BMVP was used as a framework in a more recent study that examined predisposing, enabling, and need factors potentially associated with past 30 day mental health care utilization among 305 heterosexually active homeless men utilizing meal programs in the Skid Row region of Los Angeles (Rhoades et al., 2014). In this study, need was operationalized as positive responses to screening for post-traumatic stress disorder (PTSD) and depression. The predisposing factors included demographic and substance abuse characteristics, and the enabling factors were defined as respondents' personal network characteristics. Approximately 63% of the homeless men in the study who screened positive for PTSD and depression reported they had not received or utilized any mental health services in the past 30 days, a finding that confirmed the high level of unmet mental health needs among the homeless population. Black men with PTSD or depression who had recently accessed substance abuse counseling or visited a drop-in or access center (for assistance with clean clothing, showers, or other services) had significantly higher odds of utilizing mental health services in the past 30 days.

An advantage of using the BMVP for the proposed study is that it considers factors that influence mental health service utilization and also considers the effectiveness of the services. The vulnerable domains provide insight into some of the specific issues encountered by vulnerable populations. One of the disadvantages of the BMVP is that it neglects factors such as severe psychiatric symptoms, stigma, and system bifurcation (Brekke et al., 2013) which are known to negatively affect health

service utilization. Additionally, BMVP, like several other medical utilization models, view individuals as “rational” decision-makers”. BMVP model lacks criteria to specify what the person’s beliefs are relating to their diagnosis or their perceptions of the benefits of treatment, and this could potentially play a role in whether or not people remain in treatment.

Theory of Planned Behavior

The theory of planned behavior (Ajzen, 1985) is an extension of the theory of reasoned action (Fishbein, 1967; Fishbein & Ajzen, 1975; Montaña & Kasprzyk, 2002). The theory of reasoned action was developed in an effort to understand the relationship between behavioral and normative beliefs, attitudes, intentions and behavior. The constructs of the theory of reasoned action include behavioral intention (perceived likelihood of performing behavior), attitude (personal evaluation of the behavior), and subjective norm (beliefs about whether key people in the person’s life approve or disapprove of the behavior; motivation to behave in a way that gains their approval). In expanding the theory of reasoned action to account for factors outside of a person’s control that might affect his or her intentions or behaviors, Ajzen and colleagues (1991) added an additional construct, perceived behavioral control (person’s belief that they can control a particular behavior; personal assessment of difficulty performing a particular behavior) (Ajzen, 1985, 1991; Montaña & Kasprzyk, 2002; World Health Organization, 2012). The addition created the theory of planned behavior, which postulates that for a person to achieve and maintain positive behavioral change, they must intentionally adopt a positive behavior or abandon negative behavior. Behavioral

intention is influenced by the perception of social norms, degree of perceived behavioral control, and attitude toward the behavior.

An advantage of the theory of planned behavior is that it has had success in predicting health behaviors such as health service utilization and substance abuse. Many people with SMI are highly dependent on others, and older Blacks with SMI are known to consider the opinion of others in their social world regarding health and use of mental health services. Because of the high amount of stigma associated with SMI, particularly among Blacks, having the “buy in” from support networks is likely to influence their intention to seek and engage in mental health services. However, if the support network is unsupportive of using mental health services, there could be less mental health service use.

One of the disadvantages of the theory of planned behavior is that similar to the HBM, the theory of planned behavior assumes people are rational in their decision making with the opportunities and resources to be successful in performing the desired behavior, regardless of the intent, which may be a challenge for this population. The theory of planned behavior does not account for fear, past bad experiences (including discriminatory treatment, stigma, treatment bias), or cultural mistrust that may influence the decisions of older Blacks with SMI to seek and engage in mental health treatment. Also, the theory of planned behavior does not consider how the behavior of older Blacks with SMI can change over time. With this group being highly dependent on others, they might encounter changes in living environments, their mental stability, support networks influences, personal resources, and there is a strong likelihood that they will experience

declines in their overall health, all which could lead to changes in their behavior over time.

CHAPTER FOUR: METHOD

Qualitative methods were used for the current study. Qualitative research seeks to answer questions, using a specific set of research methods (e.g., content analysis, focus group discussions, life histories, observations, visual methods) by examining people in their own natural environments (Berg & Lune, 2012; Hennink, Hutter, & Bailey, 2011). While numerous different types of qualitative designs exist, Creswell (2014) noted that the five most popular qualitative designs across the social and health sciences today are narrative, phenomenology, ethnography, case study, and grounded theory.

An advantage of using qualitative methodology in exploring mental health issues in older adults is that this approach provides the researcher with an opportunity to gather rich, descriptive, and meaningful data from older adults about issues related to mental health services. Another advantage is that qualitative methodology usually can be conducted without a large sample population to answer the research question of the study. This is especially important for the proposed study, because of the known challenges associated with recruiting Blacks into mental health research studies (Areán, Alvidrez, Nery, Estes, & Linkins, 2003; Hatchett, Holmes, Duran, & Davis, 2000; Neal & Turner, 1991). The researcher can expand his or her questions to probe for additional information, by asking follow-up questions. This cannot be accomplished when using quantitative methodology.

Using qualitative methodology has the potential to limit issues related to literacy. Because of the early onset of SMI, most people with SMI have limited education. This especially holds true for older Blacks who have experienced discriminatory treatment and have been limited in opportunities. Qualitative methodology allows the researcher to spend more time with the participant. The researcher's ability to build a relationship with a person with SMI and/or his or her caregiver is crucial for gaining a genuine understanding of what they face and for increasing the likelihood that the data will be valid. While this population might be more reluctant to complete a survey, they may be more willing to embrace the opportunity to share their experiences with a researcher who has established a relationship with them.

Qualitative methodology has a holistic focus (Creswell, 2014), which will allow the researcher to attain a deeper understanding of the participant than could be achieved through a more rigid approach. It also allows the participant to raise issues and topics which the researcher might not have included in a more structured research design, which adds to the quality of the data collected (Carr, 1994). Because qualitative methodology identifies and accounts for negative or "deviant cases" (Creswell, 2014; Royse, Thyer, & Padgett, 2010), the researcher can capture data on older Blacks with SMI whose experiences with mental illness and mental health services beyond what is typically described in the literature.

Qualitative Methodology for Investigating Stigmatized Groups

Qualitative research methods are suited for exploring what members of stigmatized groups think about their stigmatizing condition. It lends itself to understanding the perspectives of members of stigmatized groups and how stigma

impacts their everyday lives (Dinos, Stevens, Serfaty, Weich, & King, 2004). Qualitative methodology affords researchers a view of stigma informed by actual incidences of stigmatization described by stigmatized groups and their social networks (Schulze & Angermeyer, 2003).

Different qualitative approaches were used in the following two studies for investigating the lived experience of people with mental illness, a highly stigmatized group. Schulze and Angermeyer (2003) conducted a focus group study to explore concrete stigmatization experiences, from the subjective perspectives of people with schizophrenia. Collateral information was also sought from their relatives and mental health professionals. The authors identified four dimensions of stigma: interpersonal interaction, the public image of mental illness, structural discrimination, and access to social roles. All three groups agreed about the dimensions of stigma; however, they attached different weight to the areas. Depending on who described them, the aspects of the experiences assume a different meaning. Most of the people with schizophrenia indicated that their diagnosis led to a reduction of social contacts. This group also agreed that a single contact with psychiatry was enough to put a life-long stamp on them, a stigma, which determined their social identity in different situations. As a result, they recommended that others keep a schizophrenia diagnosis secret in order to avoid the associated stigma and discrimination that most often accompanies the diagnosis.

Narrative interviews were used in a different study aimed to explore: (1) the relationship between stigma and psychiatric diagnosis, and perceptions of illness and treatment; and (2) the consequences of stigma on people's lives (Dinos et al., 2004). A sample of 46 people recruited from community and day mental health centers in London

were asked to talk about the impact of their mental health problems on their work and private life. The authors found that almost all participants were concerned about stigma. Subjective feeling of stigma (even when discrimination was not present) and stigma in the context of overt discrimination were the two subcategories that emerged in this study. Feelings of stigma were often linked to the person's diagnosis. Overt discrimination was reported in social settings, as well as, work, academic, and treatment settings. The authors also found that perceptions of stigma were not always negative. In fact, some people reported positive outcomes of having a mental illness.

This chapter includes: a description of the researcher's personal characteristics; study design; sample and recruitment strategies; participant eligibility criteria; description of study sites, data collection and analysis procedures; steps taken to increase trustworthiness of the findings; and ethical considerations. This study was approved by the University of South Florida Institutional Review Board, #Pro00029850 (Appendix B).

Researcher Background

I am a Black female who during the time of this study was a graduate research assistant in the School of Aging Studies at the University of South Florida. My credentials include a Bachelor of Arts in Anthropology/Sociology, Master of Business Administration, Master of Arts in Gerontology, and graduate certificates in Geriatric Care Management and Evaluation. I am a retired law enforcement officer with over 24 years of experience at the county [corrections, research and planning, and deputy sheriff] and federal levels [federal law enforcement special agent]. I completed graduate-level coursework that addressed different aspects of aging; research methodology, including

qualitative methods in community health research, advanced qualitative methods, and focus groups research strategies, and evaluation. As a graduate research assistant, I gained experience in participant recruitment, data collection, and analysis.

Prior to this study, I had never met any of the participants. All of the participants were advised that the study was for a dissertation project to fulfill the requirements for the Ph.D. degree.

As a caregiver of an adult with schizophrenia and a former law enforcement officer who often encountered individuals with mental illness during the course of assigned responsibilities, I have certain assumptions related to the population under study and outpatient mental health services. To minimize biased assumptions in the interpretations of data, I utilized strategies such as reflexive journaling, vivid participant quotes, and maintaining an audit trail to enhance credibility and trustworthiness of this study's findings (Cope, 2014).

Study Design

A qualitative, semi-structured, interview-based study was developed to explore factors that influence the decisions of community-residing Black and White older adults (50-70 years old) who live with SMI, to seek and engage in outpatient mental health treatment, and to examine their perspectives about the accessibility, affordability, appropriateness, and availability of outpatient mental health services.

Sample and Recruitment

Purposive sampling was used to recruit 19 community-residing older Black and White adults living with SMI who were actively engaged in outpatient mental health treatment in a large metropolitan area located in the southeastern United States.

Purposive sampling is a nonprobability sampling technique, that is deliberate and flexible, and used to identify and select individuals who have specific experiences or characteristics and a wealth of information related to the phenomenon under study (Hennink et al., 2011; Miles, Huberman, & Saldaña, 2014; Palinkas et al., 2015), such as older adults living with SMI. Researchers have suggested that a purposive sampling strategy is suitable for exploratory research and hard to reach populations (Bernard & Ryan, 2010).

Three study sites, located within 35 miles of each other in Tampa, FL, were identified for recruitment because they provide an array of outpatient mental health services. Site 1 was a private, not-for-profit, organization that provided an array of community-based services (e.g., clinical services [psychiatrist, registered nurse], medication management, case management, housing assistance, day treatment, individual and group counseling, recovery coaching, vocational specialists, transportation, food, clothing, basic necessities) for individuals with mental disabilities, individuals who are homeless, veterans, and youth. Site 2 was a psychiatry clinic, within a large university health system, that provided clinical services (e.g., psychiatrist), psychotherapy, medication management, and case management for adults with mental, addictive and behavioral disorders. Site 3 was a private, not-for-profit, behavioral health care center that provided outpatient and short-term in-patient psychiatric services, crisis stabilization, and forensic services for individuals who are incarcerated, returning to the community from county jails, state prisons, and state mental health treatment facilities. Some services offered by Site 3 include: clinical services [psychiatrist, psychologist, nurse], psychiatric evaluation, crisis intervention and resolution, medication

management, case management, day treatment, patient education, psychotherapy, housing assistance, supported employment and vocational rehabilitation, transportation, food, clothing, basic necessities, and patient education.

The inclusion criteria for this study were: (1) clinical diagnosis of bipolar disorder, schizophrenia, or schizoaffective disorder (verified by a clinician); (2) self-identify as Black or White; (3) 50-75 years old; (4) engaged in outpatient mental health services (i.e., medication management, psychotherapy, case management) for at least three months; (5) ability to understand and write English; (6) ability to provide informed consent; and (7) Mini-Mental State Examination (MMSE) score ≥ 20 . The maximum age for inclusion was limited to 75 years old due to the vulnerability of the sample population (e.g., older adults diagnosed with SMI). Research indicates that people living with SMI have higher rates of chronic illnesses, increased risk of disability, and shorter life spans than the general population (De Hert et al., 2011; Laursen, 2011; Parks et al., 2006; Rössler et al., 2005; Simpson & Tsuang, 1996). Recruitment strategies were developed in consultation with management personnel at provider locations and included: posting recruitment flyers in lobby and common areas frequented by potential participants; dissemination of recruitment flyers by case managers and clinicians; assistance from case managers and clinicians (e.g., psychiatrists, psychologists, nurses; mental health counselors; social workers) who provide services to individuals in identifying potential study participants; and I made periodic visits to client group meetings in order to meet potential participants and provide information about the study.

I met with case managers and clinicians at all three provider sites and provided an overview of the study, the inclusion criteria for study participants, and gave them some of the recruitment flyers to post in areas that were visible to potential study participants (e.g., classrooms, residential units, clinic waiting areas). Potential participants contacted me in response to posted recruitment flyers and after case managers shared information about the study. I coordinated with case managers and clinicians on dates and times that I would be at the sites (e.g., day treatment center, supported housing units, group homes, clinics) to provide an overview of the study to their clients. Case managers and clinicians assisted by identifying clients who met age and diagnosis criteria for the study and notified them of the dates and times that I would be at the recruitment sites to give presentations. Potential participants approached me after presentations at the day treatment center and housing units owned by provider sites to indicate that they were interested in participating in the study.

All potential participants were screened to determine if they met study eligibility. A short questionnaire (Appendix C), was used to gather descriptive, demographic data from study participants after obtaining written informed consent was obtained and prior to completion of the MMSE. Information collected included: age, race, sex, education attainment (did not graduate high school, high school graduate, some college/trade school training, associate's degree/completed trade school, bachelor's degree, graduate degree), employment status (part-time, retired, unemployed [disability]), income (less than \$10,000, \$10,001-\$20,000), living arrangement (lives alone, roommate – spouse/significant other, roommate – other), psychiatric diagnosis (bipolar disorder only, schizophrenia only, schizoaffective disorder only, comorbid bipolar disorder and

schizophrenia, comorbid bipolar disorder and schizoaffective disorder, comorbid bipolar disorder, schizophrenia, and schizoaffective disorder) and physical health disorder (diabetes, high blood pressure, high cholesterol, back problems), understanding of treatment regimen (yes or no), current mental health services (clinical services [psychiatrist, physician, nurse], medication management, counseling, housing assistance), Baker Act history (0-8), and participant's response to how long they received mental health services at the current location (3 months-43 years). During the screening process, participants were asked about their psychiatric diagnosis. I consulted with clinicians at the provider sites to verify each participant's diagnosis, length of time in treatment with the provider, and whether a clinician thought the potential participant was clinically stable to participate in the study, prior to the interview.

A total of 22 individuals met the study eligibility requirements; however, three did not complete the interview. One died, one withdrew after being hospitalized and admitted to a rehabilitation facility for an unrelated physical illness, and another delayed scheduling the interview. Nineteen (9 Blacks and 10 Whites) individuals were interviewed for the current study.

Data Collection

Semi-structured interviews were conducted from August 2017 through January 2018. I designed an interview guide (Appendix D) in consultation with my dissertation committee members, containing open-ended questions, specifically for this study. The questions were informed by the literature and the constructs of the HBM (Glanz, Rimer, & Viswanath, 2008; Janz & Becker, 1984; Janz et al., 2002; Rosenstock, 1974) to capture the participants' experiences in seeking and engaging in outpatient mental

health treatment. The interview guide was pilot-tested with one person and adjustments were made to questions that tended to be unclear to the interviewee. Data from the pilot interview were excluded from the project. One-on-one private interviews took place in private offices, classrooms, and patio areas where participants engaged in outpatient mental health services, participants' residences, and an office on campus at USF. All participants played a role in the selection of interview locations and were cognizant of the goal to maximize privacy. Permission was obtained to audio record and take handwritten notes for all interviews. After beginning one of the interviews, a participant indicated that she did not want to be recorded. The interview was paused, and audio recording ceased. Only handwritten notes were taken for the remainder of the interview.

Participants received up to \$10.00 in Wal-Mart gift cards for participation in the current study, including a \$5.00 Wal-Mart gift card for completion of the informed consent, Demographic Information Sheet and MMSE, and an additional \$5.00 gift card for participation in the interview. Each participant was given a Community Resource Guide that contains information about local health, social and government services at the conclusion of the interview.

Data Analysis

Audio recordings were transcribed verbatim for analysis. In addition, a transcript was also produced for the participant who did not want to be recorded. The transcript included all information produced from the recording up to the participant's indication that she did not want to be recorded, as well as, handwritten notes of the participant's responses after the recorder was turned off. Data were analyzed using thematic

analysis (Boyatzis, 1998; Braun & Clarke, 2006), an approach identified by researchers as suitable to examine the perspectives of individuals and highlight differences (Braun & Clarke, 2006; King, 2004). The transcripts were read twice for a clear understanding of the data (Pope, Ziebland, & Mays, 2000), prior to the development of the initial codebook. Deductive codes derived from the six constructs of the health belief model and the research questions, and inductive codes that emerged from the review of the transcripts were included in the codebook. Deductive codes, are also referred to as a priori codes, and are developed by the researcher prior to data collection and review. They are a beginning list of codes that may come from a conceptual model (e.g., cues to engagement, barriers to engagement, stigma, benefits to engagement), the research questions, existing literature, and/or hypotheses (Miles et al., 2014).

I independently coded two transcripts using the initial codebook before providing duplicate copies of the transcripts and the codebook to a second coder for coding. The second coder was a doctoral candidate at USF, College of Education, Curriculum and Instruction, who has graduate-level training in qualitative research methods and evaluation. After she completed coding the two transcripts, we met to discuss and compare the coded transcripts. We defined discrepancies when only one of us assigned a code to a unit of text or when we assigned different codes to the same unit of text. Coding discrepancies were discussed and resolved by consensus agreement (Daaleman, Usher, Williams, Rawlings, & Hanson, 2008). During this process, the codebook was modified to revise the names and definitions of some codes, and to add new codes.

The overall inter-coder agreement, based on the two coded transcripts, was calculated at 90% which is within the recommended range for good qualitative reliability (Miles et al., 2014). Assessing inter-coder reliability using a sample of text is a practice that has been supported by other researchers (Campbell, Quincy, Osserman, & Pedersen, 2013; Hodson, 1999; Krippendorff, 2004).

Using the modified version of the codebook, I independently coded the remaining transcripts. Throughout the coding process, I made additional modifications to the codebook, by adding and merging codes. I met with the second coder again to discuss the changes to the codebook. We negotiated on codes that best represent the data and align with the constructs of the HBM and research questions. Throughout the coding process, I identified patterns and themes that provide insight to participants' unique experiences with engaging in outpatient mental health services. Illustrative quotes that captured the participants' perspectives were selected for the identified themes and included in the text. During the coding process, I consulted with members of my dissertation committee who have experience using qualitative methods for guidance and feedback. Data were coded by hand and using Atlas.ti version 7 software. I coded data using both methods. The second coder did not have access to Atlas.ti software; therefore, she coded the transcripts by hand. I then entered any coding changes and additions agreed upon from the transcripts coded by hand into Atlas.ti version 7.

Ethical Considerations

Participants who engage in research studies should do so voluntarily and be informed of all potential risks (Berg & Lune, 2012). Two areas of ongoing discussion related to the use of people with SMI for research are vulnerability and capacity to

consent. Research has shown that when the normal provisions of ethically sound research are observed, people with mental illness are generally no more vulnerable to participating in research as those without mental illness (Usher & Holmes, 1997). In a study that examined decisional capacity to participate in research studies, Moser and colleagues (2002) found that 80% of subjects with schizophrenia demonstrated capacity to consent. In another study, researchers found that decisional capacity for people with schizophrenia and bipolar disorder remained stable over time but recommended that researchers incorporate of an interactive informed consent discussion with the participants at every visit (Palmer, Savla, Roesch, & Jeste, 2013).

To address potential issues related to participants' capacity to provide consent for this study, I consulted with clinicians at the recruitment sites who were knowledgeable about their patients' psychiatric stability and ability to give consent. I also carefully explained the study to all participants and information about the study was also included in the informed consent. I asked participants to repeat the information in their own words and initial sections to acknowledge their understanding of the information. Participants were advised that their participation was voluntary, they did not have to sign the informed consent and no pressure was placed on them to take part in the study (Creswell, 2014).

Interviews were limited to no more than one hour to avoid fatigue. I used pseudonyms (i.e., Participant 1, bipolar disorder/schizoaffective disorder/schizophrenia), which represented the participant number and psychiatric diagnosis, to protect their privacy and confidentiality (Berg & Lune, 2012; Creswell, 2014). Data for this study are

stored in a locked file cabinet in my office. Records or lists with identifying information will be maintained in accordance with the University of South Florida's retention policy.

Trustworthiness Strategies

A common criticism of qualitative research is that it lacks scientific rigor (Mays & Pope, 1995). Several strategies were employed to minimize risks of subjectivity and to enhance the trustworthiness of this study's findings (Creswell, 2014; Royse et al., 2010). I used reflexive journaling to record my thoughts and my background and personal experiences. Vivid quotes from the participant interviews that characterized emerging themes in the findings were provided to minimize questions about whether the findings presented are actually derived from the data and not impacted by my personal biases. A detailed description of the methods and procedures used for data collection and analysis from which the conclusions were drawn is included in the data collection and analysis sections above. Notes and materials created during the research process, including but not limited to recordings, interview transcripts, data analysis, reports, information logs, and memos will be maintained in order to leave an audit trail. Data and researcher triangulation techniques were employed. Data from different sources, including interviews, reflexive journaling, and scientific literature were used to corroborate the findings to enhance the accuracy of my findings. Consultation was made with dissertation committee members, who have backgrounds in anthropology, gerontology, psychology, public health, and sociology, during the process of the study for periodic briefing during data analysis and interpretation. In addition, a graduate student who assisted with coding the transcripts was from a different discipline. The

diverse backgrounds and experiences of my committee members and the graduate student enabled the use of different perspectives for the interpretation of the data.

Researcher Reflexivity

During this research process, several participants expressed gratitude for including them in the study and giving them a voice about their mental health treatment experiences. I felt that some of them considered the interview as an outlet, particularly since many of them expressed a need for more individual counseling services for people with SMI. In contrast, one participant appeared to rush through the interview, most of his answers were short, and probe questions produced minimal detail. At the conclusion of the interview, he immediately asked “When do I get my gift card?” I felt that although he initially seemed interested in participating in the study, he was more interested in the gift card compensation. Early in the recruitment process, a participant who completed the screening process and agreed to the interview died after being struck by a vehicle, and another was hospitalized due to an unrelated physical illness. The two of them were close friends, and she informed me of his death after he was a “no show” for the scheduled interview. The news of his death was shocking, and I felt empathy for her knowing that he was her support system. These experiences underscore the vulnerability of the study population. I felt that my communication with the recruitment site decreased after the participant’s death, and it took a few months for me to recruit additional participants from the site. I contacted the recruitment site but the responses seemed to be much slower and I felt there was not as much enthusiasm on the part of the recruitment site as there was prior to the participant’s death, although the accident was unrelated to the current study. The change in response impacted my

approach to schedule interviews after the initial screenings. I attempted to coordinate the screenings on dates that clinicians were available to verify participant information on the spot, and if the participants agreed I interviewed them on the same day to minimize chances of losing additional participants. Chapter 5 includes the findings for this study.

CHAPTER FIVE: FINDINGS

This chapter includes demographic information for the study sample and findings for the three research questions: (1) What factors influence outpatient mental health treatment-seeking and engagement by community-residing Black and White older adults (ages 50-70 years) living with SMI? (2) What are the perspectives of community-residing older Blacks and Whites living with SMI on the issues of accessibility, affordability, appropriateness, and availability of outpatient mental health services? (3) Are the perspectives of community-residing older Blacks and Whites living with SMI on the issues of accessibility, affordability, appropriateness, and availability of outpatient mental health services different?

Thematic analysis was used to address the first research question. Themes (HBM constructs and emergent) were developed to categorize data relevant to the influences of outpatient mental health treatment engagement by older Blacks and Whites living with SMI. In addition to the themes, it was important to understand whether Blacks participants felt the need for specifically tailored services, and to gain insight from all participants about other services they would like to see offered to older adults living with SMI. Findings for the second research question are presented as summaries of participants' responses, including illustrative quotes, related to their perspectives on the issues of accessibility, affordability, appropriateness, and availability of outpatient mental health services. Findings for the third research question to address whether the perspectives of community-residing older Blacks and

Whites on the issues of accessibility, affordability, appropriateness, and availability of outpatient mental health services were different are also presented as summaries of participants' responses, including illustrative quotes. In addition, a summary of responses from Black participants related to whether they felt a need for specifically tailored mental health services is also included.

Demographic Characteristics of Sample

Nineteen participants were included in the analyses for this study. The mean age of the participants was 59, with a range of 50-70 years. While the age range for recruitment was 50-75 years old, the oldest participant in the current study was 70 years of age. The majority of the participants were female 13/19 (68%), White 10/19 (52.6%), had completed high school 13/19 (68.4%), were unemployed or retired 18/19 (94.8%), reported annual income was less than \$10,000 per year 17/19 (89.5%), and they lived with a roommate 10/19 (52.6%). Demographic characteristics for the total sample are reported in Table 1.

Table 1. Demographic Characteristics of Sample (N=19)

Characteristics	N	Mean(SD)	%
Age (in years)	19	58.9(5.0)	
Sex			
Male	6		31.6
Female	13		68.4
Race			
White	10		52.6
Black	9		47.4
Highest education level completed			

Table 1. Demographic Characteristics of Sample (N=19)

Characteristics	N	Mean(SD)	%
Did not graduate high school	6		31.6
High school graduate	4		21.1
Some college/trade school training	6		31.6
Associate's degree/completed trade school	1		5.3
Bachelor's degree	1		5.3
Graduate degree	1		5.3
Employment status			
Part-time	1		5.3
Retired	1		5.3
Unemployed (disability)	17		89.5
Income (annual)			
Less than \$10,000	17		89.5
\$10,001 - \$20,000	2		10.5
Living arrangement			
Lives alone	9		47.4
Roommate - spouse/significant other	2		10.6
Roommate – other	8		42.1
Psychiatric diagnosis			
Bipolar disorder only (BD)	7		36.8
Schizophrenia only (SCH)	5		26.3
Schizoaffective disorder only (SCH-A)	1		5.3
Comorbid (BD / SCH)	3		15.8
Comorbid (BD / SCH-A)	2		10.5

Table 1. Demographic Characteristics of Sample (N=19)

Characteristics	N	Mean(SD)	%
Comorbid (BD/ SCH / SCH-A)	1		5.3

Note. Total of percentages are not 100 for every characteristic because of rounding.

Black and White participants were compared on demographic characteristics. Overall, there was little variation between the groups. The White group was slightly older with an average age of 59.5 (range of 53-70) than the Black group (average age 58.3, range of 50-67). Gender for both groups was similarly divided. Both groups had three males and the White group had one more female than the Black group. The majority of participants from both groups graduated from high school [Blacks 6/9(67%), Whites 7/10 (70%)], with five Blacks (55.5%) and four Whites (40%) reporting education beyond high school, including one Black woman who had earned a bachelor's degree and a White woman who had earned a graduate degree. Income was also similar, with the majority of participants from both groups reporting less than \$10,000 per year [Blacks 8/9(88.9%), Whites 9/10(90%)]. The most noted difference was that more Whites 6/10(60%) lived alone than Blacks 3/10(33.3%). Demographic characteristics of Black and White participants are reported in Table 2.

Table 2. Demographic Characteristics by Race

Characteristics	Black (n = 9)	%	White (n=10)	%
Age in years, M(SD)	58.3(5.4)		59.5(4.8)	
Sex				
Male	3	33.3	3	30
Female	6	66.7	7	70

Table 2. *Demographic Characteristics by Race*

Characteristics	Black (n = 9)	%	White (n=10)	%
Highest education level completed				
Did not graduate high school	3	33.3	3	30
High school graduate	1	11.1	3	30
Some college/trade school training	3	33.3	3	30
Associates degree/completed trade	1	11.1	0	0
Bachelor's degree	1	11.1	0	0
Graduate degree	0	0	1	10
Employment status				
Part-time	1	11.1	0	0
Retired	1	11.1	0	0
Unemployed (disability)	7	77.8	10	100
Income (annual)				
Less than \$10,000	8	88.9	9	90
\$10,001 - \$20,000	1	11.1	1	10
Living arrangement				
Lives alone	3	33.3	6	60
Roommate - spouse/significant other	1	11.1	1	10
Roommate – other	5	55.6	3	30
Psychiatric diagnosis				
Bipolar disorder only	2	22.2	5	50
Schizophrenia only	3	33.3	2	20

Table 2. *Demographic Characteristics by Race*

Characteristics	Black (n = 9)	%	White (n=10)	%
Schizoaffective disorder only	1	11.1	0	0
Bipolar disorder/schizophrenia	2	22.2	1	10
Bipolar disorder/schizoaffective	1	11.1	1	10
Bipolar/schizophrenia/schizoaffective	0	0	1	10

Findings Research Question 1: What factors influence Black and White older adults who live with SMI to seek and engage in outpatient mental health services?

Themes Related to HBM Constructs

Thematic results from the participant interviews based on the six HBM constructs are presented below. Illustrative quotes that capture participants’ perspectives within each of the HBM constructs are listed in Table 3. There were no differences between Blacks and Whites related to their decisions to seek and engage in outpatient mental health services.

Perceived susceptibility to SMI. Understanding how older adults who have been clinically diagnosed with a SMI handle their diagnosis (acceptance or denial) is important because it impacts their views about the need for mental health treatment.

Recognize need for treatment. All participants acknowledged their SMI diagnosis. During the screening process, participants were asked about their psychiatric diagnosis. I verified their diagnosis with a clinician at the provider site, prior to the interviews. A few of them spoke about their need for treatment to minimize symptoms and recognize consequences of non-compliance. Participants made statements such as “so I can stay

healthy, mentally” [Participant 2, bipolar disorder] and “*without it I’ll get wacko*” [Participant 17, schizophrenia]. One participant suggested that people with a SMI should maintain a routine with taking their medications like they are supposed to, and another repeatedly stated that she was compliant with her treatment because she did not want to get sick again and have to be re-hospitalized. She was emphatic about not ever wanting to experience a mental crisis again.

Family history of SMI. Some participants mentioned that at least one other family member had a mental illness. A participant [Participant 16, paranoid schizoaffective disorder] said her cousins and aunt had mental health issues and she recalled her family talking about going to the hospital when she was young. Another stated, “*mental illness runs in my family*” [Participant 14, bipolar disorder], and shared that her great, great grandmother had been hospitalized related to a mental disorder.

Perceived seriousness (severity) of SMI. Community-residing older adults living with SMI who perceive the seriousness of a psychiatric diagnosis, including the potential consequences (e.g., social, relationships, education, employment) of living with a SMI, might be more willing to seek and maintain compliance with outpatient mental health treatment, in order to have better health outcomes and improved quality of life.

SMI impacts social interactions / stigma. Participants shared their thoughts about how the general public views people who have a mental disorder, which is oftentimes accompanied by stereotypes, stigma, and differential treatment. Several participants indicated they are no longer in communication with family members; some mentioned they are now divorced or experienced relationship break-ups since their SMI diagnosis.

One participant said, *“even families today they they they put us to the place like this.”*

[**Participant 1**, bipolar disorder, schizoaffective disorder, schizophrenia] Another spoke about a fight she had with her ex-husband, *“me and my husband were just about to break up, he threw me out of the house. He didn’t understand what was going on with me.”* [**Participant 14**, bipolar disorder] A different participant talked about being harassed because of having a mental disorder, *“I was harassed and beat up because of being bipolar you know constantly being put down and put down”*. [**Participant 11**, bipolar disorder] One participant shared her thoughts about how her diagnosis impacts potential relationships *“And then you have to accept it as a person. Would he be interested in me...if I have a mental illness?”* [**Participant 12**, bipolar disorder], and the embarrassment she feels.

Employment / education disruption. Some participants talked about their previous employment which they were unable to maintain due to some complications of mental illness. *“But I decided to keep working and I worked for thirty-two months and I got sick ill mentally ill...and then they uh started my check back up.”* [**Participant 2**, bipolar disorder] *“I had children to raise you know and I was working at the time also, so. [former occupation] like we discussed yesterday when you found out that I used to be a [occupation].”* [**Participant 6**, schizophrenia] *“I was working, doing my [education], I had a car, I had a job, I had an apartment, I had been married before for a short while.”* [**Participant 13**, bipolar disorder, schizoaffective disorder] One participant mentioned the stigma of mental illness causes employers to think that people with SMI are incapable of doing their jobs properly. *“Okay. Um it’s kinda the stigma it’s like yeah. They think something’s wrong with you and you can’t do the job properly. You think*

your doctor's appointments are gonna interfere with your job." [Participant 12, bipolar disorder] Such experiences and thoughts impact social interactions of people living with SMI.

Perceived benefits of mental health treatment engagement. Mental health treatment utilization may lead to improved mental and physical health, quality of life, and healthy socialization, and trusting relationships with mental health providers. These factors may motivate community-residing older adults living with SMI to actively seek and engage in outpatient mental health treatment. Participants shared some of the ways they have benefited from using mental health services.

Improved sense of well-being. All participants noted benefits of using mental health services. Participants said, *"I'm getting treatment for that as well as you know trying to um make myself a whole person."* [Participant 9, bipolar disorder] *"I've been with SITE 1 ever since and they literally have saved my life."* [Participant 11, bipolar disorder]

Increased socialization. Socialization was cited as a benefit of utilizing mental health treatment and services. Participants made statements such as, *"I I gets get to uh meet people...and I get to socialize."* [Participant 18, schizophrenia]; *"Um, well you get to make friends here."* [Participant 14, bipolar disorder]; and *"I get to talk with the teacher, make friends at SITE 1. Get to go on outings."* [Participant 16, schizoaffective disorder]

Participants' trust in mental health staff. There was a strong sense that participants' trust in their case managers and other mental health staff at provider sites to ensure their well-being played a role in their decisions to engage, remain, or return to

outpatient mental health treatment. Participants described their interactions with mental health staff and how they looked out for them. Some no longer have relationships with their family members and said staff at provider sites was the only family they now have. One participant said, *“All my family pass away...Passed on, passed away or whatever the case was.”* [Participant 7, bipolar disorder, schizoaffective disorder] Participants shared how receptive case managers were when they reached out to them in times of need, whether they were actively engaged with mental health services or had left services and needed to be reconnected with services. Some expressions that illustrated participants’ trust in the service providers include: *“Cause how are you gonna help me if I don’t tell you the truth?”* [Participant 9, bipolar disorder], *“I said coming to you it seems like I feel that I can be comfortable with you”* [Participant 19, bipolar disorder], and *“We have a problem they’re always on it. The staff here are good to people.”* [Participant 1, bipolar disorder, schizoaffective disorder, schizophrenia]

Perceived barriers to mental health treatment engagement. Poor mental health literacy, stigma, and lack of information about available mental health treatment are often hindrances to outpatient mental health treatment engagement. Lack of understanding about mental illness, lack of knowledge about where and how to access mental health services, and negative community responses to mental illness might overshadow the known benefits of mental health treatment. As a result, some individuals might not engage in mental health treatment.

Poor advertisement about mental health services. Participants spoke about a need for the community to know about mental health services, *“You know cause a lot of*

people before I came into this program I didn't know what SITE 1 had to offer."

[Participant 10, bipolar disorder, schizophrenia]

Poor mental health literacy contributes to stigma about mental illness. Some statements made by participants related to poor mental health literacy and stigma include, "they need to be educated about us" [Participant 14, bipolar disorder] and "When you have a mental illness ain't nobody crazy you just have a few problems."

[Participant 8, bipolar disorder, schizophrenia] One participant said,

"They, they um they don't know what they know is what the TV tells them. And like they think all people with mental illness now have um [background noise from air conditioning unit] are gonna go out and get guns and shoot everybody you know the perception out there is really bad right now. I I think that you know they just don't know enough to understand what we go through. You know we're not all criminals and and we're being made out to be that way. So I I think the majority of the people out there think that you know if you have mental illness you're really sick you should be locked away." **Participant 11, bipolar disorder**

Lack of knowledge about where to go for services. Several participants reported that other than the services they currently receive, they had no knowledge of any other available mental health services in the community. When asked about how people in their communities and churches or other religious organizations view mental health services, and what they learned about mental health treatment and services growing up, most participants indicated that conversations about mental illness and treatment were almost non-existent. Emphasis was placed on a need for positive advertisement about available mental health services and mental health outreach in the community. One

participant suggested that “scouts” are needed to go into the community and look for people who have mental disorders and assist them with getting mental health treatment. He advised that he has seen them near the basketball courts in the area, and suggested that they are easy to spot by their physical reactions to things such as loud thumping sounds. Some examples that illustrate participants’ views concerning the need for people in the community to know where to go for mental health treatment include: “*just floundering around not knowing what where to go, what to do and how to get help*” [Participant 11, bipolar disorder] and “*You know and uh I think that the community need to know more about SITE 1 because there’s a lot of mental illness out there and people don’t realize what they have or what you know their diagnosis is.*” [Participant 10, bipolar disorder, schizophrenia]

Cues to action. Individuals living with SMI oftentimes experience symptoms which prompt them to seek mental health treatment. Some individuals recognize the need for treatment while others are prompted by recommendations from others. Some triggers to mental health treatment engagement include recommendations by a health care provider after suicide attempts and Baker Act or emergency hospitalization due to mental crisis.

Health care provider recommendation. When asked about what prompted their engagement in services at the current site, the majority of participants said they were referred by a health care provider. A participant said, “*SITE 3 came in and talked to me and told me they could give me professional help if I wanted it. And I, I did. Because nobody really wants to die.*” [Participant 3, bipolar disorder] The participant had been hospitalized after taking 50 pills of morphine. Another participant stated, “*I was suicidal*

and I had checked myself in. And this dude from he said he was from SITE 1 wanted to be my case manager and I said no I don't want to be case managed.” [Participant 9, bipolar disorder]

Baker Acted / emergency hospitalization. Participants mentioned being hospitalized for complications of mental illness after drug use, “*Well I got some LSD and I uh it affected me wrong. And then I went to the [University name] hospital which is [University medical name] and they treated me for the mental illness.” [Participant 18, schizophrenia]*, and having a “nervous breakdown”, “*Uh huh and when I had this nervous breakdown it drove me into the mental hospital to get some medication.” [Participant 6, schizophrenia]*

Self-efficacy. Older adults living with SMI who have high self-efficacy are likely to have a better outlook on life, desire sense of purpose, be conscientious about their personal appearances, and better manage their mental illness. Self-efficacy may be impacted by participants’ understanding of their diagnosis and treatment, their ability to attend to their personal needs, and cope with mental illness-related stigma.

Understanding of diagnosis, related symptoms, and embracing treatment. Participants shared how mental health treatment has taught them about their illness, associated symptoms, and coping skills. One participant shared, “*I notice my I know my ups and downs, I know my changes that I go through that I didn't never recognize it when I was out there getting high.” [Participant 10, bipolar disorder, schizophrenia]* Another participant stated, “*Uhhh tells me more about the illnesses than anything else. The therapist works on recovery in coping skills strengthening your coping skills but also*

monitoring your attitude about your illness do you accept it immediate accept it, do you just manage with it?" [Participant 13, bipolar disorder, schizoaffective disorder]

Expressed ability to cope with shame and stigma of mental illness. Several participants shared that they used to be ashamed of having a mental illness but this is no longer the case. Participants expressed, *"I was. I, I was ashamed for myself. But now I'm not."* [Participant 3, bipolar disorder], and *"Yes, I was ashamed that people would find out oh say, "Oh she crazy"... Now I don't care if people say that I she you know I don't care if people know that I have a mental illness."* [Participant 8, bipolar disorder, schizophrenia]

Desire for sense of purpose / pride in personal appearance. Some participants expressed a desire for a sense of purpose. They talked about wanting to work or volunteer and felt that having a mental illness should not limit them from doing so. One participant said, *"Just give us a chance to go out and prove ourselves to the world that we can work and that we can you know, take care of ourselves and things like that"*. [Participant 6, schizophrenia] Another participant shared that she wanted to volunteer at her doctor's office, *"I want to volunteer at my primary doctor's office...during the week and he said it was okay. The office manager said that it was okay. I'm just waiting for a phone call so I can go to work."* [Participant 9, schizophrenia] Interestingly, the oldest participant in the study was conscientious about his personal appearance and during a discussion about treatment affordability he expressed, *"I gotta get a haircut you know. You know so so I could at least look respectable."* [Participant 4, schizophrenia]

Table 3. *Health Belief Model Constructs - Data Themes and Illustrative Quotes*

HBM Construct	Data Themes	Illustrative Quotes
Perceived susceptibility	Recognize need for treatment	<ul style="list-style-type: none"> <li data-bbox="968 337 1896 748">• <i>“I continue I continue to get my treatment because I don’t want to get sick ‘cause I know if I stop taking my medication where I might end up at...And that’s in in Crisis or um I forgot what the other name for it is and I don’t want to end up back in the hospital. So I take my medications regularly every day doing the day and at night I and I don’t want to get sick any more. So I take my medications like I’m supposed to take my medications and I have no problem.” Participant 8, bipolar disorder, schizophrenia</i> <li data-bbox="968 764 1896 935">• <i>“Uh, I have to take my medicine every month. Without it I’ll get wacko. And my other treatments I go through I have to go through um because I’m not normal, I got schizophrenia.” Participant 17, schizophrenia</i>
	Family history of SMI	<ul style="list-style-type: none"> <li data-bbox="968 951 1896 1284">• <i>“Mental illness runs in my family...and my great, great grandmother was hospitalized...and they at that time, they just put her in a hospital...and let her go crazy. And that’s what happened to her...So I guess they figured the same thing was gonna happen with me. So, you know...But they’re not up with times is what I’m tryin’ to tell ya.” Participant 14, bipolar disorder</i>

Table 3. Health Belief Model Constructs - Data Themes and Illustrative Quotes

HBM Construct	Data Themes	Illustrative Quotes
		<ul style="list-style-type: none"> • <i>“My cousins had mental health issues and I just would hear family talk about going to the hospital. My aunt had mental health issues and my mom was afraid of her.”</i> Participant 16, paranoid schizoffective disorder
Perceived severity	SMI impacts social interactions/stigma	<ul style="list-style-type: none"> • <i>“They fear us, they fear us. I don’t know why because I think a lot of people when they they’ve heard this on the street and then when they kill somebody they say well they have a mental illness and that may that could be lying to blame it on us. You know and it makes us look bad. Even families today they they they put us to the place like this and don’t get me wrong these people take SITE 3 takes care of us. They take care of us. That’s our family the only family we really got is people here.”</i> Participant 1, bipolar disorder, schizoffective disorder, schizophrenia • <i>“So and I was bipolar at the time. I was harassed and beat up because of being bipolar you know constantly being put down and put down and everything so it was had to get any um adequate help that I needed.”</i> Participant 11, bipolar disorder

Table 3. Health Belief Model Constructs - Data Themes and Illustrative Quotes

HBM Construct	Data Themes	Illustrative Quotes
		<ul style="list-style-type: none"> • <i>“Yeah, cause when me and my husband were just about to break up, he threw me out of the house. He didn’t understand what was going on with me. He just throws me out of the house. I had a night gown on it was in the middle of the night...I landed in a mud puddle and um I’ll never forget that. And um but he he was sorry he did that. He didn’t realize it was a mud puddle right there and he knew I had on a night gown but and that mud don’t come out too easy cause it...and um yeah we made up since then but you know there for a while.” Participant 14, bipolar disorder</i>
	Employment / education disruption	<ul style="list-style-type: none"> • <i>“I uh I did a couple times I decided to strike out on my own. I had a good job. I was working for [previous employer] uh and I I cut off my check my uh disability check and I tried the trial work period that they give you. Nine months um and you uh they you can make as much as you want...for nine months and then uh you need to you have to either continue working or quit and get your check back started. But I decided to keep working and I worked for thirty-two months and I got sick ill mentally ill...and then they uh started my check back up.” Participant 2, bipolar disorder</i>

Table 3. Health Belief Model Constructs - Data Themes and Illustrative Quotes

HBM Construct	Data Themes	Illustrative Quotes
		<ul style="list-style-type: none"> • <i>“I had children to raise you know and I was working at the time also, so. [former occupation] like we discussed yesterday when you found out that I used to be a [occupation].” Participant 6, schizophrenia</i> • <i>“Okay. Um it’s kinda the stigma it’s like yeah. They think something’s wrong with you and you can’t do the job properly. You think your doctor’s appointments are gonna interfere with your job. And then you have to accept it as a person. Would he be interested in me...if I have a mental illness. It’s embarrassing.” Participant 12, bipolar disorder</i> • <i>“I was working, doing my [education], I had a car, I had a job, I had an apartment, I had been married before for a short while.” Participant 13, bipolar disorder, schizoaffective disorder</i>
Perceived benefits	Improved sense of well-being	<ul style="list-style-type: none"> • <i>They take care of us over here. They get us help, they talk to us. We have a problem they’re always on it. The staff here are good to people. I’ve never had no trouble with them.” Participant 1, bipolar disorder, schizoaffective disorder, schizophrenia</i>

Table 3. Health Belief Model Constructs - Data Themes and Illustrative Quotes

HBM Construct	Data Themes	Illustrative Quotes
		<ul style="list-style-type: none"> • <i>“I’m getting treatment for that as well as you know trying to um make myself a whole person.”</i> Participant 9, bipolar disorder • <i>“SITE 1 saved my life. Um I was aware of SITE 1 before. I was in the hospital for 42 days at [hospital name] and uh they found me a place with SITE 1 in '07 and I’ve been with SITE 1 ever since and they literally have saved my life.”</i> Participant 11, bipolar disorder • <i>“I don’t know what I would do without SITE 1. SITE 1 is very good”</i> Participant 16, schizoaffective disorder
	Increased socialization	<ul style="list-style-type: none"> • <i>“They take care of us over here. They get us help, they talk to us. We have a problem they’re always on it. The staff here are good to people. I’ve never had no trouble with them.”</i> Participant 1, bipolar disorder, schizoaffective disorder, schizophrenia • <i>“Um, well you get to make friends here. And a lot of them are sweet and nice and considerate. Some of them are butt holes [laughs] but you know which ones those are you just avoid them. [laughs]”</i> Participant 14, bipolar disorder

Table 3. *Health Belief Model Constructs - Data Themes and Illustrative Quotes*

HBM Construct	Data Themes	Illustrative Quotes
		<ul style="list-style-type: none"> <li data-bbox="968 334 1850 423">• <i>“I I gets get to uh meet people...and I get to socialize.”</i> Participant 18, schizophrenia <li data-bbox="968 516 1898 732">• <i>“I get to talk with the teacher, make friends at SITE 1. Get to go on outings. I am part of the FACT team. The FACT team is really good to me. SITE 1 has group and classes. There are no downsides to coming to SITE 1.”</i> Participant 16, schizoaffective disorder
	<p>Participants’ trust in mental health staff</p>	<ul style="list-style-type: none"> <li data-bbox="968 766 1850 982">• <i>“They take care of us over here. They get us help, they talk to us. We have a problem they’re always on it. The staff here are good to people. I’ve never had no trouble with them.”</i> Participant 1, bipolar disorder, schizoaffective disorder, schizophrenia <li data-bbox="968 1010 1898 1349">• <i>“And she keeps saying to me, “[Participant 9] don’t let no one steal your joy. Not even you”. And once in a great while I’ll go into her office all flustered you know upset or whatever and she’ll say, “Okay, come on we’re taking a walk”. So we take a walk around the parking lot or we go go to [street name] and cut back and um you know uh behind the store, not behind the store, in front of the stores but um um she she knows me better</i>

Table 3. Health Belief Model Constructs - Data Themes and Illustrative Quotes

HBM Construct	Data Themes	Illustrative Quotes
		<p><i>than I know myself...And I told her I said [Recovery Specialist name] there is one thing I will never do to you. She says what's that? I says lie to you. Cause how are you gonna help me if I don't tell you the truth? And she said you know that makes sense. It really does, Participant 9, bipolar disorder</i></p> <ul style="list-style-type: none"> <li data-bbox="968 639 1885 1338"> <p><i>• "Yes, uh pretty much he shares uh the same thing as far as my treatment uh and maybe how I'm dealing with things. Uh certain you know things like how do he ask me how do I feel about driving out here. Did I drive by myself because I had told him that and he was saying pretty much do, he ask did I want to find a doctor on that side. I said coming to you it seems like I feel that I can be comfortable with you from the way that you are acting or ask or your mannerism seems like I can work with you and right now I don't feel a need of changing and I said that the distance it is far but you know and if I get a special time when the traffic isn't so heavy, I would drive myself, otherwise if your appointment kind of like changes for me I'll have to have to have one of them to drive." Participant 19, bipolar disorder</i></p>

Table 3. *Health Belief Model Constructs - Data Themes and Illustrative Quotes*

HBM Construct	Data Themes	Illustrative Quotes
Perceived barriers	Poor advertisement	<ul style="list-style-type: none"> • <i>“To make the community more aware of SITE 1...You know cause a lot of people before I came into this program I didn’t know what SITE 1 had to offer. I ain’t know what kind of program it was til I got here. You know and uh I think that the community need to know more about SITE 1 because there’s a lot of mental illness out there and people don’t realize what they have or what you know their diagnosis is.”</i> Participant 10, bipolar disorder, schizophrenia • <i>“People need to know that there’s help out there...You know. I mean cause if we don’t know then how can we get the help? You know. Either you have to have someone that’s a very strong support and says let’s go try this or you’re out there on your own just floundering around not knowing what where to go, what to do and how to get help...And it’s very frustrating.”</i> Participant 11, bipolar disorder
	Poor mental health literacy contributes to stigma	<ul style="list-style-type: none"> • <i>“I just have a mental illness. I’m not crazy. I just have problems. And so I’m not crazy. But other people when rate you crazy. When you have a mental illness ain’t nobody crazy you just have a few problems. That’s all.”</i> Participant 8, bipolar disorder, schizophrenia

Table 3. Health Belief Model Constructs - Data Themes and Illustrative Quotes

HBM Construct	Data Themes	Illustrative Quotes
		<ul style="list-style-type: none"> <li data-bbox="968 337 1896 857">• <i>“They, they um they don’t know what they know is what the TV tells them. And like they think all people with mental illness now have um [background noise from air conditioning unit] are gonna go out and get guns and shoot everybody you know the perception out there is really bad right now. I I think that you know they just don’t know enough to understand what we go through. You know we’re not all criminals and and we’re being made out to be that way. So I I think the majority of the people out there think that you know if you have mental illness you’re really sick you should be locked away.” Participant 11, bipolar disorder</i> <li data-bbox="968 889 1896 1287">• <i>“They need to be educated about us. There needs to be go on TV and um there needs to be somebody. You know what I’m saying. Somebody needs to say something about about us...that we’re not that crazy...On mental illness. Everybody needs that. It’s not just the policeman or you know the cafeteria woman or whatever. It’s everybody needs to be educated on it, I think. Because it’s a lot of people that don’t know anything about it. And there should be a lot more on TV about it or in the</i>

Table 3. Health Belief Model Constructs - Data Themes and Illustrative Quotes

HBM Construct	Data Themes	Illustrative Quotes
		<p><i>radio or somewhere where they can be, you know. I think.”</i> Participant 14, bipolar disorder</p> <ul style="list-style-type: none"> <p><i>P: “I think they need to uh instead of making fun of everybody quit putting it on the news and um be much more gentler.”</i></p> <p>I: How can how do you think that can be changed?</p> <p><i>P: “I don’t know. Someone has to go to the news stations and tell them to cut their crap.”</i></p> <p>I: So you think by positive media</p> <p><i>P: “Yes, yes. Like if someone’s a killer, label them as a killer. Don’t say oh that it’s not they don’t do that they go this person has a mental illness. I mean that’s against the HIPAA law anyway. And then they go on and on the news making fun of person but the person’s a psychopath, he’s a psychopath. I mean as mental illness should be separated from saying he did this and he did that. I mean he’s a fruit cake. I wouldn’t say he’s mentally ill, I’d just say you know, he’s he’s a fruitcake. I mean, there’s a difference in mental illness and someone doing top criminal activity. That’s what I feel.”</i> Participant 12, bipolar disorder</p>

Table 3. Health Belief Model Constructs - Data Themes and Illustrative Quotes

HBM Construct	Data Themes	Illustrative Quotes
	Lack of information / knowledge about where to go for services	<ul style="list-style-type: none"> • <i>“To make the community more aware of SITE 1...You know cause a lot of people before I came into this program I didn’t know what SITE 1 had to offer. I ain’t know what kind of program it was til I got here. You know and uh I think that the community need to know more about SITE 1 because there’s a lot of mental illness out there and people don’t realize what they have or what you know their diagnosis is.” Participant 10, bipolar disorder, schizophrenia</i> • <i>“People need to know that there’s help out there...You know. I mean cause if we don’t know then how can we get the help? You know. Either you have to have someone that’s a very strong support and says let’s go try this or you’re out there on your own just floundering around not knowing what where to go, what to do and how to get help...And it’s very frustrating.” Participant 11, bipolar disorder</i>
Cues to Action	Health care provider recommend	<ul style="list-style-type: none"> • <i>“I took 50 pills of morphine number tens and they sent me to [state in-patient MH]. I stayed there for about six months and SITE 3 came in and talked to me and told me they could give me professional help if I wanted</i>

Table 3. Health Belief Model Constructs - Data Themes and Illustrative Quotes

HBM Construct	Data Themes	Illustrative Quotes
		<p><i>it. And I, I did. Because nobody really wants to die. You just get that way sometimes.”</i> Participant 3, bipolar disorder</p> <ul style="list-style-type: none"> • <i>“Well the doctor and and and yeah they suggested that”</i> Participant 7, bipolar disorder, schizoaffective disorder • <i>“Well, I was in the hospital. I was suicidal and I had checked myself in. And this dude from he said he was from SITE 1 wanted to be my case manager and I said no I don’t want to be case managed. I wanna go home. But at the time I had no home to go to. So they kept me in the hospital and um when the doctor and everybody signed the release for me to be able to leave the hospital, um they did the release and and uh I was at first in [name and location of another MH provider].</i> Participant 9, bipolar disorder
Self-efficacy	Understanding diagnosis, related symptoms and embracing treatment	<ul style="list-style-type: none"> • <i>“And it tells and it teaches about your illness. What your like I’m I am bipolar schizophrenic and um I notice my I know my ups and downs, I know my changes that I go through that I didn’t never recognize it when I was out there getting high.”</i> Participant 10, bipolar/schizophrenia

Table 3. Health Belief Model Constructs - Data Themes and Illustrative Quotes

HBM Construct	Data Themes	Illustrative Quotes
		<ul style="list-style-type: none"> <p><i>“Pretty good. Pretty good. They are trying to one of the things the class five days a week uh and I am here five days a week...Uhhh tells me more about the illnesses than anything else. The therapist works on recovery in coping skills strengthening your coping skills but also monitoring your attitude about you illness do you accept it immediate accept it, do you just manage with it? Are you waiting for the day when you can just be done with the pills, you know all those ideas...So I manage to get the full support, the full support.”</i> Participant 13, bipolar, schizoaffective disorder</p>
	<p>Expressed ability to cope with shame and stigma of mental illness</p>	<ul style="list-style-type: none"> <p><i>“Yes, I was ashamed that people would find out oh say “Oh she crazy”. You know I was ashamed to have people find that I was mentally ill because people would make fun of me. Now I don’t care if people say that I she you know I don’t care if people know that I have a mental illness.”</i> Participant 8, bipolar disorder/schizophrenia</p> <p><i>“Well it is not as a stigma as before. And it’s, it’s like it’s another disease. Uh like diabetes, a heart condition, uh epilepsy whatever. It’s just another disease and for me personally, chemical imbalance in my brain no big deal.”</i> Participant 9, bipolar disorder</p>

Table 3. *Health Belief Model Constructs - Data Themes and Illustrative Quotes*

HBM Construct	Data Themes	Illustrative Quotes
	<p>Desire for sense of purpose / Pride in personal appearance</p>	<ul style="list-style-type: none"> • <i>“I gotta get a haircut you know. You know so so I could at least look respectable.” Participant 4, schizophrenia</i> • <i>“Just give us a chance to go out and prove ourselves to the world that we can work and that we can you know, take care of ourselves and things like that because. Just because you get on medication don’t mean you know that you should go down to the lowest. You know.” Participant 6, schizophrenia</i> • <i>“I want to volunteer at my primary doctor’s office...during the week and he said it was okay.” “I am a medical assistant but I’ve forgotten everything that I’ve learned and I’m gonna do some filing, some talking on the phones, maybe I’ll get to learn the computer, setup appointments for the patients. Now I did tell the doctor that I would be very detrimental to his patients and why...and he appreciated that.” Participant 9, schizophrenia</i>

Emergent Theme: Risk of Homelessness

Participant interviews revealed an emergent theme that impacted the likelihood of both older Black and White adults who reside in the community and live with SMI to seek and engage in outpatient mental health treatment which was the risk of homelessness. Housing security was mentioned by almost all participants (i.e., by both Blacks and Whites) and was at the forefront of their decision to seek and remain in treatment, or return if they had prematurely terminated treatment in the past. Housing assistance ranged from independent living, which included HUD-housing, vouchers provided by mental health providers to subsidize rent and utility expenses in the community, and single-unit apartments owned by mental health providers, shared apartments owned by mental health providers, and group homes.

Participants who were threatened with homelessness, or who were homeless prior to their engagement with the current mental health services, included individuals who had been hospitalized, served time in jail or prison and had nowhere to go after being released, a former graduate-degreed professional who indicated she walked from another state while experiencing a mental health crisis, someone who had been evicted after experiencing a mental health crisis, former state mental hospital patients who attempted to live on their own after they were released back into the community, and individuals who could not afford to pay for a place to stay and who were not welcomed by their families. A resounding sense of gratitude for the provision of housing was expressed by many participants as they attributed their decision to seek and engage in mental health treatment to a need for a secure place to live. Illustrative participant quotes are listed in Table 4.

Table 4. *Emergent Theme: Risk or Homelessness and Illustrative Quotes*

Data Theme	Illustrative Quotes
Risk of homelessness	<ul style="list-style-type: none"> <li data-bbox="611 321 1801 350">• <i>“I have home I have a place to stay here while I’m in this services. They give me a place to stay.”</i> Participant 1, bipolar disorder/schizoaffective disorder/ schizophrenia <li data-bbox="611 444 1877 474">• <i>“Because I had been here in the past and I came back here because I couldn’t find nowhere else to go.”</i> Participant 7, bipolar disorder/schizoaffective disorder <li data-bbox="611 568 1686 597">• <i>“They help you find a house. Housing.”</i> Participant 10, bipolar disorder, schizophrenia <li data-bbox="611 626 1902 721">• <i>“They gave me uh a secure place to live. A safe and secure place to live. Um they took me right in off the hospital not knowing anything about me.”</i> Participant 11, bipolar disorder <li data-bbox="611 750 1896 909">• <i>“I when is it. I’m tryna think. I was committed by my landlord at [hospital name] and then I was gonna be homeless cause my landlord didn’t want me to move back in with him. And so I uh went through [hospital name] suggested SITE 1.”</i> Participant 12, bipolar disorder <li data-bbox="611 938 1845 1032">• <i>“SITE 1 has helped me all these years. It could be me on the street.”</i> Participant 16, schizoaffective disorder <li data-bbox="611 1062 1896 1156">• <i>“Uh I was in prison. I got out of prison. I didn’t have nowhere to go and I was having a little bit of illusions so I contacted SITE 1”</i> Participant 17, schizophrenia

Participants' Recommendations for Additional Mental Health Services

All participants were asked about additional services they would like to see offered to older adults living with serious mental illness. Their responses included: more counseling staff, medical and dental services exclusively for people living with mental illness, more independent housing, mental health outreach and education, more Black mental health staff, stigma reduction, transportation, food stamps and food banks, in-home mental health services, job skills training, transition preparation, and peer-to-peer support programs. Participants shared recommendations as follows:

- *“A food bank there because when you are broke and you’re uh don’t have no transportation you’re borderline homeless, it’s terrifying. Always make sure they have housing or you’re always end up homeless I don’t know why. We get you spend everything in a bipolar mania you spend you’re out of conscious awareness. So you end up being flat broke. But then when once you’re flat broke you gotta think “Oh my gosh something’s wrong with me. I need to get transportation to go get that place.” Then you’re usually out of food so a food bank would be wonderful.” [Participant 12, bipolar disorder]*
- *“Well I would like to see like there are people who can’t get out, you know even if they had transportation they can’t get out. It would be good if they had more staff that could go to you know more staff that could go to the people and say “hey” you know and not spend ten minutes and say “you know what’s going on da da da da”. You need time...So they need more staff to allow them to have more time with the people they have.” [Participant 11, bipolar disorder]*

- *“Yes, I think a person they should be more aware of that that that’s a hurting feeling when the person go around calling you retarded and crazy and. How would a person feel if they was called retarded and off and all I mean. That we’re just like everybody else only we have something else wrong with us.”*

[Participant 8, bipolar disorder, schizophrenia]

Research Question 2: What are the perspectives of community-residing older Black and White adults living with SMI on the issues of accessibility, affordability, appropriateness, and availability of outpatient mental health services?

Participant perspectives on the issues are presented in this section.

Accessibility and Availability of Services

During interviews, participants at Sites 1 and 3 indicated that mental health services were provided on-site at some of the site-owned residential properties. They advised that some services were also provided at day treatment centers, community support center, and other locations. Some participants at Sites 1 and 3 shared that, if needed, they were provided with transportation to access mental health services. Others indicated they utilized public transportation, had their own vehicles, or were provided with transportation assistance from family or friends. A participant from Site 1 said, *“Every morning...they come the big white vans out there...they go round to the housing houses and pickup people and bring ‘em here. They get breakfast, they get lunch.”* [Participant 11, bipolar disorder] A participant from Site 3 shared, *“Well they give us transportation [staff name] he is the driver here and we gotten if we got rides to SITE 3, he’ll come and pick us up.”* [Participant 1, bipolar disorder, schizoaffective disorder, schizophrenia]

Case managers at Sites 1 and 3 also provided transportation and accompanied participants to other appointments related to their overall care and well-being. One participant provided insight into her experience with receiving assistance from a case manager,

“I make all of my own doctors appointments. I get my own shopping done. At the apartments in the office and certain SITE 1 apartments have this if not all of them. They have somebody in the office who runs interference for you...on things like transportation. My Recovery Specialist is what they’re called and he provides transportation to doctors appointments, to the pharmacy and things like that. Um I do my own food shopping and any of the shopping that comes up. Um I make my own appointments for doctors, administrative. Things like going to Social Security he would take me there but I would manage the appointment, you know. I can talk for myself and tell them I need to process my direct deposit from my Social Security to my checking account and I handle that on my own.” [Participant 13, bipolar disorder, schizoaffective disorder]

There was only one participant at Site 2 and she appeared to be relatively independent. She owned her own vehicle, scheduled her own appointments, and with the assistance of her husband and children was able to manager her own affairs. The participant said that she went wherever she was told to go for mental health treatment, regardless of the distance, and did not believe in changing providers unless it was necessary.

Participants were asked if they knew about any other places in the community where they could receive mental health treatment and if so, would they change the

locations or times the services were offered. Participants who were knowledgeable about other mental health services in the community indicated that they would not change the locations or times that services were offered. One participant responded, *“Well [provider site] is pretty easy to get to it’s right down on [street name] and there’s a bus that runs up and down it all day long...So as far as getting to there fairly easy riding the bus or the trolley.”* [Participant 11, bipolar disorder]

Affordability of Services

During interviews with participants, I asked, *“Do you feel that treatment for your mental health condition is affordable?”* A majority of the participants said that affordability of mental health treatment was not an issue for them. I learned that most of the participants received disability, including health care, related to their psychiatric diagnosis. A participant at Site 1 mentioned that she had not been approved for disability and was currently without health care coverage. She further advised that someone at Site 1 was assisting her with applying for disability benefits, but in the meantime, Site 1 was providing the services for free.

“The blessing is the meds. And the doctor’s visit. And then of course, outpatient therapy...And they don’t charge you until you settle with soc- SSI I guess or something like that. So you don’t have to worry about the burden of um finances...You know they provide all that. And if you don’t have that, they still provide...They just provide everything.” [Participant 12, bipolar disorder]

Two participants, one Black and one White, mentioned affordability issues and it was related to co-payments for services. The Black participant [Participant 19, bipolar disorder] said she had to cut her visits to a psychologist for counseling because her

insurance changed and the cost doubled from \$40 to \$80. She stated she changed the frequency of her visits from every three months, to every six months and did not feel the visits to the psychologist were essential. When asked if cost was not an issue and she could go for free, she immediately responded that she would have continued to go every three months. The White participant mentioned that his co-payments for prescriptions ranged from \$60-\$80 per month. He indicated that he receives minimal food stamps; therefore, he has to use his personal funds to supplement his food. The high medical co-pays limit the amount of money he has to take care of his personal needs like a haircut. [Participant 4, schizophrenia]

Appropriateness of Services

To address appropriateness of mental health services, participants were asked questions related to how they felt about the treatment and services they currently receive, if they felt the services aligned with their personal beliefs and values, and if they felt their personal beliefs were respected. Most participants indicated they were satisfied with their current services received and felt the services positively aligned with their personal beliefs and values, and that their personal beliefs and values were respected by the mental health providers.

Other sentiments expressed by participants related to the appropriateness of their current mental health treatment and services include: *“Cause they do everything they say they would; they follow through; they are very loyal.”* [Participant 12, bipolar disorder]; *“Because all the things that I need they provide; Housing, uh what I need a doctor or something like that; uh he make sure I’m doing good.”* [Participant 2, bipolar disorder]; and *“I don’t think that he has infringed upon that issue or any other thing. If*

it's not dealing with his his area or his lane then he he stayed in his lane...He stayed in his lane." [Participant 19, bipolar disorder].

However, one Black and one White participant indicated they had conflicts with staff at provider sites and did not feel their personal beliefs were respected. The White participant, [Participant 5, bipolar disorder, schizophrenia] indicated that she did not see a point in discussing her personal conflict with staff because they were not receptive and shut people down if they had too much of an opinion. She stated it was about what the staff thought and said, but felt the harassment was not enough that she could afford to leave. The Black participant [Participant 17, schizophrenia] stated that he felt "50-50" about whether his personal beliefs were respected. He attributed his response to personal conflicts that he had with staff at his residential site and classroom teachers at the day treatment center. He indicated that staff at the residential site "argue at clients for nothing", ask them the same questions repeatedly, and stated, "they treat you sorta rough now like they mad cause they don't make enough money." His comment about staff at the day treatment was, "Mostly teachers most of staff treat you good. A few of them sorta prejudice and stuff...I had to get out of the class of one of them and go to another class cause he was messing with me and so. But other than that it's pretty good." [Participant 17, schizophrenia]

Research Question 3: Are the perspectives of community-residing Blacks and Whites, who live with SMI, different on the issues of accessibility, affordability, appropriateness, and availability of outpatient mental health services?

Accessibility and Availability of Services

There were no differences noted in the perspectives of community-residing older Blacks and Whites living with SMI on current or previous issues of accessibility and availability of outpatient mental health services. When asked whether they ever experienced challenges accessing mental health services, a Black participant stated, *“Only when I had my first episode of mental health issues. Since being diagnosed I have always been able to receive mental health services.”* [Participant 16, schizoaffective disorder]. A white participant said, *“Always been able to access it in one way I just choose to do it.”* [Participant 13, bipolar disorder, schizoaffective disorder]

Affordability of Services

There were no differences in the overall sentiment of the Black and White participants on issues of affordability of outpatient mental health services. Two Black participants stated, *“Well it’s affordable with the insurance what you get...Magellan that’s who my insurance is with so...I can use that. You know to uh you know pay for my mental health treatment.”* [Participant 6, schizophrenia], and *“I don’t know because it is paid through my Social Security or Medicaid. I don’t have to worry about it.”* [Participant 16, schizoaffective disorder]. Two White participants said, *“I’m not paying anything for it.”* [Participant 5, bipolar disorder, schizophrenia], and *“well medical care is already taken care of so I don’t have to worry about doctor office visits, hospitals, prescriptions or none of that.”* [Participant 9, bipolar disorder].

Appropriateness of Services

Black and White participants appeared to have similar positive feelings about their current mental health services. A Black participant said, *“I think SITE 1 is a very good program. It helps you out, it helps you get to know yourself, get to know, you get to work on your um mental illness.”* [Participant 10, bipolar disorder, schizophrenia] Similarly, a White participant stated, *“Yes...Every way. Made me look out for myself and others.”* [Participant 3, bipolar disorder] Another said, *“A I like the, I like what SITE 1’s got set up here. I just love it because I don’t have this back home. You know, I don’t have a big nice cafeteria and you know lots of buses and [laugh]. We don’t have all that.”* [Participant 14, bipolar disorder]

Perspectives of Older Blacks on Need for Specifically Tailored Services

To gain insight into whether Black participants perceived a need for mental health services specifically tailored to older Blacks, they were asked, “What types of services would you offer specifically for older Blacks living with mental illness?” There was a common expression that mental health services should be the same for Blacks and Whites. One participant said, *“They treat everybody right and with respect. I think that Blacks and Whites need the same.”* [Participant 16, schizoaffective disorder]

This sentiment was echoed by another participant [Participant 19, bipolar disorder],

“Um basically to me there’s no difference as to treating a Black or White. The same issue that you will find in, a Black issue are the same thing that are going along in a White issue...I can’t see that you would be treating Blacks because they’re Black for whatever Black have...which I don’t recognize from a White...It’s not a White or a Black issue. It’s something that happens to people.”

CHAPTER SIX: DISCUSSION

Despite the availability of community-based mental health programs, older adults who live SMI in the U.S. are less likely than younger adults to use outpatient mental health treatment and services. The first aim of the current study was to explore how community-residing Black and White older adults, who live with SMI, seek and engage in outpatient mental health treatment. Themes were identified related to factors associated with outpatient mental health treatment engagement, based on the six HBM constructs. Risk of homelessness emerged from the data as the greatest factor that influenced the decisions of Black and White older adults to seek and engage in outpatient mental health services. The second aim of the study was to examine their perspectives on the issues of accessibility, affordability, appropriateness, and availability of outpatient mental health services. Participants reported minimal to no issues. Overall, participants had positive feedback related to their current mental health services. The third aim of the study was to determine whether the perspectives of Blacks and Whites were different on the issues of accessibility, affordability, appropriateness, and availability of outpatient mental health services. No differences were found. In addition, none of the Blacks indicated a need for services specifically tailored to older Blacks who live with SMI.

An individual's acceptance or denial of a psychiatric diagnosis impacts his or her views about the need for treatment. All participants in the current study acknowledged having a mental disorder, had been actively engaged in treatment for at least three

months, and were aware of the consequences of underutilization of mental health treatment. They understood the importance of maintaining treatment compliance for the most favorable outcomes. Nonadherence to psychotropic medications is high among people with SMI and is associated with negative consequences (Gilmer et al., 2004; Lanouette, Folsom, Sciolla, & Jeste, 2009). Reinforcing the importance of taking prescribed medications and showing empathy and understanding to older adults living with SMI is important. Peer support (Solomon, 2004), and interventions that promote treatment engagement and retention are needed for community-residing older adults living with SMI.

The desire for socialization was not a surprising finding, particularly with past research indicating that people with SMI experience social isolation (Akamigbo & Wolinsky, 2007). Some participants did not have a support network and their communication and socialization was limited to staff and other clients at the mental health center, making relationships important. A few participants mentioned they did not like for providers to criticize them, and did not like how their providers talked to them sometimes. Providers should keep in mind that participants' trust factor into their decisions to continue treatment. Lack of trust and difficulty in relationships with providers has been found as a reason for disengagement from mental health services (Frank et al., 2016).

Because stigma is a known barrier for treatment (Corrigan, 2004; Rüscher et al., 2005), the participants' discussion about the public's negative portrayal of people with SMI and negative media messaging was not surprising. Mental health outreach and community education are tools that can help eradicate mental-illness related stigma.

Opportunities exist for media outlets and community organizations to leverage their resources to help spread awareness about mental health in the community.

Participants in the current study cited lack of knowledge about where to go for services as a reason they either delayed treatment or did not receive treatment in the past. In previous studies, researchers found that many older adults do not know about, or have limited knowledge of, available mental health services (Morrell et al., 2008; U.S. Department of Health and Human Services, 2001b; Yang & Jackson, 1998), and most of them have challenges identifying and navigating appropriate services in the complex mental health care system (Knight & Sayegh, 2011). The finding in the current study also aligns with data from the National Survey on Drug and Health, 2016, which indicates that over 1.3 million adults with SMI (18+ years old) reported an unmet need for mental health services. Approximately 386,000 individuals reported “Did not know where to go for services” as the reason for their unmet mental health need. As indicated above, oftentimes, individuals who are in need of mental health services simply do not know where to turn, an issue that must be addressed.

Many people are motivated to engage in mental health services only after experiencing a crisis. It is important, therefore, to educate community-residing older adults living with SMI about changes in their thinking, feeling, or behaviors that may be warning signs of an impending mental illness-related crisis. Most participants in the current study were referred to outpatient mental health services by a health care provider; some after hospitalization for suicide attempt or Baker Act. Teaching older adults about the prodromal signs of their mental disorder and associated symptoms,

may prompt them to engage in outpatient treatment prior to experiencing a psychotic episode or other crisis that leads to hospitalization or Baker Act.

Recovery in SMI is not the same for every individual. For some individuals, it means that their symptoms are diminished or are in complete remission, while for others, in spite of their disability, they are capable of living productive, fulfilling lives (Davidson, O'Connell, Tondora, Lawless, & Evans, 2005; Glynn, Cohen, Dixon, & Niv, 2006; President's New Freedom Commission on Mental Health, 2003). Hope is fundamental to recovery in SMI (President's New Freedom Commission on Mental Health, 2003). In its 2003 final report, titled "*Achieving the Promise: Transforming Mental Health Care in America*", the President's New Freedom Commission on Mental Health (2003) recommended a transformation of the mental health service delivery system to include consumer and family-centered mental health treatment and services that incorporates consumer choices about treatment options and providers, and mental health care that goes beyond symptom management and incorporates resilience building, teaching coping strategies, and facilitating recovery.

Most participants in the current study attend a day treatment program where they learn about their mental disorder, symptoms, and coping skills. Some of them also participate in individual and group counseling. Participants shared that they were more aware of how to recognize mental illness-related symptoms, and better able to cope with mental illness-related stigma. Some participants at Site 1 mentioned they had a Recovery Specialist who assisted them with various needs. One participant stated, "*And she (Recovery Specialist) keeps saying to me, '[Participant 9] don't let no one steal your joy. Not even you'. And once in a great while I'll go into her office all flustered you*

know upset or whatever and she'll say, "Okay, come on we're taking a walk".

[**Participant 9**, bipolar disorder] A different participant, [**Participant 13**, bipolar disorder, schizoaffective disorder], mentioned that her Recovery Specialist provided assistance, *"My Recovery Specialist is what they're called and he provides transportation to doctors appointments, to the pharmacy and things like that."* and the therapist teaches coping skills, *"The therapist works on recovery in coping skills strengthening your coping skills but also monitoring your attitude about your illness do you accept it immediate accept it, do you just manage with it?"* The positive outlook of participants in the current study related to appropriateness of outpatient mental health services may be related to recovery-oriented mental health services offered at these sites.

Successful mental health treatment engagement and retention requires high self-efficacy. Mental health providers can encourage self-efficacy in several different ways. They can provide positive feedback to participants when they share examples of demonstrating appropriate behavior. Some participants expressed a desire to work and volunteer. One expressed that people with SMI should be given a chance to prove themselves, another expressed fear of having to disclose to employer and take days off, and others had to discontinue work as a consequence of their mental illness. Wanting to work is a common desire among people with mental illness (Donovan, Regehr, & George, 2013; Palinkas et al., 2015). Providers can also help participants identify volunteer and employment opportunities, as appropriate. Supported employment programs designed to integrate people with SMI into the workplace are available (Khalema & Shankar, 2014) and may promote recovery (Whitfield & Baker, 2014).

Providers can also encourage self-efficacy by including participants in treatment planning and program development. Using a person-centered approach for mental health treatment planning may enhance treatment engagement (Grabowski, 2004; Tsemberis & Eisenberg, 2000).

For most participants, mental health treatment engagement was a conduit for them to receive secure housing and it was a major factor in their decision to engage in treatment. Housing was discussed more than the need for medications or any other services. Previous research indicates that homelessness among people with SMI is higher than the general public (Bhui, Shanahan, & Harding, 2006; Caton et al., 1994; Folsom et al., 2002; Lingam & Scott, 2002). It is known that homeless people (Gordon, Rosenheck, Zweig, & Harpaz-Rotem, 2012) and those with SMI (De Hert et al., 2011; Larsen, Attkisson, Hargreaves, & Nguyen, 1979; Parks et al., 2006) are at increased risk of morbidity and mortality. Engaging in mental health services to secure housing is possibly indicative of participants prioritizing their needs for safety and security for survival, over the needs for medication.

The fact that all participants in the current study had been engaged in outpatient mental health services for at least three months, and all but one had either Medicaid or some other form of health care insurance, more than likely contributed to the minimal to non-existent issues of accessibility, affordability, appropriateness, and availability of mental health services. Medicaid and disability insurance or SSI played a significant role in access of services for older adults who live with SMI. Participants in the current study were recruited from three different locations, two of which offered a comprehensive array of mental health services. There were no transportation issues;

two of the sites provided transportation and a few individuals owned vehicles. Transportation was even provided to appointments that were off-site. Black and White participants alike reported no current or previous issues related to access and availability of treatment. This finding is contradictory to previous research on issues of mental health care access for older adults (U.S. Department of Health and Human Services, 2001b).

Lack of or limited financial resources has been previously cited as a barrier to mental health services access (Snowden, 2001; Thompson-Sanders et al., 2004; U.S. Department of Health and Human Services, 2001b). Medicaid provided mental health and medical coverage for most participants in the current study which eliminated most issues related to affordability of services. Only two participants (one Black, one White) suggested that copayments for services were too high. This underscores the importance of Medicaid for mental health care access, and addressing mental health disparities.

A surprising finding was that none of the Black participants indicated a need for services specifically tailored to Blacks, although previous work has highlighted the importance and need for such programs to meet the special needs of racially and ethnically diverse older populations (Morrell et al., 2008; U.S. Department of Health and Human Services, 2001b). For Black participants in this study, the common need for mental health services among all people with SMI appeared to be more important than services specifically tailored to older Blacks. These findings may be suggestive of the consequences of mental illness-related stigma for participants are more prevalent than racial stigma.

Implications

Health belief model. Using the HBM as a theoretical framework for the current study allowed me to gain insight into what beliefs and attitudes older Black and White adults living with SMI had about outpatient mental health services. It provided me an opportunity to learn about their fears and some obstacles they encountered in seeking and engaging in outpatient mental health treatment. Further, the HBM helped me to identify factors that elevated older Black and White adults' confidence to go through with mental health treatment engagement, what was it specifically about the benefits that prompted them to decide to remain in treatment, what caused them to prematurely leave treatment in the past, and the depth and breadth of their support networks. This type of information will be useful for future programmatic development and interventions focused on addressing the concerns of community-residing older adults living with SMI related to outpatient mental health services. This information will also be helpful to service providers so that they may become aware of concerns this group has about the need for increased marketing of available mental health treatment and services in the community, community education about mental illness, and need for more individual counseling services and housing.

Practice. There are opportunities for providers to better promote available outpatient mental health services in the community. A need for the community to be educated about mental illness and available services was echoed. One strategy is for providers to partner with local community organizations (e.g., churches, sororities, fraternities, social clubs, law enforcement agencies) and to participate, on a regular basis, in community events to spread awareness about mental illness and available

services. By partnering with local organizations, providers might reach a larger audience, since people in the community are usually aware of individuals who are in need of mental health services, including those who are homebound and socially-isolated. In addition, there is an opportunity for providers to interface with media outlets to promote conscientious messaging aimed to reduce stigma associated with mental illness. One participant mentioned that police officers often visit the mental health treatment site to learn about how to identify people who might be experiencing a mental health crisis and other people should also be trained. Identifying strategies to increase mental health treatment engagement and retention are critical to improving health outcomes for this population.

Policy. Costs for outpatient community-based mental health treatment is significantly less than emergency room, psychiatric in-patient, and nursing home care. With the majority of older adults living with SMI remaining in the community (Cummings & Kropf, 2011; Lefley, 1987), many of them rely on family members for social support and assistance managing their illnesses and daily living activities (Lefley, 2009). The benefits of informal caregiving are enormous. Family support has enabled older persons with SMI to remain in the community rather than be placed in a nursing home (Meeks et al., 1990). Possibly linked to the care and support they receive from caregivers, persons with schizophrenia who live with informal caregivers are less likely to have been hospitalized during the previous year compared to those without informal caregivers (Tucker, Barker, & Gregoire, 1998). Not only are these results indicative of better health outcomes for the care recipients, but reduced hospitalizations and delayed and/or averted nursing home placement translate to significant public savings.

Caregivers need support, including training, respite, interventions to manage stress, and financial compensation to help them manage daily challenges of caring for older adults with SMI, who may also have a chronic physical illness. Funding for caregiver support also requires endorsement of policymakers.

Among other things, individuals with SMI are at increased risk of homelessness and substance abuse. Some participants mentioned they had a history of drug use, which is common among people with mental illness. Individuals who have mental illness are less likely to adhere to treatment regimens, specifically psychiatric medications, when they use illicit drugs (Lingam & Scott, 2002; Novick et al., 2010). Increased funding for public housing and programs that address co-occurring substance abuse and mental illness also require support and endorsement of policymakers.

For the past few decades, researchers have called attention to critical shortages of geropsychologists and geriatric mental health professionals (Corrigan, Swantek, Watson, & Kleinlein, 2003; Karlin & Duffy, 2004; Knight & Sayegh, 2011; President's New Freedom Commission on Mental Health, 2003; U.S. Department of Health and Human Services, 2001a; Yang & Jackson, 1998) who are needed to address the unmet needs of the expanding population of older adults with mental health issues. As the aging population is becoming more diverse, more clinically-trained racial and ethnic minority mental health professionals are needed to meet their needs. A participant in the current study said, *"they need more Black staff"* [**Participant 17**, schizophrenia], which is consistent with the findings of a previous study that investigated access challenges for diverse older adults (Solway, Estes, Goldberg, & Berry, 2010). The scarcity of clinically-trained Black mental health professionals makes it highly unlikely

that Blacks will find a provider of the same race (U.S. Department of Health and Human Services, 2001a). In a report to the National Institute of Health (NIH), the National Research Council (NRC) recommended that NIH should increase efforts to identify and support underrepresented minorities for careers in basic biomedical and clinical research (Novick et al., 2010) in an effort to address diversity in mental health research careers. Funding to increase the number of mental health professional, specifically those clinically-trained to treat older adults will also require support and endorsement of local, state and national policymakers.

Limitations

There were several limitations to the current study. A qualitative approach was used which limited generalizability of the study's findings. Generalizability of the findings were also reduced due to the use of purposive sampling. In contrast, using quantitative methodology would have allowed me to collect data from a larger number of people in a shorter period of time, using random sampling which increases the likelihood of the findings being generalizable. However, random sampling is time-consuming, and if the sample is too small, it can inhibit the generalizability of the findings which uses larger sample sizes and random sampling which increases the likelihood of the findings being generalizable (Carr, 1994). The sample size was small; however, the use of in-depth interviews allowed me to gather rich data about the participants' experiences with outpatient mental health services engagement from a traditionally hard to reach population (e.g., elderly, Blacks, SMI) with longstanding recruitment challenges for research.

As a dissertation project, there were constraints with time and resources which impacted recruitment. Another limitation was that because the participants were all actively engaged in mental health services, and the majority had minimal to no out-of-pocket costs, their expressed perceptions on issues of accessibility, affordability, and availability of treatment were possibly biased by their circumstances at the time of the interview. Data were self-reported and I was unable to verify whether the participants' depiction of their experiences was representative of what actually occurred. My interaction with the participants in the current study was limited; I only conducted one interview with them and did not track them over time. Thus, I was unable to determine what, if any, changes they would experience with outpatient mental health service engagement, and how changes in their personal situations might impact their perceptions on issues of accessibility, affordability, appropriateness, and availability of services.

Contributions

The current study makes a significant contribution to the literature. In assessing the importance of this research, one specific participant quote stood out that illustrates the impact of SMI on the lives of individuals, the desire to be understood and accepted; and the need for resources to assist them with the best health outcomes and quality of life, *“Um I think it’s a really cool idea what you’re doing...I think any getting any information out there about mental health is definitely a positive thing because people do need to know. You know that we’re not all crazy and we’re not trying to kill people and we just want to live our lives you know to the best of our abilities. When we need a little help we reach out.”* [Participant 11], bipolar disorder

The focus of the current study was to identify issues that impact a very narrow population, community-residing older Black and White adults living with SMI, who face many challenges and are at increased risk of poor health outcomes. Specifically, the subpopulation of older Blacks living with SMI has been understudied, recruitment and retention for this population has been challenging (Areán et al., 2003; Whitfield & Baker, 2014), and there is a lack of information concerning how to best treat mental illness in this population (U.S. Department of Health and Human Services, 2001b). I was able to capture the perspectives of this group about their experiences with outpatient mental health services and gather data about their recommendations for treatment. These insights could assist in programmatic development and interventions that facilitate the uptake of outpatient treatment engagement among community-residing older adults living with SMI.

Another significant contribution that the current study adds to the literature is that, Black participants had similar responses to White participants on issues related accessibility, affordability, appropriateness, and availability of outpatient mental health services, and when specifically asked, none of the Blacks expressed a need for culturally-tailored mental health services. A possibility exists that the provider sites provided culturally competent mental health care and the programs were developed to meet the unique needs of clients from different racial and ethnic backgrounds. Previous research has indicated that training providers and organizations how to effectively communicate with individuals from different racial and ethnic backgrounds, including social and cultural history and beliefs, may eliminate disparities and improve quality of care for racial and ethnic minorities (Nelson, 2002). The findings may also suggest that

cultural-tailoring for diverse populations (President's New Freedom Commission on Mental Health, 2003), should consider that certain personal characteristics such as having a SMI, being relatively impoverished, or bearing the stigma of mental illness may overshadow other personal characteristics such as race and ethnicity as factors to be considered in culturally competent treatment planning.

Future Directions

Future research should focus on examining the perspectives of mental health providers (e.g., clinicians, case managers) on issues of service delivery (counseling, housing, program marketing and outreach, client interaction). Information gleaned from mental health providers could assist with development of programs and interventions to increase outpatient mental health treatment engagement for community residing older adults living with SMI. In addition, research that examines perspectives of older caregivers on issues of accessibility, affordability, appropriateness and availability of outpatient mental health services for family members is needed. There may be challenges in the recruitment of older caregivers; however, their insights may yield dividends in explaining barriers to outpatient mental health treatment for their family members. In addition, information garnered from older family caregivers may be helpful in developing appropriate interventions that teach them coping strategies and provide supports to help them with caregiving challenges.

Conclusion

Throughout this dissertation, I identified and discussed how SMI impacts community-residing older adults, challenges they face, with attention to older Blacks, support needs, factors that influence their engagement in outpatient mental health

services, and issues on accessibility, affordability, appropriateness, and availability of mental health services. Addressing the needs of this vulnerable population may help improve mental and physical health, socialization, quality of life, and reduce disparities in mental health care.

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APPENDECIES

Appendix A: Copyright Approval

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Title of the article or chapter the portion is from	Chapter 3: The Health Belief Model
Editor of portion(s)	n/a
Author of portion(s)	Victoria L. Champion and Celette Sugg Skinner
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Publisher of New Work	University of South Florida
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Estimated size (pages)	150
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7/6/2017

Rosalyn Roker
School of Aging Studies
13301 Bruce B Downs Blvd.
MHC 1300
Tampa, FL 33612

RE: Full Board Approval for Initial Review

IRB#: Pro00029850

Title: Perspectives of older Blacks and Whites living with serious mental illness and their care partners about outpatient mental health services

Study Approval Period: 5/19/2017 to 5/19/2018

Dear Ms. Roker:

On 5/19/2017, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents contained within, including those outlined below.

Approved Item(s):

Protocol Document(s):

[IRB Study Protocol_ver1_062617.docx](#)

Consent/Assent Document(s)*:

[IRB Consent Form SB Adult Minimal Risk_062317.docx.pdf](#)

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent documents are valid until the consent document is amended and approved.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

A handwritten signature in black ink that reads "John A. Schinka, Ph.D." The signature is written in a cursive style with a large initial 'J'.

John Schinka, Ph.D., Chairperson
USF Institutional Review Board



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11/16/2017

Rosalyn Roker
School of Aging Studies
13301 Bruce B Downs Blvd
MHC 1300
Tampa, FL 33612

RE: Expedited Approval of Amendment

IRB#: Ame2_Pro00029850

Title: Perspectives of older Blacks and Whites living with serious mental illness about outpatient mental health services

Dear Ms. Roker:

On 11/15/2017, the Institutional Review Board (IRB) reviewed and **APPROVED** your Amendment. The submitted request and all documents contained within have been approved, including those outlined below, as described by the study team.

1. Change total number of participants to be recruited for this study from 24 to 16. The original study application included 24 total study participants, including 16 mental health service users and 8 care partner participants.
2. Remove care partner participants from this study. This study will only include 16 mental health service user participants. All mention of care partner removed from study description and protocol.

Rationale: During recruitment for study participants, this investigator learned from both potential service user participants and clinical staff at locations where recruitment is taking place that most mental health service users who meet the criteria for this study do not have a person who meets the criteria of the care partner participant described in this study. It was learned that most older adults who utilize outpatient mental health services do not have close family or friends who assist with overseeing their care but instead case managers (or similar staff) fill that role. This investigator share this information with her dissertation committee and it was agreed that for purposes of this study not to include the care partner participant. No care partner participants have been recruited thus far.

3. Change study title to remove "care partners".
4. Removed two Study Aims (4 and 5) because they were directly related to the care partner study participant.
5. Include additional recruitment site - Northside Mental Health Center Access House. A Letter of Support and a Recruitment Flyer for Northside Mental Health Center Access House are included with this amendment.

Rationale: To increase opportunities for recruiting mental health service user participants who meet the study criteria.

6. Informed consent modified to remove mention of care partner participant.
7. Demographic Information Sheet for Care partner removed.
8. Care-Partner Interview Guide removed.
9. Study protocol revised to incorporate all changes to study noted above.

Approved Item(s):

Protocol Document(s):

[IRB Study Protocol_V2_clean_103017.pdf](#)

Consent Document(s)*:

[IRB Consent Form SB Adult Minimal Risk ServiceUser version3_clean_103017.pdf](#)

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab on the main study's workspace. Please note, these consent/assent document(s) are valid until they are amended and approved.

The IRB does not require that subjects be reconsented.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with USF HRPP policies and procedures and as approved by the USF IRB. Any changes to the approved research must be submitted to the IRB for review and approval via an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,



John Schinka, Ph.D., Chairperson
USF Institutional Review Board



RESEARCH INTEGRITY AND COMPLIANCE
Institutional Review Boards, FWA No. 00001669
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX(813)974-7091

5/18/2018

Rosalyn Roker
School of Aging Studies
13301 Bruce B Downs Blvd
MHC 1300
Tampa, FL 33612

RE: **Full Board Approval for Continuing Review**

IRB#: CR1_Pro00029850

Title: Perspectives of older Blacks and Whites living with serious mental illness about outpatient mental health services

Study Approval Period: 5/19/2018 to 5/19/2019

Dear Ms. Roker:

On 5/18/2018, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents contained within, including those outlined below.

Approved Item(s):

Protocol Document(s):

[IRB Study Protocol V3 clean 121117.pdf](#)

The Board determined the over enrollment of study participants to be not serious, not continuing noncompliance.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with USF HRPP policies and procedures and as approved by the USF IRB. Any changes to the approved research must be submitted to the IRB for review and approval via an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

John Schinka, Ph.D., Chairperson
USF Institutional Review Board

Appendix C: Demographic Information Sheet - Service User

ID No. _____ Telephone No: _____

Age: _____ Sex: Female _____ Male _____

Race: Black _____ White _____

Education Level:

<input type="radio"/> Did not graduate high school	<input type="radio"/> Some college or trade school training	<input type="radio"/> Bachelor's degree
<input type="radio"/> High school graduate	<input type="radio"/> Associate's degree / completed trade school	<input type="radio"/> Graduate degree

Employment Status:

<input type="radio"/> Full-time	<input type="radio"/> Part-time	<input type="radio"/> Retired	<input type="radio"/> Unemployed
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Current Occupation: _____

Income Level:

<input type="radio"/> Less than \$10,000 year	<input type="radio"/> \$20,001 - \$30,000 year	<input type="radio"/> Over \$40,000 year
<input type="radio"/> \$10,001 - \$20,000 year	<input type="radio"/> \$30,001 - \$40,000 year	

Do you live alone or with someone else? _____ Who? _____

Do you have any physical health disorders (e.g., diabetes, cancer, asthma)? _____

If so, what conditions? _____

Are you currently receiving treatment for these conditions? _____

Last time you visited healthcare provider related to condition? _____

Do you understand the advice and/or treatment regimen(s) provided by the healthcare service provider to control or cure the condition(s)? _____

Are you in compliance with the treatment regimen(s)? _____

Have you ever been Baker-Acted? _____ If so, how many times? _____

How long have you received mental health services? _____

How many different places have you obtained mental health treatment from? _____

Location(s) of current mental health services: _____

What type of services are you currently receiving at this location (**study sites**)?

How long have you received services at this/these current location(s)? _____

Reason for services:

Appendix D: Mental Health Service User Interview Guide

Date: _____

Location: _____

Name of Interviewer: _____

Code Assigned to Interviewee: _____

Hello, my name is Rosalyn Roker and I am a doctoral candidate at the University of South Florida. Thank you for participating in this interview. The purpose of this study is to identify factors that may increase the likelihood of adults, ages 50-75 years old, with bipolar disorder, schizophrenia, or schizoaffective disorder to look for and engage in mental health services in the community. Additionally, I am interested in your views and concerns about outpatient mental health services in the community. The goal of this research is to obtain information that researchers and mental health service providers may use and will potentially improve access to and increase sustained engagement of outpatient mental health treatment among older adults in the community.

Your participation is voluntary and we can stop the interview at any time. Everything you say will be kept confidential with the exception of if you tell me that you want to hurt yourself or someone else. In this event, I will have to notify a staff member at [study site]. Information discussed is going to be analyzed in its entirety and individual names will not be used in any analysis of the discussion. Feel free to speak openly and honestly.

Our discussion today will take approximately **one hour**. In appreciation of your time you will receive a Wal-Mart gift card in the amount of \$5.00 at the end of our discussion.

PROCEDURES

Before we begin here are some important reminders:

- ◆ I am interested in all of your ideas, comments and suggestions.
- ◆ There are no right or wrong answers.
- ◆ All comments, both positive and negative, are welcome.
- ◆ I will be using an audio recorder and I will also take notes. This is to help me capture your important ideas. Again, all your comments are confidential and are used for research purposes only.
- ◆ I have a lot of ground to cover, so at times I may change the subject or move ahead. Please stop me if you want to add something.
- ◆ If you are unclear about a question, please let me know. I am here to ask questions and listen.

[Participant Consent]

Ask: Because what you have to say is so important to me and do not want to miss anything, I would like to tape record the interview. Do I have your permission to tape record the interview?

Do you have any questions before we get started? [Address any concerns or questions]

[If permission is granted to record the interview: begin recording]:

State: Today's Date and Interview Number

For our records, please state if it is OK to tape record the interview.

Thank you. I am going to take some notes as we talk as well, so I don't forget anything important. Is that OK with you?

Lets begin: I would like to learn about why you decided to seek professional assistance for your mental illness.

To address research aim (1): What factors influence the decision-making of community-residing older adults to seek and engage in outpatient mental health treatment?

- 1) *Tell me about your current diagnosis.*
- 2) *What brought you to get/receive treatment and services at [study sites]?*
 - a. *Probe: Did you decide on your own or was it suggested by someone else? If by someone else, who?*
 - b. *Probe: Tell me about the mental health treatment and services you receive from [study sites].*
 - c. *Probe: What are the benefits/what are the downsides? Why do you continue your treatment?*
- 3) *How do you cope/deal with mental illness?*
 - a. *Probe: Do you feel that you can cope with your mental illness on your own without mental health treatment?*
 - b. *Probe: Are there places you go in your community to get help for a mental illness other than professional mental health treatment? (e.g., church)*
- 4) *Describe a time when you decided not to use mental health services.*
 - a. *Probe: Did you not use them because you feared someone would find out that you had a mental illness?*
 - b. *Probe: Did you not use mental health services because you were embarrassed?*

- 5) Has a different health issue affected your access to mental health services in the past? If so, what condition?
- 6) Tell me about who handles your personal affairs (e.g., arranging your doctor visits, paying bills, shopping)
- 7) Tell me about any family members/friends that you can count on for assistance, if needed (excluding assisted living, boarding homes, etc.)? If so, who?
- 8) Would your family members support you seeking mental health treatment?

Now I would like to learn about your views of mental health services in the community.

To address research aim (2): What are the perspectives of community-residing older adults living with serious mental illness regarding accessibility, affordability, availability, and appropriateness of outpatient mental health services?

- 9) Aside from **[study sites]**, what mental health services do you know about?
 - a. Probe: Are these available to you?
 - b. Probe: What would you change about these other services that you mentioned?
 - i. Probe: Would you change the time? Location?
- 10) If applicable, describe a time when you felt you needed treatment for your mental health condition but you were not able to obtain the services.
 - a. Why were you unable to obtain services?
 - b. How long were you without services?
 - c. What did you do?
- 11) Do you feel that treatment for your mental health condition is affordable?
- 12) If applicable, tell me about a time when you stopped going to counseling, or other recommended treatment related to your mental health condition.
 - a. Why did you stop?
 - b. What prompted you to start your treatment again?
 - c. Growing up, what did you hear or learn about using mental health treatment and services?
 - d. If you attend church or a religious organization, what are their beliefs about mental health services and treatment?
 - e. How does your community [or how do Blacks (if participant is Black)] view mental health services and treatment?
- 13) How do you feel about the treatment and services you receive at **[study sites]**?
 - a. Probe: Are they in line with your personal beliefs and values? How so?

b. Probe: Are your personal beliefs respected?

14) What other services would you like to see offered to people who are living with mental illness?

15) **[Ask only to Blacks]** What types of services would you offer specifically for older Blacks living with mental illness?