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Lois Jihae Son
Exploring the Lives of
African Americans Living
With Mental Illness

ABSTRACT

This qualitative research study sought to explore the effect mental illness has had on the lives of African Americans, the language these individuals employ to describe their experiences, and how African Americans' experiences with racial discrimination have informed how they view their psychiatric diagnoses. The study sample included seven individuals who (a) were English-speaking (b) were males or females 18 years of age and over (c) self-identified as African American (d) carried a primary diagnosis of schizophrenia or schizophrenia-spectrum disorders or any major affective disorder (e) and were in current stable mental health. Interviews with study participants were conducted in person on an individual basis and lasted anywhere between 20 to 60 minutes. The major themes which emerged from these interviews include the following: (1) mental illness as labeling and stigmatizing; (2) issue of normalcy; (3) mental illness occurring within the context of other life stressors; (4) acceptance of diagnosis; (5) support from others; (6) experience of racial discrimination; and (7) differences in experiences between whites and blacks.

EXPLORING THE LIVES OF AFRICAN AMERICANS
LIVING WITH MENTAL ILLNESS

A project based upon an investigation at ALSO-
Cornerstone, New Haven, Connecticut, submitted in
partial fulfillment of the requirement for the degree
of Master of Social Work.

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2009

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I am most grateful to the study participants, who were willing to share their experiences with me. I feel very privileged to have had the opportunity to meet, listen to, and learn from these individuals, and am humbled by their resilience, strength, and sense of hope. I will carry their stories with me, as I continue to work and gain more knowledge within the social work field.

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INTRODUCTION

The purpose of this qualitative research study was to capture as well as examine the life experiences of African Americans diagnosed with mental illness. The research questions explored included the following:

1. How has living with a mental illness affected the lives of African American individuals?
2. What kinds of language do these individuals use to describe their experience of living with a psychiatric diagnosis?
3. How has individuals' experience of racism/discrimination informed how they view their mental illness?

Throughout history, countless individuals have conceptualized as well as written about the notion of stigma and its role within different cultures and groups within society. Goffman (1963) writes about how stigma arises when individuals possess an “undesired differentness” (p. 5) from what is seen as appropriate and natural in society. This creation of the “other” or the “deviant” is something that has occurred repeatedly throughout various contexts within society and throughout different time periods.

The scope of research on stigma is one which is extensive as well as multilayered and researchers have and continue to work on dissecting the complex qualities of this concept. Considering this, this research project strove to examine a small piece of the larger puzzle, by focusing on the concepts of mental illness stigma, stigma of race, and the intersection of these two.

This study is relevant to the field of social work, and specifically to mental health providers in the sense that it provides implications for working with African American

populations. This study points to the importance for all of us to deeply consider the intersection of race (and implicitly class, gender, and other aspects of social identity) with mental health when working with clients of color. Along with this, this study encourages us to explore our own internal racisms and to examine in what ways our own biases affect interactions with clients.

CHAPTER II

LITERATURE REVIEW

Throughout the history of the United States, African Americans have experienced firsthand the pervasiveness of racism and discrimination, in both overt as well as passive forms. Undoubtedly, this experience has affected these individuals' experience of the world, as well as their personal identities. Related to this, those living with psychiatric diagnoses have had to cope with the stigma and negative stereotypes that accompany mental illnesses. Considering these two stigmatized aspects of identity, the focus of this literature review is to delineate some of the available research on the conceptualizations of stigma, research specifically on the stigma of race as well as mental illness, and research on the experiences of African American individuals living with mental illness. Moreover, this literature review concludes with an examination of the resiliency present within the African American community.

Stigma

Erving Goffman (1963) writes in his seminal work entitled *Stigma: Notes on the Management of Spoiled Identity*,

The Greeks...originated the term stigma to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier. The signs were cut or burnt into the body and advertised that the bearer was...a blemished person, ritually polluted, to be avoided, especially in public places (p.1).

In applying this original concept of stigma to modern times, Goffman (1963) describes how society establishes means of categorizing individuals, and ascribes certain traits and characteristics seen as desired and acceptable for individuals belonging to these categories. Considering this, stigma arises when individuals possess an "undesired

differentness” (p. 5) from what is seen as normal or natural in society (Goffman, 1963). And as Hinshaw (2007) explains, cultural tenets surrounding normalcy within a society are very much embedded into everyday life, and are so pervasive that individuals may not readily think to even question why certain traits and characteristics are stigmatized.

Consequently, Goffman (1963) writes, “We construct a stigma-theory, an ideology to explain his inferiority and account for the danger he represents We use specific stigma terms such as cripple, bastard, moron in our daily discourse as a source of metaphor and imagery” (p. 5). And in studying the situations of these socially unaccepted individuals within society, Goffman (1963) makes a distinction between discredited versus discreditable stigma. In regards to the former, Goffman (1963) describes discredited stigma as being associated with physical appearances (i.e., any physical deformities or other observable disabilities or handicaps) which forces discredited individuals to deal with stigma in essentially all of their social interactions. This notion of stigma is further explicated by Hinshaw (2007) who writes, “. . . harsh stigmatization can apply to attributes that are completely outside of one’s personal control. The clearest example pertains to ethnicity and skin color, uncontrollable traits that have nonetheless evoked harsh prejudice and stigma throughout history.” (p. 153). Besides this notion of discredited stigma, Goffman describes discreditable stigma as “blemishes” (p. 4) on an individual’s character, which could be hidden from others (i.e., these marks on one’s character that might be related to one’s drug addictions, criminal history, sexual orientation, etc). Considering this definition, in some cases, mental illness may be an example of a discreditable stigma.

Corrigan and Watson (2002) also offer a definition of stigma, and according to these researchers, stigma is composed of three factors: stereotype, prejudice, and discrimination. According to Corrigan and Watson (2002), stereotypes can be defined as “knowledge structures” learned by most individuals in a social group, and are a “means of categorizing information about social groups” (p. 37). Although an individual may have knowledge about stereotypes, it should not be implied that he or she subscribes to them. On the other hand, those people who are prejudiced may agree with negative stereotypes, and consequently form negative emotions as well as attitudes towards the group that is being stigmatized. According to Corrigan and Watson (2002), prejudice is essentially a cognitive as well as affective response which leads to discrimination, “the behavioral reaction” (p. 37).

Considering what has been discussed thus far, Yang, Kleinman, Link, Phelan, Lee, and Good (2007) offer a different interpretation of the concept of stigma. These authors argue that “Stigma takes on its character of danger by threatening interpersonal engagements and what is most at stake” (p. 1532). And since stigma is a social as well as subjective process, they suggest that understanding stigma in a local world requires that the perspectives from multiple participants (i.e., the stigmatized and the non-stigmatized) must occur. Interestingly, Yang et al. (2007) note that “Eliciting perspectives from stakeholders in differing social positions regarding how stigma threatens the labeled individual’s moral standing may be especially suited to investigate how multiple devalued statuses . . . interact to exclude individuals from a local world’s meaningful everyday activities” (p. 1534).

Considering some of the conceptualizations of stigma that have been offered by various researchers, a relevant aspect of this concept to be examined is the different kinds of responses that marginalized individuals have to the stigma they experience. As Miller and Kaiser (2001) interestingly note, “Despite differences among different types of stigma, what all stigmatized people have in common is that they have a devalued social identity that exposes them to stressors they would otherwise not experience” (p. 89). And considering this, all stigmatized individuals react in some way to these stressors. Bearing this in mind, Miller and Kaiser (2001) focus on revealing how research developments on general stress and coping can influence thoughts about how to manage stress associated with stigma, as well as how adaptive these responses are (Miller & Kaiser, 2001). In doing so, these researchers find that despite similarities between general stress and coping along with coping with stigma-related stress, different stressors stir up different kinds of reactions in individuals. And stigmatized individuals are faced with other kinds of stressors than individuals who are not stigmatized (Miller & Kaiser 2001). Moreover, these researchers find that responses to stigma-related stress can be involuntary or voluntary (or a combination of both), and can range from emotional, physiological, behavioral, to cognitive responses.

Along these same lines, Hinshaw (2007) believes that the internalized responses stigmatized individuals have to stigma lie on a continuum. As he points out, researchers have made efforts to understand some of “the reasons some stigmatized individuals respond with righteous anger, some ignore the prejudice and stigmatization and proceed with their lives, and still others show the classic pattern of internalization of negative messages with resultant damage to self-image” (Hinshaw, 2007, p. 148). In considering

some of the responses stigmatized individuals may have to stigma, Corrigan and Watson (2002) also discuss the range of possible internalized responses to stigma, by placing righteous anger on one end of the spectrum, while placing low self-esteem along with low self-efficacy on the other. And as Corrigan and Watson (2002) describe the concept of righteous anger, “. . . rather than beating one’s self with these negative attitudes, people rebound and response with strength and indignation” (p. 39). According to these researchers, the effect which stigma has on the psyches of stigmatized individuals is influenced by a number of factors, including the collective representation of the stigma in a society, whether an individual views the stigma as justifiable, and the individual’s identification with the group of people possessing the stigma (Corrigan & Watson, 2002).

Interestingly, Goffman (1963) adds a different dimension to this discussion by writing about how individuals may cope with the stigma placed on them (considering how they have internalized the stigma) out in the external world. In doing so, Goffman elucidates the differences between the situations of individuals dealing with discredited as opposed to those dealing with discreditable stigmas. In the case of discreditable individuals, the possibility of “passing” arises, as well as “information control”. He explains that the dilemmas faced by these individuals in dealing with their stigma include, “to display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where” (p. 42). However, in the case of discredited individuals, because their stigmas are apparent and remain out in the open these individuals must deal with “managing tension” (p. 43) in their social interactions.

Stigma and mental illness

In shifting gears and examining a specific stigmatizing aspect of identity, the stigma associated with mental illness is something that can be traced back in time, throughout different points in human history. For instance, Simon (1992) explains that mental illness carried a sizeable amount of shame in ancient Greece. Individuals with chronic mental illness were often shunned or hidden away, and in rare cases, put to death. According to Simon (1992), Greek tragedies were filled with depictions of madness. He writes: “The notion of pollution, that the madman is polluted and also can pollute . . . is interwoven with the sense of shame” (p. 31). As Simon (1992) notes, nevertheless there were attempts within Greek society to normalize mental illness (along with illnesses in general, which carried a certain degree of stigma), and Greek medicine played a large role in this.

Jumping ahead in time, Mora (1992) explains that during the middle ages, individuals with mental illnesses were not hidden away, and instead, “. . . were to be exposed as examples of the frailty of man constantly at the mercy of the battle between the temptation of evil and the atonement achieved through grace” (p. 42). Moreover, there was a belief that “behavioral abnormalities were part of the divine plan for mankind” (Mora, 1992, p. 44). As a result of this, stigma was not common in medieval attitudes towards the mentally ill. However, this view diminished with the onset of the Renaissance, as the theocentric perspective of Christianity lost its momentum with the disintegration of the official Church and the ensuing religious wars (Mora, 1992). As these occurred, Mora (1992) explains that there was a search for a scapegoat. During this witch hunt, mental illness became associated with witchcraft and magic, and women who

were persecuted were marked as possessing mental illnesses. Interestingly, as Hinshaw (2007) notes, “. . . it is likely that most of those persecuted in witch hunts and with trials were not initially mentally disordered, but the extremes of torture used to extract confessions may have led . . . to hallucinations and delusions” (p. 62).

Moving forward, Brizendine (1992) writes about the history of the Devon Asylum, to outline the shifts in the concepts of mental illness as well as treatment during the early 19th century. In doing so, Brizendine (1992) explains that with the further development of medical practices and knowledge in Europe, “moral treatment” and “non-restraint” (p. 60) were promoted in dealing with individuals with mental illness. Brizendine (1992) continues on to note that the goal of this new movement was restoring the individuals’ self-control, since there was a belief that mental illness was curable. Despite the more humane approach to treatment as well as care for the mentally ill, asylums were often overcrowded, due to lack of funding.

In looking at more recent times in human history, Hinshaw (2007) writes about conceptions of mental illness during the last one hundred years, and specifically about the stigmatization which these illnesses continued to carry within society. In doing so, Hinshaw (2007) spends some time writing about the eugenics movement, which espoused the belief that “humanity was becoming infested with genetically inferior ‘stock’” (p. 76), including individuals with mental illnesses and mental retardation. With the support of influential people such as scientists, the first state sterilization act (for individuals with mental illnesses and mental retardation, along with other individuals viewed as being genetically inferior) was passed in Indiana, in 1907. And as noted by Hinshaw, by the year 1940, thirty states had passed sterilization laws.

Considering this long history of stigmatization, it is interesting to examine the effects these deep seated notions of mental illness have had, on the present day experiences of individuals living with them. In examining current empirical studies on the topic, it is evident that a continuum of experiences for individuals living with mental illness does exist. However, examining the available research, it appears as though an underlying commonality in the experiences of individuals is that psychiatric diagnoses do have an effect on their personal identity as well as on how they view and relate to the people and world around them.

For instance, the research completed by Link, Cullen, Struening, and Shrout (1989) sought to challenge the then prevailing labeling theory posited by Scheff (1966). Scheff (1966) initially posited that once an individual is labeled according to societal conceptualization of mental illness, they are subjected to responses from other individuals which reinforce these cultural beliefs. Labeled individuals are then constrained into the role of a mentally ill person, and once they internalize societal conceptualizations as well as mold their identity around this role, chronic mental illness becomes the consequence.

Link et al. (1989) instead proposed a modified labeling theory, which emphasized the importance of early socialization in shaping individuals' internal negative beliefs about "mental patients" (p. 402). Considering these internalized stereotypes of the mentally ill, the researchers noted that when an individual becomes labeled with a psychiatric diagnosis, he or she utilizes strategies such as secrecy, withdrawal, or educating others, as means of coping with anticipated devaluation and discrimination.

Along these same lines, Wahl (1999) conducted a research study that involved a nationwide survey (of 1,301 mental health consumers) as well as 100 follow up telephone

interviews. Using this data, it was found that individuals experienced mental illness stigma from a number of sources, including families, coworkers, mental health providers, as well as others (Wahl, 1999). Wahl also found that a majority of study participants tended to hide their illnesses and were concerned about the discrimination they would possibly face due to their diagnoses.

On the other hand, Camp, Finlay, and Lyons, (2002) studied the “ways in which understandings of stigma, mental health problems, and self-concept were related in a sample of ten British women with chronic mental health problems” (p. 825). In doing so, these researchers strove to challenge the idea that stigma of mental illness negatively as well as automatically impacts self-esteem. They also found that, although individuals were cognizant of society’s negative perceptions of mental illness and the effects this had on their lives, they refused to apply these labels to themselves, and instead articulated positive conceptions of themselves (the women did not deny their mental illnesses, but were critical of the labels and stereotypes attached to disorders).

In terms of mental illness stigma on identity, Williams (2008) emphasized the importance of looking at the social experiences associated with obtaining a psychiatric diagnosis. In specifically looking into the experiences of individuals diagnosed with schizophrenia, Williams (2008) sought to challenge the presumption that diagnosis was the “precursor to taking on a ‘schizophrenic’ or ‘chronic case’ identity” (p. 248). According to Williams (2008), shifts in one’s identity post-diagnosis is affected by the social context in which they live, and the experiences they have had within it. When considering the stigma associated with psychiatric diagnoses, Williams (2008) suggests,

. . . individuals are capable of negotiating stigmatized identities by making decisions about the extent to which they will identify psychologically and behaviorally with the social group, and making decisions about the extent to which they will reinforce the stigma by internalizing negative stigmatizing ideologies. (p. 250-251)

When combining these two decisions described by Williams (2008), at least four post-diagnosis identities become possible for individuals, which include the “engulfed” identity, “resistant” identity, “detached” identity, as well as the “empowered” identity.

Along the lines of developing a post-diagnosis identity, Corrigan and Matthews (2003) offer a perspective on the costs and benefits which individuals with mental illness possessed, in publicly disclosing their disorders. For instance, Corrigan and Matthews (2003) write about the parallels between coming out in the gay and lesbian community and the experience of mental illness stigma. In doing so, Corrigan and Matthews (2003) write about various models that outlined the stages for successfully coming out (i.e., identity confusion and comparison, identity acceptance and immersion, as well as identity synthesis).

Racism and the Stigma of Race

Besides the stigma of mental illness, history has also shown that race is an aspect of identity which, for some, has and continues to remain deeply stigmatized. As Miller and Garran (2008) explain “. . . the concept of race, both scientific and cultural, has been used ever since the inception of the United States to justify severe exploitation and terrible economic and social inequalities” (p. 17). Considering this explanation, African Americans constitute a racial group which has been deeply marginalized within society, and has been subject to various levels of racism. And as Tatum (1997) also observes, “. . . racism, like other forms of oppression, is not only a personal ideology based on racial

prejudice, but a system involving cultural messages and institutional policies and practices as well as the beliefs and actions of individuals” (p. 7). One example of this is the institution of slavery which denied African Americans any basic human rights. And as Miller and Garran (2008) note, even after slavery was abolished in the United States following the Civil War, African Americans were still considered second-class citizens, and still experienced racism at all levels of society. This legacy of discrimination has undoubtedly left this group with unequal access to education, stable employment, housing, as well as other resources that would improve their quality of life (Williams & Williams-Morris, 2000). Considering this, various researchers (Clark, Anderson, Clark, & Williams, 1999,; Klonoff, Landrine, & Ullman, 1999; and Williams & Williams-Morris, 2000) have studied the effects racism has had on the overall wellbeing and health of African Americans.

Williams and Williams-Morris (2000) write about the effect racism has on the ego identity of African Americans, due to the negative as well as pervasive depictions of this racial group within society (i.e., through stereotypes). As these researchers note, “Categorical beliefs about the biological and/or cultural inferiority of some racial groups can attack the self-worth of at least some members of stigmatized racial groups and undermine the importance of their very existence” (Williams & Williams-Morris, 2000, p. 255). Along these same lines, Clark, Anderson, Clark, & Williams (1999) studied the biopsychosocial effects of racism on African Americans, and in doing so, proposed the idea that perception of an external event or situation as racist can result in both psychological as well as physiological stress. This stress of course is influenced by a complex combination of individuals’ socio-demographic factors, coping skills, as well as

psychological, physical, and behavioral factors. Over a period of time, these responses to stress have an affect on individual health (Clark et. al (1999)).

Moreover, Klonoff, Landrine, and Ullman (1999) sought to investigate the contributions which racial discrimination, generic stressors (i.e., getting fired from a job, being unemployed) and social status (i.e. education level, income) each had on the psychiatric symptoms of blacks. In doing so, these researchers found that racial discrimination was the strongest predictor of psychiatric symptoms. Considering this, Klonoff et al. (1999) point to the implications these results have for examining both the prevalence as well as occurrences of psychiatric symptoms and disorders.

The Intersection of Identities: Race and Mental Illness

In bridging the gap between racial discrimination and mental illness stigma, it is important to consider the experiences of individuals who carry not just one, but both of these marginalized aspects of identity, and how this compounded stigma affects them on a daily basis. As Miller and Garran (2008) emphasize, “. . . race is a significant dimension of social identity, but racism . . . does not stand alone. Nobody is defined solely by race. This dimension of social identity interacts with gender, social class, sexual orientation, and other axes of identity” (p. 135). Considering this, a number of researchers have written about the help-seeking struggles of African Americans living with mental illnesses (Cruz, Pincus, Harman, Reynolds, and Post, 2008; Dana, 2002; Gary, 2005; Kendrick, Anderson, and Moore, 2007; and Matthews, Corrigan, Smith, and Aranda, 2006; Schnittker, Freese, Powell, 2000).

Gary (2005) proposed the concept of “Double Stigma,” and defined it as “. . . discrimination based on minority group status and the burden of having to live with a

mental disorder” (p. 981). In further explicating this concept of “Double Stigma,” Gary (2005) also noted that ethnic minorities who live with, or possess histories of mental illnesses experience different access to as well as outcomes to treatment, as opposed to those who are Caucasian. According to Gary (2005), “Double Stigma,” along with public stigma, self-stigma, and the lack of cultural competence of mental health providers, all contributed to delayed or “aborted” treatment by ethnic minorities, in their attempt to preserve their self-esteem, self-efficacy, and well-being (p. 983).

Along these same lines, Kendrick, Anderson, and Moore (2007) focused their study on 28 African American men between the ages of 18 and 25, in an attempt to identify their perceptions as well as experiences of depression. Using a mix of both individual interviews as well as group discussions, they discovered that the chronic misdiagnosis, undiagnosed depression, and inappropriate treatment given to African Americans may be attributable to the differences in how they report their symptoms. Kendrick et al. (2007) also found that these men were not always upfront about reporting their symptoms due to their perceptions that therapists depended more on research about African Americans, rather than focusing on their individual stories and experiences. Moreover, these researchers noted that in attributing social stressors to their experience of depression, study participants spoke about feeling as though they were continually targeted and racially profiled by individuals in the community, especially by police officers. This finding by Kendrick et al. (2007) is supported by the work of Dana (2002), who reports, “. . . the mental health establishment has been slow to recognize the magnitude of cultural/racial differences in consciousness, emotionality, spirituality, self, symptomatology, problems in living, and a history of racism” (p. 14). Because of this,

mental health services for African Americans remain deficient, as well as incomplete and biased in favor of European Americans (Dana, 2002).

In considering other obstacles to mental health treatment for African Americans, Cruz, Pincus, Harman, Reynolds, and Post (2008) conducted a qualitative study with a group of low-income, depressed African Americans engaged in psychotherapy, and found that shame as well as denial of mental illness, intertwined with public stigma, greatly contributed to the barrier to help-seeking for African Americans. Matthews, Corrigan, Smith, and Aranda (2006) also utilized qualitative research methods to explore African Americans' thoughts on mental illness as well as related treatment. Among their many findings, these researchers found that some barriers for treatment included mistrust of the mental health system, lack of awareness, cultural beliefs and attitudes regarding mental illness, and costs of treatment.

Resiliency within the African American culture

Considering what has thus been presented about the struggles faced by individuals dually stigmatized by both their mental health status as well as racial identity, it seems worthwhile to conclude this literature review with some focus on the factors which promote resiliency within the African American culture.

Utsey, Chae, Brown, and Kelly (2002) examined the effect that ethnic group membership had on ethnic identity, race-related stress, as well as on quality of life, and found that African American participants reported experiencing higher levels of race-related stress than other ethnic groups (Latino and Asian Americans). Despite this, these researchers found that this group had a greater identification with their ethnic identity, as well as higher scores on a scale which measures psychological wellbeing. According to

Utsey et al. (2002), these results speak to the strengths within the African American group, and their ability to adaptively cope with race related stressors. This sentiment is echoed by Utsey, Giesbrecht, Hook, and Stanard (2008), who note that with supportive familial and cultural resources, African Americans are able to develop positive skills as well as character traits such as higher self-esteem to help them face challenges.

Related to this, Fischer and Shaw (1999) found that the relationship between perceptions of racist events and poorer mental health was lessened for African Americans who received more racial socialization messages as well as preparation from their families to cope with racism related struggles. Brown (2008) as well as Utsey, Giesbrecht, Hook, and Stanard (2008) agreed with this finding, by emphasizing the importance of family support in the development of a positive racial identity: “African American families have developed unique strengths and characteristics as an adaptive mechanism in the face of a history of race-related injustices” (Utsey et al., 2008, p. 59). Moreover, Utsey et al. (2008) goes on to explain, “Transmitting the values, norms, morals, and beliefs needed to survive in a racist environment begins with the family, and racial identity development and affirmation continues in the context of sociocultural organizations (e.g., the Black church)” (p. 59). In reinforcing this finding, Brown (2008) also discovered that African Americans who perceive that they have social support out in the community (e.g., through church networks) have a great sense of self-resiliency.

In also assessing the strengths present within the African American community, Boyd-Franklin (2003) further explicates the role of church as well as spirituality, as noted by Brown (2008) as well as Utsey et al. (2008), in encouraging as well as empowering African Americans. In doing so, Boyd-Franklin (2003) writes about the role of the Black

church historically, and about how in times of overt segregation in the United States the church was a place of refuge for African Americans. As Boyd-Franklin (2003) notes, “They were and often still are, one of the few places where African American men and women could feel that they were respected for their own talents and abilities” (p. 128). And as noted, African Americans continue to use the church as a coping mechanism to deal with the stressors related to racism and discrimination.

Summary

I began this literature review with an exploration of different conceptualizations of stigma, as well as an examination of the research available on both the stigma of race and the stigma of mental illness (along with the intersection of these two aspects of identity). I concluded this review of literature with some discussion of the factors which promote resiliency and ability to cope with stigma-related stress within the African American community. This literature also provided the framework to develop the research questions which were explored:

1. How has living with a mental illness affected the lives of African American individuals?
2. What kinds of language do these individuals use to describe their experience of living with a psychiatric diagnosis?
3. How has individuals’ experience of racism/discrimination informed how they view their mental illness?

In the next chapter, I will outline the design of the research study, as well as the specific methodology which was implemented.

CHAPTER III

METHODOLOGY

The purpose of this qualitative research study was to capture as well as examine the life experiences of African Americans diagnosed with mental illness. The research questions explored included the following:

4. How has living with a mental illness affected the lives of African American individuals?
5. What kinds of language do these individuals use to describe their experience of living with a psychiatric diagnosis?
6. How has individuals' experience of racism/discrimination informed how they view their mental illness?

For this research project, flexible methodology was utilized, primarily due to the fact that “unstructured data are used in order to capture the phenomena of interest in the words or actions of those who embody or live them and to capture them in context in terms that are as ‘experience-near’ as possible” (Anastas, 1999, p. 57). When rephrased to reflect the purpose of this study, flexible methodology was utilized because,

To truly understand and appreciate what stigma is and how it affects people with mental illnesses, we have to hear from the ones who face that stigma on a daily basis. They can best inform us...what stigma is, what it does, and how it is conveyed. (Wahl, 1999, p. 468)

This type of methodology allowed for explorations into the nuances and quiet subtleties present in the lives of African American individuals living with mental illness.

Sample

The inclusion criteria for participants in this study included: (a) being English-speaking (b) males and females 18 years of age and over (c) self-identifying as African American (d) carrying a primary diagnosis of schizophrenia or schizophrenia-spectrum disorders or any major affective disorder (that has been diagnosed by a licensed mental health provider) (e) and in current stable mental health (i.e., overtly psychotic, not actively homicidal, suicidal, etc).

The researcher recruited study participants through ALSO-Cornerstone (a nonprofit agency providing services to individuals affected by mental illness and/or substance abuse) in New Haven, CT. This organization signed a letter of permission allowing research to take place in its agency (see Appendix F). Initially, recruitment flyers describing the study were sent to various ALSO-Cornerstone locations throughout New Haven (ALSO-Cornerstone Outpatient Clinic, Dwight House, Park Street Inn, Park Street Residence, Norton Court/Family Support Collaborative, Pendleton House, Ruoppolo Manor, Wolfe Support Services, and the West Village Support Services), with the intent that potential participants would self-select themselves. However, after this method did not prove to be effective in recruiting potential participants, the researcher attended a weekly staff meeting for all ALSO-Cornerstone program directors, and offered a brief presentation on the thesis research project being pursued. Program directors interested in involving their clients in the study offered this researcher their business cards, and each of these individuals was consequently contacted a few days following the meeting.

The researcher was given permission by interested program directors to visit Dwight House, Park Street Inn, Norton Court, and Wolfe Support Services. Prior to these visits, program directors of each of these ALSO-Cornerstone locations screened potential research participants for this researcher, and a mutually agreed upon time was set for this researcher to come and conduct interviews on-site.

Data Collection

The application for approval to conduct this study was received by the Smith College Human Subjects Review Committee in December 2008. The Human Subjects Review application approved delineates this study's compliance as well as adherence to federal guidelines regarding the confidentiality of study participants. All recorded audio files were kept in a secure location, along with signed Informed Consent forms, by the researcher. Both of these audio files and Informed Consent forms were connected through a numerical code. No personal identifying information was used to mark the recorded audio files, and after securely keeping these files for three years, they will be destroyed in compliance with federal guidelines.

Interviews with study participants were conducted in person on an individual basis, digitally recorded, and transcribed by the researcher. Each interview lasted anywhere between twenty minutes to sixty minutes, and took place at a mutually agreed upon time and date, at an ALSO-Cornerstone location. Research participants were offered a \$5 Dunkin Donuts gift card in exchange for their time, and were informed that if they decided to withdraw from the study at any point, they would still be compensated, without any retribution. At the start of the interview, participants were asked to read as well as sign two Informed Consent forms (one for the participant's records, and one for

the researcher's records). Participants were also asked to fill out a brief demographic questionnaire (i.e. questions about monthly income, gender, and psychiatric diagnosis received). An Interview Guide contained semi-structured, open-ended questions designed to focus on eliciting information on the topic of this study. Although the Interview Guide served as a script, the researcher remained flexible during interviews, and was receptive to the organic ways in which new subject matter may arise as participants provided narrations of their lives.

Data Analysis

The transcribed data from the interviews were analyzed both thematically as well as linguistically. After each interview was transcribed, it was carefully read and data specific to the research questions were found. Transcripts were then reread, and notes were made on other themes which emerged, along with the kinds of language that were used to describe these budding themes. Through multiple drafts of coding of these interviews, major themes were identified, and the corresponding parts of the transcribed text were grouped under these themes. In determining the most appropriate labels to name these themes, quotations from the text that best embodied the theme were selected and utilized.

This study does have several limitations. Firstly, the generalization of the data may be restricted by the small sample size, as well as by the small geographic area from which research participants were recruited. Moreover, generalization of the data may be limited by the very specific characteristics of the sample of research participants; individuals interviewed primarily belonged to a low socioeconomic status, identified as

either black or African American, and were actively involved in receiving mental health treatment.

CHAPTER IV

FINDINGS

This qualitative research study explored the nuances present in the life experiences of African Americans diagnosed with mental illness. The research questions explored included the following:

7. How has living with a mental illness affected the lives of African American individuals?
8. What kinds of language do these individuals use to describe their experience of living with a psychiatric diagnosis?
9. How have individual experiences of racism/discrimination informed how they view their mental illness?

Data was collected through personal interviews with each research participant. Despite the use of semi-structured questions to guide the dialogue, interviews were flexible, and allowed for the organic development of new topics. As a result, whenever unanticipated and interesting topics of discussion arose, they were explored and given space to develop. Seven interviews took place, and while some of the themes emerged directly from the interview questions asked, others materialized in the process of data analysis.

The major themes which emerged from the transcribed data include the following: (1) mental illness as labeling and stigmatizing; (2) issue of normalcy; (3) mental illness occurring within the context of other life stressors; (4) acceptance of diagnosis; (5) support from others; (6) experience of racial discrimination; and (7) differences in experiences between whites and blacks.

Description of Sample

The sample included seven individuals who met all of the inclusion criteria.

While only one of these individuals self-selected herself and responded to the recruitment flyers initially placed in ALSO-Cornerstone locations, the other six individuals were recruited with the help of ALSO-Cornerstone program directors, who actively sought out potential participants amongst their clientele whom, they felt, would be interested in taking part in this study. All interviews were conducted in ALSO-Cornerstone locations.

The demographic surveys filled out by research participants included questions regarding gender, age, race/ethnicity, average monthly income, highest level of education completed, specific psychiatric diagnosis, and number of years diagnosed with a mental illness (See appendix D). Within the research sample, there were four female participants and three male participants. The age range of research participants was 27-53 years, with a mean age of 41.6 years. Three of these individuals identified their race/ethnicity as black, two identified themselves as African American, one identified himself as black, French, and Indian, and another individual identified himself as Indian and black. The average monthly income of participants ranged from \$212-\$1800, with a mean income of \$808.25, and three individuals chose not to disclose this information. In terms of highest level of education completed, three participants reported finishing the 12th grade, one participant reported finishing the 10th grade, and another individual reported that he had finished the 3rd grade. One research participant reported that she completed community college, and also attended business school. In regards to specific psychiatric diagnosis, three participants reported having a diagnosis of schizophrenia, while two individuals reported having a diagnosis of depression. One participant reported having multiple

diagnoses, including schizophrenia, depression, bipolar disorder, and borderline personality disorder. Moreover, another research participant reported having a diagnosis of anxiety as well as depression. The number of years since being psychiatrically diagnosed ranged between 4-41 years, with a mean of 19 years.

Mental illness as labeling and stigmatizing: "I-I don't like labels too much- . . . labels is kind of like putting a stigma on somebody-I don't like that"

When asked about when they were first psychiatrically diagnosed, a majority of participants described their negative reactions to being told they had a mental illness:

Lisa: (age 49) I didn't want to be like that.

Wanda: (age 36) Well I was afraid I wouldn't be able to do anything with my life.

Michelle: (age 47) Whoo . . . I had a lot of mixed emotions. I um at one point I didn't want to take the medication, that's what it was. Because I had heard a lot of bad things about you know having mental illness and you have to take all this medication and it's gonna make you dopey and all that stuff. And at one time when they first diagnosed me, I'm like I'm not taking no medicine.

Angela: (age 33) I didn't want to accept it. I really didn't want to accept it, but I had to accept it. Um, I didn't want to accept it . . . I couldn't see myself like that. I didn't want to see myself like that.

These individuals were aware of the societal stigma associated with mental illness, and were aware of the judgments made by others about mental illness. In addressing these judgments, some individuals offered their opinions:

Lisa: I'd kind of joke and say I'm a nut, I'm crazy.

Jake: (age 28) . . . a lot of people take labels and try to use labels to keep you controlled in a certain mindstate, you know what I'm saying. And me, I don't like doing that, I like to feel free. So if you put a label on me, that's like keeping me stuck on that label, and I have a problem with that. I like-like to feel free and feel like even though I may have an issue, I can overcome the issue and by having that label kind of hinders you from overcoming it, you know what I'm saying?

Michelle: That stigma is-I mean now that I think about it, it's kind of over the top, because no matter if you have a mental illness or not, we're still human. I don't think we should be labeled where they put us in the corner. I don't like that. I really don't. At one time I was very offended when I hear somebody say "oh well she's nuts or he's"-no don't say that. Please don't say that. That's not nice. You don't know what they've been going through.

Dean: (age 50) Some people said whoa, look at him. Gee why would he do something like that, you know? They don't understand that I was sexually abused, I was hearing voices, I was depressed, anxiety, um lonely, I have no friends, all that stuff, you know?

Dean: (age 50) People judge me different when they know I got a mental illness. They treat me bad. They take advantage of me . . . That they can get over on me. Do what they want to do to me.

Issue of normalcy: "Normal people"

Interestingly, in talking about living with a mental illness, most research participants often used the word "normal," and spoke about the notion of living their lives like people without mental illnesses:

Jake: If you come off normal and act yourself and act chill, people don't think about it-most people ain't going really to bother you about it.

Eric: (age 53) . . . when my thoughts got clearer [when taking medications] I started feeling better and I start functioning like everybody else normally . . .

Lois: Okay. What do you mean by normal?

Eric: You know, normal as-normal life. Normal routines in life, going to the store, taking care of my daughter, working, you know, a normal life.

Eric: I function normally now, because I take medicine.

Wanda: Normal people can filter things out but it's like when you're mentally ill, it's not like you're in crisis, but I am under a bit of stress.

Wanda: I'm what they call high functioning. I can cope with reality a little bit.

Michelle: Unless somebody tells you or lets you see-and we can live like normal people.

Wanda: I'm one of the fortunate ones. I can function pretty good. Some people just can't do it. It's not their fault and some people, they just can't live . . . I'm so high functioning. I have a job, my own apartment. I have books.

Mental illness occurring within the context of other life stressors: “. . . My life's been a rollercoaster, it really has. I've had a lot of ups and a whole lot of downs”

When asked about their experiences of living with a mental illness, individuals made references to other major stressors which have and continue to impact their lives. Some of these struggles included drug addiction, sexual abuse, significant losses of loved ones, and growing up in an unstable home environment:

Lisa: . . . when my kids were born. Went to the doctor to get checked out everyyyy, every week I had an appointment. Then I got pregnant after my first daughter, had a miscarriage. . . met my husband, and I already had a child out of wedlock. Got pregnant with my youngest daughter now. Got married two years ago . . . walked away from God. Um . . . quit smoking cold turkey. Went to Meriden after my youngest daughter was born and after we got married. Let me see-hold-yeah, yeah, yeah. Um my husband was emotionally abusive to me. I left him. We separated for five years. Went to Meriden at the battered women's shelter, got my own apartment, raised my kids alone . . . my husband and I were taking counseling . . . um . . . we were taking marriage counseling. And thennnn he did some things with his life that didn't include us. He went back to his ex-wife more than one time . . . um . . . I was going to church rather than going to the hall for years just to keep peace in the home . . . um . . . I blame my husband for the way my children turned out. They have problems with the law, the school, they would get bad in school. My oldest daughter graduated, my youngest one didn't because my husband was sleeping with his ex-wife. We almost got a divorce . . . a couple months ago because of what happened long time ago. Remarried two years ago.

Lisa: I got two kids that look up to me. I don't want them to say “Oh my mother's a prostitute, she's a drug dope addict. She does this, she does everything she could to make me look bad.” I don't want my kids to say that about me.

Dean: Umm . . . female, male voices, telling me to hurt myself and uh I was sexually molested as a kid by my father uumm I was beaten, I was put in the hospital at nine years old for six years . . . the hospital was really bad to me, cruel

to me, they hit me, they abused me, uumm women abused me, uum stuff like that. My father sexually molested me um and I have flashbacks.

Jake: I was taken away from my mother as a young child- but five years old- I wasn't away-she gave me away to foster care and to the state so, from there I've been of the state all my life . . . she had alcohol problems and personal problems and stuff like that. She didn't have the-the best-the best situation so . . .

Michelle: . . . see my, my depression. It's like a sock that has old holes-you know how you get a hole and then you mend it up? And you wear it again, you wash it, then you get another hole and it rips open up again? That's how it was from the time my dad died till I got clean and sober. And then when my son passed away, it's like the sock opened up again, and soon as I get it mended, this happens again. [This individual's sister passed away in February 2009].

Michelle: . . . I was molested by one of my uncles and I never told anybody . . . and then I-I mean now I think about it and it's like yeah it was because of you know that-that made me desperate and I kind of clammed up and I would never tell anybody. And when I was thirteen-fourteen, I was raped. And this is-is so strange; the guy that-the guy that raped me, actually became my boyfriend...

Lisa: Yeah, I-I mean I took lots of medicines back then, I can't even remember which ones . . . um I know I've been on Prozac, Wellbutrin, um, let's see Seroquel, uh . . . let's see Trazadone, Zoloft, um there was a few other ones but I can't remember but as long as I was on them I was okay. Then the problem was when I thought I was ok and I got off them, and then being off them at the time, and then my addiction kicked in and it's like everything kind of fell out of place again and it took a while for me to actually get back into it. There was a time where I was out for like two months on a drug binge . . . Crack, cocaine, lots of alcohol and stuff. And I think that I had a nervous breakdown because I ended up being in the hospital and I didn't realize I was in the hospital until like the day after.

Acceptance of diagnosis: "It's what you make of your diagnosis. Think you're a nut, you'll be a nut."

Despite the stigma of mental illness and despite the other struggles they were faced with on a daily basis, most research participants emphasized positive affirmations about who they were:

Jake: . . . I don't-I don't let it hinder me for nothing-I still present myself as a normal person-a regular guy. Some other people may look at me funny, just act like it's nothing, you know what I mean-I act like-I try to act as normal and as smart and as normal as I possibly could. So, to me, I don't try to dwell on that fact that I'm so poor me because I got a mental illness-I just look at it as okay, I'm just a normal dude, coming through to my health-health proper and all this stuff and going on about my business, you know what I mean?

Michelle: Because I tell my kids just because you have a mental illness or you have an addiction, doesn't make you a bad person. You learn from your mistakes. I've learned that in order for somebody else to love me, I have to love myself first. And regardless of whether or not I have a mental illness, I can function.

Lisa: I got two kids-I got two kids that love me, and I love them. I have a husband. I got God.

Lois: So how does mental illness come into play there?

Lisa: It just fits right in. Makes me, me.

Wanda: And I'm really working on freedom of thought, freedom of expression, free to do the things that I want to do.

Wanda: I'm living proof that you can do something with your life. Even despite mental illness.

Angela: I don't let it stand in my way from doing things that I want to do. I don't let it stand in my way.

Angela: Um, I don't let it get me down. I just go about my business, do what I got to do.

Michelle: So I'm like, just because you have a mental illness, doesn't mean you have to stop your life.

Eric: I spend most of my time now that I'm better, trying to help make things better, like Obama is trying to do . . . Helping out everyway that I can, to make things better in the world . . . to make things better in the communities.

Support from others: "I know that I'm not by myself"

In making positive affirmations about who they were and about their successes in life, individuals commonly acknowledged and gave credit to the sources of social support

in their lives, that assisted them in maintaining their mental health. These supports included family, religion, outpatient therapists, as well as other mental health agencies:

Jake: I am spiritual. I believe in prayer and God . . . God helps me by changing my circumstances. He changes circumstances for me and gives me morals and beliefs . . . to do the right thing and treat people fairly. Ummm God helps me in many ways. I wouldn't be who I am if it wasn't for God.

Eric: [In regards to God] He heals-he heals-he heals me. That's the way he's supportive.

Michelle: I remember the other day, I was reading and, you know the Bible says in order for God to forgive you, you have to forgive somebody who hurt you. And I did. I had to let that go. [In regards to encountering a man who raped her when she was aged thirteen or fourteen]

Lisa: My faith more or less took away all the pain that I had. I go to church every week.

Michelle: It's like in the last fifteen years of my mental disease, in the last-these last four, is when I went through my trials and tribulations and it's like I said, if it wasn't for my faith in God, the people in my church, Deborah and ALSO-Cornerstone staff, and the staff at the Village of Power, I honestly and truly believe I would have had a nervous breakdown.

Michelle: Because I know that I'm not by myself. I have my sisters who also have the same, you know, some of the same problems I have, or even worse. And I'm like, I'm not in this by myself. It actually feels good, that I can go and pour my hear-my heart out and nobody will judge me. And that is one of the things I always had a problems with-somebody judging me.

Wanda: I wasn't you know, treated like a leper. I was treated very well. They had respect for me, they believed in me . . . [In regards to talking about her family]

Wanda: My mental illness does put a limit on some things, you get a little dependent.

Experience of racial discrimination: "I can sense it, but . . . it's not obvious to me, you know what I'm saying?"

When the interviews shifted focus from experiences with mental illness to experiences with racial discrimination, most research participants were quick to state that they had never encountered overt acts of racism or that overt acts of racism no longer existed:

Lois: Do you believe that people experience discrimination and prejudice because of the color of their skin?

Lisa: On T.V.

Lois: On T.V. What do you think the difference is between I guess um like your life/reality versus what you see on T.V.?

Lisa: It's not real. Some of it's real. Black was treated pretty bad years ago.

Lois: But you don't think that's the case now?

Lisa: [Shakes head no]

Lois: No?

Lisa: I can get on a bus and sit in the front, I can sit in the back. I see an old woman get on the bus I'll give up my seat. If there's a pregnant woman I'll give up my seat. I have no problems.

Dean: I think it doesn't exist like it used to back in the sixties when I was growing up but, it's less now I guess.

Michelle: Have I been discriminated against? If I have, I probably didn't notice it.

Michelle: . . . I've never heard anybody call me out of my name, I've never heard anybody say well she's a black woman, you know she can't do anything or she's not educated or whatever. I've never you know, went through that.

However, upon further questioning, individuals began to talk about instances and situations in which they sensed that they were being treated differently, due to the color of their skin:

Jake: Ummm I believe people are still racist, but they don't necessarily come out and tell you that you're a nigger or, or I don't like you cuz you're black or whatever. If anything a lot of them blend in with people and they pretty much act

weird with you without actually letting you know about it. There's still racism going on but it's just in a more sneakier, adaptable, more smoother way, where people pretty much don't notice it but it's there, you know what I'm saying? So I-I don't really encounter-I have encountered it but indirectly.

Lisa: Uhh . . . only discrimination I've really been into is like I'm um-a woman in East Haven-my car breaks down in East Haven. Those white people out there will break their neck to help me to get out of their area. West Haven, New Haven, Hamden-they don't even want you in Hamden to shop. They want to hurry up and get you out of Hamden.

Michelle: Only . . . only time that happened is when okay, parts of Dixwell Avenue they call the hood. Okay the parts between what is it . . . it's Dixwell and Webster Street all the way down to going towards Hamden, alright. I was on the corner of Dixwell and Henry, getting ready to cross the street. And there was this lady in the car. As I was coming across the street, I was going to go around her car and go that way, she locked the door. A white lady. And I experienced that a couple of times. Yeah. But as far as like going to stores and stuff or people-you know, I've never experienced that. If they did it, they did it without me noticing it. But that's the only time cuz it's like I guess there's a stereotype that all people-all black people steal. Or you know, they jack your car or whatever. And that's the only thing. I'm like . . . I mean I don't want your car, you know. I'm going around. But that's the only time that when I've seen somebody locking their door when I'm crossing the street, that's about the only discrimination, when I've actually went across, so. I've never had anybody just call me out of my name or anything.

Michelle: . . . Last year. We went out more, more so involved in the Village of Power in my last year, which was last year, in 2008. Um, we had a show which we held in the Westville area, and now that I think about it, it may have been um . . . and now how did it, how did it play out? It had to do with um . . . dang. We did a show, in an art gallery. The people who were there, I think most of them were from Jewish background. And, I don't know-maybe-I don't know if it was my imagination or what, but the women were like-they were coming around checking out all the stuff we had, but, there were two women who came in together, and they were more or less clutching their bags, or you know, we had to tell them about the product or whatever, and they just said we'll be back. I don't know if they were you know, being them or what. I don't know if it was discrim-because I mean I really, really . . . um . . . it's like I'm not 100% sure whether they were being you know, I don't know . . . it may have been. I didn't think it was done to me before, and I guess there are stereotypes out there.

Angela: . . . Walking downtown, there was this big help wanted sign, and I was like can I get an application. And the lady was like, "the position has been filled."

And it's like what? And I was like, "well, you have a sign out there." Oh we forgot to take it out the window, but the position has been filled. But yeah, that happened.

Lois: Out of curiosity, was there anything in the way she said it or she acted towards you that made you feel-

Angela: A little bit because she was like far away, like she didn't want to come near me or nothing.

Lois: Okay. Any other experiences you feel like . . . has there ever been times when people not directly said it to you, but you felt it?

Angela: Sometimes I know . . . [Laughs] this white man-I was standing waiting for the bus and this white man walked past me and knocked the purse out of me real hard . . . He bumped into me real hard, and I looked at him and he kept walking. And I was like . . . it was a bad experience.

Differences in experiences between whites and blacks: "They may have more advantages because they-they are closer to the democratic majority; and majority wins"

When asked whether they felt white individuals experienced discrimination, research participants made references to the disparities between whites and blacks, which included the fact that white individuals possess more advantages, and encounter less discrimination:

Jake: I mean there are some that believe that white is a, is a more innocent color is a, is a um is a color of what you would call a high-high uh high uh what's-what's the word you use a high government of whatever you know what I'm saying. It's more of a brighter color, it's more of an innocent color, it's more of a, a color of honesty and stuff and is better than black, you know what I'm saying?

Michelle: Um, when my nephew went to jail, he was selling drugs, and he got caught with the drugs. There was also a white kid in there, cuz me and my sister went, and they gave my nephew more time than they gave him. And the white kid had a lot more you know, and because I mean it's-it's sad to say, more or less if there's a white person and a black person and they have-they do the same exact crime, I've seen it- . . . The black kid would get more time than the white kid.

Wanda: Because they're white and everybody expected them to have money and stuff. I'm learning that, you know there's differences in the white culture-there's Italians, there's Irish, there's couple others. But, you know, I think sometimes they may be, they may feel some discrimination. Because they are higher up on the food chain, so they may feel it more than someone who's a little bit lower . . .

You don't know how to deal with it when you don't experience it your whole life and suddenly you experience discrimination for the first time.

When describing the experiences between white individuals living with mental illness versus black individuals living with mental illness, research participants made references to the fact that skin color played a major role in services sought after, as well as the quality of services rendered.

Wanda: Maybe have more chances of having better care because they can afford it . . . and it's like they're able to afford like private therapists or something

Eric: Because a black person is being discriminated against cuz of his color and not his mental illness. So I think it's different.

Angela: Because I think a white person will get more of, more of a help than a black person . . . Because . . . it seems like there's a chance for the white person, it would be a better chance for the white person. But for a black person, like there wouldn't be no chance . . . I think that insurance for the doctor. I think the doctor would take out more time for the white person than the black person.

Michelle: When I was in YPH [Yale Psychiatric Hospital], I think it was maybe the second to the last time I was in there . . . in order to watch T.V., you have to put your name on the list. Okay there was me, there was this young kid who was white, a white girl I forgot her name, I think her name was Judy. And then there was this other guy who was black and he was just there. Um, and the white kid, he wanted to watch something else-I'm watching the Discovery Channel, he comes in and changes my channel. So I say something to him, and this was so funny. I'm just remembering it. And I remember that he was-his parents were rich. And I heard somebody say, well, is your name on the-the list? I said my name was up there first and he's gonna come over here and change the channel. And I'm getting offensive, and I think it was one of the nurses that said, well just let him go ahead and you know, NO! I'm not gonna do that. Just because he came in here-just because you're you know, a little spoiled brat, you're not getting away with it. I really wanted to say I'm going to get up and throw him through the window. And I think because he thought I was some dumb black woman that he could get through and get whatever he wants, and I just showed him that I am not dumb by any means whatsoever. Cuz I will put you out that window. I know that's bad to say but that's just the way I felt, so that-that may have been the only time-and it's so funny that I thought of it. I mean, that's the only time I actually remember about any kind of discrimination.

Summary

This study sought to explore the effects mental illness has had on the lives of African Americans, the language these individuals employ to describe their experiences, as well as how African Americans' experiences with racial discrimination have informed how they view their psychiatric diagnosis. Analysis of interview data revealed the following themes: (1) mental illness as labeling and stigmatizing; (2) issue of normalcy; (3) mental illness occurring within the context of other life stressors; (4) acceptance of diagnosis; (5) support from others; (6) experience of racial discrimination; and (7) differences in experiences between whites and blacks. In the next chapter, the findings will be further explicated and the relevance of the findings to previously reviewed literature will be discussed.

CHAPTER V

DISCUSSION

This qualitative research study sought to examine the nuances present in the lives of African American individuals living with mental illness. Within this chapter, findings from the study will be discussed in relation to previous research completed on this particular subject.

The analysis of the interview data from this study revealed the following themes: (1) mental illness as labeling and stigmatizing; (2) issue of normalcy; (3) mental illness occurring within the context of other life stressors; (4) acceptance of diagnosis; (5) support from others; (6) experience of racial discrimination; and (7) differences in experiences between whites and blacks.

Mental illness as labeling and stigmatizing: "I-I don't like labels too much- . . . labels is kind of like putting a stigma on somebody-I don't like that"

Simon (1992), Mora (1992), Brizendine (1992), and Hinshaw (2007) all offer a historical perspective on mental illness and, in doing so, reveal the extent to which negative conceptualizations of mental illness have a long history. Along with this, other researchers have offered more recent information about the enduring presence of mental illness stigma within society. In studying the interviews collected within this research project, the findings were found to support the past work of researchers on the subject of mental illness stigma.

Most research participants were mindful of mental illness stigma prior to being given their own psychiatric diagnoses, and thus had negative reactions towards their diagnoses when they initially received them. For individuals who did not necessarily

understand what mental illness was prior to being given their psychiatric diagnoses, mental illness stigma was something that they became more familiar with as they began navigating through the mental health field. Yang, Kleinman, Link, Phelan, Lee, and Good (2007) note that “Stigma takes on its character of danger by threatening interpersonal engagements and what is most at stake” (p. 1532). For research participants prior to as well as after being psychiatrically diagnosed, fears about their abilities, futures, and relationships with others amongst other fears, very much became a reality. And as noted by researchers such as Wahl (1999), Link, Cullen, Struening, and Shrout (1989), and Corrigan and Watson (2002), individuals, after being diagnosed, were forced to think about how they would cope or not cope with their mental illnesses.

Issue of normalcy: “Normal people”

Interestingly, as individuals spoke about the concept of normalcy, their use of language seemed to create a dichotomy between being normal and having a mental illness. For example, as Eric, age 53, stated, “I function normally now, because I take medicine.” In making this distinction between normal versus having what Goffman (1963) describes as an “undesired differentness” (p. 5), it seemed as though being normal as well as being perceived as normal was very much a value for research participants. Considering this, this finding is reminiscent of what Goffman (1963) writes about in regards to the concept of normalcy.

The stigmatized individual tends to hold the same beliefs about identity that we do; this is a pivotal fact. His deepest feelings about what he is may be his sense of being a “normal person,” a human being like anyone else, a person, therefore, who deserves a fair chance and a fair break. (p. 7)

This sense of wanting to be seen as a person with the ability to function, complete tasks related to daily life, and to live life like everyone else, was a theme that seemed to permeate throughout the interviews. For some individuals, being perceived as normal meant behaving in ways that were seen as socially appropriate, and perhaps acting in ways that erased physical or noticeable traces of having a mental illness. For example, as Jake, age 28, stated, “if you come off normal and act yourself and act chill, people don’t think about it-most people ain’t going really to bother you about it.” This notion of “passing,” is described by Goffman (1963), who noted that discreditable stigma could be hidden from others (i.e., these marks on one’s character that might be related to one’s drug addictions, criminal history, sexual orientation, etc). And in this particular case, mental illness is an example of a discreditable stigma. However, as Wanda, age 36, stated, “I’m one of the fortunate ones. I can function pretty good. Some people just can’t do it. It’s not their fault and some people, they just can’t live . . . “ As noted, for some individuals, acting and passing as someone without a mental illness can be a difficulty (i.e., if an individual is overtly psychotic).

Mental illness occurring within the context of other life stressors: “. . . My life’s been a rollercoaster, it really has. I’ve had a lot of ups and a whole lot of downs”

During the interview process, research participants talked directly about or alluded to experiences with rape, sexual molestation, physical abuse, substance abuse, absence of primary caregivers during childhood, death of loved ones, and failed marriages or marital struggles. These experiences are a reminder that mental illness does not occur within a vacuum; it occurs alongside and within the context of other life

stressors and experiences, both positive, or in the case of many of the research participants, negative or painful.

Miller and Garran (2008) write about the different dimensions of identity, as well as the “intersectionality” (p. 135) of these identities and the impact this has on individuals’ lives. Just as class, race, gender, and sexual orientation are aspects of one’s identity, being a survivor of painful and traumatic experiences is undoubtedly another aspect of identity. And as revealed through interviews, participants were willing to share some of their experiences. Although this aspect of their personal histories was not further delved into throughout interviews, it can be presumed that participants’ painful experiences played a strong role in shaping their identities and their current functioning.

In their work, Miller and Kaiser (2001) focus on revealing how research developments on general stress and coping can influence thoughts about how to manage stress associated with stigma, as well as how adaptive these responses are. Considering this, one can speculate that individuals’ capacity to cope with tough and painful experiences in the past may have influenced their ability to confront and deal with mental illness stigma.

Acceptance of diagnosis: “It’s what you make of your diagnosis. Think you’re a nut, you’ll be a nut.”

A striking aspect of the research findings was the ability of participants to retain positive self-images of themselves, despite recognition of as well as personal experiences with societal stigma of mental illness. This finding is contrary to the work of Cruz, Pincus, Harman, Reynolds, and Post (2008) along with researchers such as Matthews, Corrigan, Smith, and Aranda (2006), who found that shame as well as denial of mental

illness, intertwined with public stigma, greatly contributed to the barrier to help-seeking for African Americans. Instead, the participants in this study were well connected to mental health services, including outpatient psychotherapy as well as psychiatry, and were involved in other community agencies such as Fellowship Place, Village of Power, and of course ALSO-Cornerstone.

This finding from this study certainly supported the work of Camp, Finlay, and Lyons, (2002), which challenges the idea that stigma of mental illness negatively and automatically impacts self-esteem. In line with the findings of Camp et al. (2002), participants in this study accepted their diagnoses, yet were critical of being labeled or stereotyped. In vocalizing this wariness, participants also spoke about their determination not to let their mental health status hinder them from living the life they envision for themselves. These self-affirmations are reminiscent of the “righteous anger” written about by Corrigan and Watson (2002). Michelle, age 47, is an individual who particularly conveyed this motivating anger. As she stated,

I can think I can do anything that I put my mind to . . . Um, I’ve even thought about writing a book. Because I’ve told my story to so many people and I sometimes do it in detail and when they hear it it’s like “you should . . .” I heard more lines before people told me that, that I should write a book. That’s nice I kind of want to do that.

Along with conveying her desire to write a book about her experiences, Michelle also spoke about wanting to give testimony about her experiences in front of the congregation at the church she attended, and spoke about how she was always willing to tell her life story to anyone who would listen. Michelle, along with others participating in this project, seemed to display the “empowered” identity described by Williams (2008).

Support from others: “I know that I’m not by myself”

This finding from this study supported the findings of other researchers who have attested to the strengths and resilience present in the African American culture. Interestingly, in talking about their experiences, none of the research participants vocalized any sentiments that they were alone in their suffering, or that no one understood them. On the contrary, these individuals were able to name at least one source of social support out in their community, whether it was family, friends, church, or community providers. Strikingly, all research participants referred to God or a spiritual being as a major source of comfort, guidance, as well as support. This particular observation supports the work of Boyd-Franklin (2003), Utsey, Giesbrecht, Hook, and Stanard (2008), along with Brown (2008), who writes that African Americans who perceive that they have social support out in the community (e.g., through church networks, cultural networks) have a great sense of self-resiliency. Something to wonder then, is whether this sense of self-resiliency from having supportive networks, contributed to some participants’ abilities to cope with their histories of traumas (which was found to be a commonality amongst several individuals).

Utsey, Chae, Brown, and Kelly (2002) as well as Fischer and Shaw (1999) discovered that a sense of ethnic identity membership as well as positive racial socialization during childhood increased the resiliency and strength of African American individuals. Although the results of this project may hint towards these researchers’ findings, this study’s findings do not necessarily support past researchers’ work. This is because the objective of this research project was not to elicit information about

individuals' sense of ethnic identity, nor about the messages they received about their culture or their race while growing up.

Experience of racial discrimination: "I can sense it, but . . . it's not obvious to me, you know what I'm saying?"

A noticeable aspect of the findings was the commonality in participants' verbalizations about the existence of racism. When initially asked, most individuals were quick to state that racism had lessened in the United States, and alluded to the absence of overt racism in society (i.e., slavery no longer existed and black individuals could sit in the front of buses). However, with further questioning, individuals began to talk about instances in which they could sense that they were being treated differently due to their skin color. In describing these instances, individuals spoke about the subtle shifts in others' behaviors (i.e., white individuals clutching their purses tighter and locking their car doors in the presence of participants). Jake, a 28-year-old man seemed to describe these experiences by individuals in a poignant way: "There's still racism going on but it's just in a more sneakier, adaptable, more smoother way" And as Miller and Garran (2008) write, "Durable inequalities, such as racism, are replicated in all institutions and practices of society, although their form adapts and changes" (p. 63).

Differences in experiences between whites and blacks: "They may have more advantages because they-they are closer to the democratic majority; and majority wins"

In writing about the concept of "double stigma," Gary (2005) notes that ethnic minorities who live with, or possess histories of mental illnesses experience different access as well as outcomes to treatment, as opposed to those who are Caucasian. The findings from this project are reminiscent of the work completed by Gary (2005), in that

research participants were able to sense the differences in access to services as well as treatment by community providers between African Americans and their white counterparts. Despite this recognition, it appeared that with the exception of one research participant, most individuals did not make known any experiences with discrimination within the mental health field; they continued to seek and receive the services that they needed and were treated in a respectful manner by the individuals with whom they worked. As a result, the findings from this study cannot necessarily support the work of Kendrick, Anderson, and Moore (2007) and Dana (2002), who both write about the racism and discrimination faced by African Americans seeking and receiving mental health treatment. However, this discrepancy in findings warrants questions about the reasons for these differences, and warrants questions about the findings about this particular research project. For example, do participants' experiences within the mental health field say something positive about the cultural competency of the mental health professionals they have encountered? Have participants experienced discrimination in ways they have not recognized but nevertheless impinge on their well being?

Limitations of the Study

Although the findings of this study contribute to the existing foundation of information and knowledge on mental illness stigma as well as racism, this research project contains certain limitations. Firstly, the sample lacked diversity; individuals all belonged to a low socioeconomic status, and lived in the inner city of New Haven. Moreover, because research participants were already connected to various support services (i.e., outpatient therapy, housing), their views about themselves and their mental illnesses may be different from individuals without any services in place. Moreover, the

perspectives of research participants may be different from those of individuals with higher levels of education as well as higher incomes, and live in different areas of the country.

The lack of diversity was undoubtedly affected by the size of the sample; because of the small sample size, generalizability of the findings is limited. Considering this, it seems important to mention that during the recruitment, it was difficult to find participants who met the inclusion criteria, who were also willing to be individually interviewed. A contributing factor to this difficulty was that when various community agencies were initially approached during the recruitment phase of this research project, community providers were hesitant to expose their clients to the subject matter of this project. Their rationale was that because their clients already constituted a vulnerable population (i.e., due to their race, socioeconomic status, etc), they did not want their clients to be re-traumatized through talking about the ways in which they were oppressed or discriminated against in society.

Another limitation worthy of mentioning is that this research project took place in a city already inundated with clinical research studies from local educational institutions. As a result, this may have impacted potential participants' opinions about research studies, and their desire to partake in another project. Moreover, the lack of substantial monetary compensation in this research study (as compared to other clinical research studies taking place in New Haven), may also have affected individuals' desire to participate.

Implications for Social Work Practice

This study highlights a number of implications for social work practice, one of which is the importance of opening up dialogue with clients about issues of racism, and how they are impacted by various levels of discrimination in their daily lives. The individuals in the study all sensed the racism they experienced, but lacked the language to describe their experiences. Perhaps by equipping individuals with words as well as information, they could feel more validated about their experiences, and perhaps feel more empowered. This also applies to talking more with clients about mental illness stigma; perhaps with increased candor, shame would be decreased, and individuals would also feel as though they were not alone in their experiences.

Doing this however also implies that clinicians must first examine their own views and values related to racism as well as mental illness stigma. This is important, because our own beliefs can and are inevitably conveyed to clients, and thus we should be aware of what these personal beliefs are. Moreover, in order to assist individuals in reflecting on their own thoughts, emotions, and beliefs about racism and the stigma of mental illness, we should be able to do this ourselves.

Implications for Social Work Research

This study also highlights implications for further research, one of which is to repeat this particular project, by refining the research methods implemented. For example, perhaps with a larger sample size, as well as with a more diverse sample, the findings could be more generalizable to the larger population. Moreover, it may be worthwhile to explore different themes (i.e., substance abuse) during the interview

process, which were not touched upon during this project (which appeared to greatly affect individuals' lives).

Summary

This study sought to explore the effects mental illness has had on the lives of African Americans, the language these individuals employ to describe their experiences, as well as how African Americans' experiences with racial discrimination have informed how they view their psychiatric diagnoses. Despite limitations, this study did produce meaningful findings through the help of several individuals willing to share about their lives and experiences. These findings certainly provide both implications for social work practice as well as future social work research. On a more personal note, while formulating, implementing, and examining the various components of this research project throughout the past several months, I found this experience to be an enriching one, which pushed me to think about and do things outside of my own comfort level. Hearing directly from individuals about their lives and how stigma affects them, was a humbling experience, and solidified my own thoughts about the importance of qualitative research.

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Appendix A

Informed Consent Form

Dear Potential Participant,

My name is Lois Son and I am a student pursuing a Masters of Social Work at the Smith College School for Social Work in Northampton, MA. I am interested in conducting a research study exploring the life experiences of African Americans diagnosed with a mental illness. In conducting this study, I am working in affiliation with ALSO-Cornerstone, who will be given a summary of my research findings. The data from the interviews I conduct will be used for my Masters thesis, and for possible future presentation and publication.

The criteria for participation in this study include: (a) being English-speaking (b) males and females 18 years of age and over (c) self-identifying as African American (d) carrying a primary diagnosis of a mental illness that has been diagnosed by a licensed mental health provider (e) and in current stable mental health

After determining eligibility and obtaining your consent to participate in the study, you will be interviewed about your experiences. Prior to this interview, you will be asked to fill out a demographic questionnaire. The interview itself will last between 45-60 minutes, will take place at a mutually agreed upon time and place, and will also be digitally recorded and transcribed by me. Any individuals helping to transcribe interviews will sign confidentiality agreements. To protect your privacy, I will keep any recorded material along with any written text in a locked secure space. I am required by federal regulations to keep all of the data I collect for three years. If I need this data beyond the minimum three years required by federal law, I will continue to securely store it, and destroy it when I no longer need it. Moreover, my research advisor will have access to the data that is collected after any identifying information has been removed.

There may be a small risk to individuals choosing to participate in this study. For instance, discussing sensitive topics about your racial identity as well as experiences with mental illness stigma may cause you to feel upset, uncomfortable, or embarrassed. I urge you to alert me during the interview process, if you find yourself feeling triggered in any way. I will provide all research participants with a resource list, which contains information about support services available in the local New Haven area. I would like to also remind you that you can seek support from someone within ALSO-Cornerstone.

Despite the risks, a benefit of participating in this study is that you may gain a sense of empowerment from having your voice heard, as well as from knowing that you are helping to inform clinicians working in the mental health field, and in turn helping other individuals of color navigate through mental health services. Moreover, you will be given a \$5 Dunkin Donuts gift card in exchange for your participation. You will be rewarded even if you withdraw from the study or do not complete your participation.

Your participation in this study is voluntary, and if you withdraw from the study at any time or choose not to answer any questions on the demographic questionnaire, or in the interview portion, you may do so without any penalties. If you decide after participating that you would like your data to not be included in the study, please contact me by March 31, 2009, at which time I will destroy any materials pertaining to you.

If you have any questions about your rights or about any aspect of this study, I encourage you to contact me at (253)332-9971, or at lson@email.smith.edu. Moreover, you are welcome to contact the Chair of the Smith College School for Social Work Human Subjects Review Committee at (413)585-7974.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

Thank you again for your participation.

Please keep a copy of this consent form for your records.

If you have any questions or would like to withdraw your consent, please contact:

Lois Son
(253)332-9971
lson@email.smith.edu

Signature of participant

Signature of researcher

Date

Date

Appendix B

Recruitment Flyer

Exploring the Life Experiences of African Americans Living With Mental Illness

A Qualitative Research Study

I am looking to interview African American individuals diagnosed with mental illnesses to explore:

- How has living with a mental illness affected your life?
- How do you describe your experience of living with a psychiatric diagnosis?
- How has your experience of racism/discrimination informed how you view your mental illness?

I am seeking individuals who fit these criteria:

- Are 18 years of age or older
- Identify as African American
- Have been diagnosed with a mental illness by a licensed mental health provider
- Are in current stable mental and emotional health.

Please contact Lois Son at (253)332-9971 or at lson@email.smith.edu

Participation in this study is completely voluntary, and you will be compensated with a **\$5 Dunkin Donuts gift card** for your time.

Contact:
Lois Son
lson@smith.edu
(253)332-9971

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Appendix C

Interview Guide

1. First off, I want to ask you about the supportive structures in your life. Who do you turn to for help or support? (i.e., Family, friends, therapist, support groups, God, etc) In what ways are these individuals helpful to you?
2. Where do you feel the most comfortable, and feel like you can be yourself?
3. Before being diagnosed with a mental illness, when did you start noticing that you were having problems? How old were you? (Did problems start in childhood or adolescence?) What were these problems?
4. Going back to the beginning, when were you first diagnosed with a mental illness? Can you tell me about the process leading to the diagnosis? (Who diagnosed you? Where were you? What led you to seek help in the first place?) What were your emotions and thoughts about being diagnosed at the time?
5. Thinking back to before you were diagnosed, what did you think about people with mental illnesses? From where did you learn about these thoughts?
6. After being diagnosed, who did you tell about this diagnosis? What were these individuals' responses? Did you hide this diagnosis from anyone in your life? Why or why not?
7. Can you tell me about your life since you have been diagnosed? How has being diagnosed with a mental illness changed how you view yourself? How has it/has not changed your relationships with individuals in your life (i.e. family, friends)? Has this affected your ability to find/seek employment? How?
8. As someone who identifies as African American, have you ever experienced prejudice and discrimination? In what way(s) have you experienced this?
9. Considering your experiences as someone who identifies as African American, do you think that your experiences with racial prejudice and discrimination have affected how you view your psychiatric diagnosis? Please describe.
10. Do you think that people who identify as white/Caucasian and are diagnosed with mental illnesses, experience discrimination? Explain. Do you think that their experiences with discrimination are different from your own?

Appendix D
Demographic Questionnaire

Participant number code (birth date): ___/___/___

1. What is your age? _____
2. What is your gender? _____
3. How do you identify your race/ethnicity? _____
4. What is your average monthly income? _____
5. What is the highest level of education that you have completed? _____
6. How many years have you been diagnosed with a mental illness? _____
7. What is your specific psychiatric diagnosis? _____

Appendix E

Resource List

This list of resources is intended to help connect you to any services that you may find useful.

The Connecticut Mental Health Center

P.O. Box 1842, 34 Park Street, New Haven, CT 06508

(203) 974-7300

Some of the services offered by this urban community mental health center include crisis intervention, long-term outpatient care, case management, outreach programs for individuals who are homeless, as well as a co-occurring disorders program.

24 Hour Crisis Line:

9:00am to 10:00pm: (203) 974-7735 or (203) 974-7713

10:00pm to 8:00am: (203) 974-7300

Safe Harbor Warm Line (New Haven/Shore Line)

Is a companion phone line for individuals in recovery, and is available for individuals who are lonely and would benefit from hearing a friendly voice, or have a problem they would like to talk about. This warm line is operated by individuals who are in recovery themselves and have been trained to listen to as well as offer support.

5:00-10:00pm, 7 days a week, 365 days a year

1-800-258-1528 (toll free)

NAMI (National Alliance on Mental Illness) of Connecticut

241 Main Street

5th Floor

Hartford, CT 06106

(860) 882-0236

Toll Free: (800) 215-3021

NAMI-CT, along with its local affiliates, offers a number of different support groups throughout the state, including groups for parents, siblings, people diagnosed with psychiatric disorders, spouses, and parents of children/adolescents.

NAMI New Haven County (Support group only)

Whitney Center, 200 Leeder Hill Drive

6th Floor Conference Room

3rd Wednesday, 7:00-9:00pm

Contact: Laura (203) 389-6325

NAMI Connection Recovery Support Groups

Connecticut Mental Health Center

34 Park Street

New Haven, CT

Contact: Pete (203) 715-2537 or petect27@yahoo.com

Appendix F

Agency Letter of Permission



ALSO-CORNERSTONE, INC.

205 ORANGE STREET • NEW HAVEN, CONNECTICUT 06510
PROGRAMS AND SERVICES

TEL: (203) 776-9900 ext 1105

FAX: (203) 787-5599

November 12, 2008

Smith College
School for Social Work
Lilly Hall
Northampton, MA 01063

To Whom It May Concern:

ALSO-Cornerstone, Inc. gives permission for Lois Son to locate her research in this agency. We do not have a Human Subjects Review Board and, therefore, request that Smith College School for Social Work's (SSW) Human Subject Review Committee (HSR) perform a review of the research proposed by Lois Son. ALSO-Cornerstone, Inc. will abide by the standards related to the protection of all participants in the research approved by SSW HSR Committee.

We understand that we will have the right to review the final questionnaire and receive a copy of the reports derived from said research. ALSO-Cornerstone also holds the right to cancellation of this research if necessary.

Sincerely,

Marcie Dimenstein, LCSW
Director of Programs and Services

Appendix G

Human Subjects Review Committee Approval Letter

December 17, 2008

Lois Son

Dear Lois,

Your revised materials have been reviewed and all is now in order. We are happy to give final approval to this very interesting project.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your study. It's really helpful that you can locate this within a collaborating agency as otherwise, recruitment would be very difficult.

Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Joan Laird, Research Advisor