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Paula Daniela Mazzotta
(CIDAR, Boston, MA)
The Impact of Race and
Psychosocial Factors on
Help-Seeking Behaviors
Among Young Adults in the
Prodrome to Psychosis

Abstract

Few studies have examined how the mental health system in the U.S. presents barriers to help seeking especially among non-White populations. The purpose of this investigation was to identify racial disparities and psychosocial barriers to help seeking among clients in the prodrome to psychosis vulnerable to progression into schizophrenia. Using secondary data from a mixed-methods questionnaire, this study collected descriptive data relaying the perspectives of People of Color and their White prodrome counterparts on their perceived needs, attitudes, and experiences of professional mental health services. Using a sample (N=15) of prodromal individuals in the Boston-metro area, a semi-structured questionnaire measured early decisions in the pathways to care. Despite limitations of a small sample size, results suggest that People of Color found more systems-level barriers to mental health services than White participants. White participants, in comparison, found more stigma-related barriers. No statistically significant relationship was found between the magnitude or the content of discrimination experiences and the level of satisfaction with mental health services obtained. However, using an interpretive phenomenological framework, qualitative themes emerged suggesting that ethnic and race disparities are evident in the meaning-making of symptoms, mental health literacy, and attitudes that promote concordance or discordance

between client and provider. Recommendations for early psychosocial intervention in psychosis and implications for social work and schizophrenia research are discussed.

**THE IMPACT OF RACE AND PSYCHOSOCIAL FACTORS ON HELP-
SEEKING BEHAVIORS AMONG YOUNG ADULTS IN THE PRODROME TO
PSYCHOSIS**

A project based upon an investigation at the Center for
Intervention Development and Applied Research, Boston,
Massachusetts, submitted in partial fulfillment of the
requirements for the degree of Master of Social Work.

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2011

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CHAPTER ONE

Introduction

It is hardly surprising that speculations about mental health care in America should abound in recent times. The recent proliferation in current mainstream media of reports of acts of violence by ‘troubled youth’ with impaired perceptions of reality has made these concerns unavoidable. In the United States, the cost of schizophrenia—including direct costs (outpatient, inpatient, drugs, and long-term care) and non-health care costs (law enforcement, homelessness, work productivity loss, and unemployment)—was estimated to be \$62.7 billion in 2002 (Wu et al., 2005). Our nation has finally begun to acknowledge the full spectrum of psychotic experience and the debilitating losses incurred is evidenced in the ongoing political debates around mental health parity legislation and health care reform. The interaction of human rights issues involving medicine and law, health and justice, is in itself difficult to gauge. It is even more difficult when we confront the unique vulnerabilities among a population of ethnically and racially diverse patients. We all grasp (or should grasp) the need to ground these questions, and the people most affected by them, in complex, socio-culturally specific realities that give rise to them. One particular question that appears to be a crucial component of the complex situation, and will be addressed in the following pages: what prevents families and individuals from seeking help when problems become apparent? The enormous impact of compromised mental health on identity development, social stability, and family health has offered indisputable evidence that more research is needed. Thus, this thesis can be seen as an effort to both bring a clear perspective on

this problem and to help social work practitioners evolve toward current evidence-based research, delivery of services and practice in early psychosis and young adult mental health.

The overall goal of my study is to broaden the understanding of the psychosocial factors that may impact an individual's help-seeking behavior. This study will contribute to filling the gap in the literature by exploring differences in the subjective experiences of White participants and self-identified Persons of Color (POC) about their perceived needs, barriers and preferences in the clinical encounter during early psychosis. More precisely, using a descriptive, mixed-methods questionnaire, I will examine the ways in which racial status interacts with other mediating psychosocial structures to impact how pre-psychotic patients use and do not use the U.S. mental health system. Content analysis of the narratives of a sample of respondents ($N=15$) revealed a set of themes that explicate cultural identities in help-seeking attitudes and experiences of mental health services.

The body of literature about the phenomenon of ultra high risk for psychosis and prodrome period of schizophrenia is recent. There is unfortunately a dearth of research identifying the specific psychosocial barriers and facilitators that may influence patients and their families' help-seeking behavior and decision making about mental health care. It is well documented that the predominant paradigm for conceptualizing schizophrenia research and practice has been a biomedical framework, represented by psychiatry, and psychopharmacology (Boyd, 2010) at the exclusion of socio-cultural and psychosocial rubrics. While in more recent decades we have witnessed a movement toward culturally competent health care for providing effective mental health services to diverse cultural populations and needs (Simich, Waiter, Moorlag & Ochocka, 2009; Sue, Zane, Hall & Berger, 2009; Sue, 2006; Yamada & Brekke, 2008), until recently, schizophrenia research was focused more on the population as a whole and not specifically on

the needs of ethnically and racially diverse populations (Merritt-Davis & Keshavan, 2006; Morgan et al., 2005). First, since the inception of the field of psychiatry roughly 100 years ago, the racial composition of the United States has shifted vastly. Despite the rapid rate of expansion of ethnic minority populations and cultural diversity, the field of psychiatry, however, has not kept pace responding to the clinical needs of ethnic minority clients (Mindt, Byrd, Saez, & Manly, 2010; U.S. Census, 2010). It has been well documented that health care disparities persist along access, delivery and quality of mental health services (State Department of Health and Human Services, 2003). Current population demographics, birth rate, and immigration rates, according to the most recent Census Bureau data (2010) give a sober view of this reality:

The examination of racial and ethnic group distributions nationally shows that while the non-Hispanic White alone population is still numerically and proportionally the largest major race and ethnic group in the United States, it is also growing at the slowest rate. Conversely, the Hispanic and Asian populations have grown considerably, in part because of relatively higher levels of immigration. Among American children, the multiracial population has increased almost 50 percent, to 4.2 million, since 2000, making it the fastest growing youth group in the country (US Census 2010).

Given such evidence that the U.S. is faced with ever-increasing immigration of predominantly non-White populations, it is surprising that so few American studies address the issue of ethnicity and access to care for mental health problems. Historically, the U.S. Census has arguably been a structure for major policy decisions and distribution of privileges among U.S. citizens has viewed language as an index of race. Speaking a language other than English and immigrant status has been tantamount to not claiming full citizenship rights. Linguistic

diversity has presented an additional challenge to research for its exclusion of non-English speaking clients and making their preferences known.

Nearly a decade ago, the President's New Freedom Commission on Mental Health (Hogan et al. 2003) issued a report acknowledging racial, cultural, and ethnic problems in access, quality and outcomes for minorities. The report concluded that there exists a higher burden of disability for minorities. Furthermore, in its report entitled "Unequal Treatment: Confronting Racial and Ethnic Differences in Health Care," the Institute of Medicine emphasized that disparities went beyond differences in health status and access, which might be explained by clinical care appropriateness and patient preferences (Smedley, Stith, & Nelson, 2003; Snowden & Yamada, 2005). The significance of these findings highlights many problems of racial disparities and testify that the many facets of the present mental health system are not adequate. This rationale lays the foundation and provides the impetus to finding a new approach in culturally competent mental health services. Awareness of ethnocultural issues is vital in the process and outcome of psychotherapy (Comas-Díaz & Jacobsen, 1991; Shonfeld-Ringel, 2001). This study will examine how the present mental health service delivery system in the United States presents barriers to help-seeking behavior especially for immigrant and non-White populations.

First, however, for the sake of clarity, important operational terms should be defined. Borrowing from the American Psychological Association's (APA) Guidelines on Multicultural Education, Training, Research, Practice, and Organizational Change for Psychologists (APA, 2003, p. 380) "all individuals are cultural beings who possess a cultural, racial, and ethnic heritage." These are abridged terms with diverse resonance, if not elusive meanings. Here, culture is defined as the belief systems and value orientations that influence customs, norms, practices, and social institutions, including psychological processes (language, care taking

practices, etc.) and organizations (media, educational systems, etc.). This understanding is consistent within a framework set forth by previous authors' conceptualization of cultural competence namely by Sue (1998).

Equally problematic is the definition of race. According to the APA Guidelines the definition of race is a much-debated socio-cultural concept, rather than biologically determined category, according to which people are treated. "Race, then, is the category to which others assign individuals on the basis of physical characteristics, such as skin color or hair type, and the generalizations and stereotypes made as a result" (APA, 2003, p. 380). Finally, the term "ethnicity" does not have a commonly agreed upon definition; in the Guidelines, ethnicity connotes the "acceptance of the group mores and practices of one's culture of origin and the concomitant sense of belonging" (APA, 2003, p. 380). For the purposes of this discussion I will refer to persons of culturally, racially, and/or ethnically diverse backgrounds as ethnic minorities consistent with current US Census Bureau terminology. The phrase "Person of Color" (e.g., African Americans, Hispanics/Latinos, Asians/Asian Americans, Native Hawaiians and other Pacific Islanders, American Indians and Alaska Natives) will alternately be used.

This literature review will first offer definitions of operational terms relevant to this study, including prodrome to psychosis. Confusion about the nature of prodromal features and concerns regarding the reliability of their measurement are highlighted. A description of recent literature of the past decade describes pathways to care for the population at risk for first psychosis. Finally, research is presented regarding socio-cultural factors, including ethnicity and age, that exert internal and external influences relating to stigma and discrimination on help-seeking attitudes and behaviors.

CHAPTER TWO

Review of the Literature

Prodrome to Schizophrenia

For a review of the literature, online databases searched include PubMed, EBSCO and PsychInfo. Findings suggest that (1) for prodrome individuals the needs, issues, and specific risk factors have been limited; (2) the impact of cultural factors upon help-seeking behavior in ultra high risk population has not been well investigated; (3) few studies in the United States examine how social support and medical institutional structures impact help-seeking behavior; (4) additional qualitative research is required to evaluate patient perspectives about their social support needs, the challenges they experience and their preferred support interventions.

An essential point of departure is the operational definition of “prodromal” and “prodrome” to psychosis as related to this research protocol. Clinical usage and diagnostic criteria for a prodromal syndrome belies a rich past. Increasingly in the last decade, researchers and practitioners have described a prolonged period of attenuated negative and positive symptoms and impaired functioning. This is termed the prodromal phase, preceding the first psychotic episode of schizophrenia, and is considered a preliminary stage that signals a substantial and imminent risk of progression to frank psychosis (Bota, Sagudyu, Filin, Bota & Munro, 2008; Woods et al., 2009; Yung, Phillips, Yuen & McGorry, 2004). Indeed, prior studies have widely relied on “basic symptoms,” the subjective phenomena suggestive of a schizophrenia prodrome: inability to divide attention, thought interference, thought pressure, thought blockages, disturbance of receptive speech, disturbance of expressive speech, disturbances of abstract

thinking, unstable ideas of reference and captivation of attention by details of the visual field (Addington, 2007; Correll, Hauser, Auther, & Cornblatt, 2010; Yung & Nelson, 2011).

Throughout the body of literature, symptom recognition is extensively used almost interchangeably alongside other terms including “at-risk mental state,” “ultra high risk,” “clinical high risk,” and “putative prodrome” (Hafner & Maurer, 2004; McGorry et al., 2009; Niendam, Jalbrzikowski, & Bearden, 2009; Yung & McGorry, 1996).

Since the dawn of the new millennium, a paradigm shift in the treatment of schizophrenia has occurred and is marked by the tendency toward early intervention beginning with the stage of the prodrome (Hafner & Maurer, 2004; McGorry et al., 2009; Niendam et al., 2009; White, Anjum & Schulz, 2006; Yung & Nelson, 2011). The recent flourishing of this field of research can be understood strategically as part of a wider interest in early psychosis because the population is typically comprised of drug-naïve individuals prior to engagement with treatment, thereby minimizing confounding factors to enhance comparability across studies (Cuesta, 2002; Keshavan and Schooler, 1992). The focus of recent research on clinical trials for antipsychotic medication and its role in symptom management highlights that the predominant paradigm for conceptualizing schizophrenia has been subject to the influence of the biomedical framework, psychiatry, and psychopharmacology (Boyd, 2010).

A century ago, the term “latent schizophrenia” emerged from a retrospective understanding of the early course of the illness (White et al., 2006). Indeed Kraepelin pioneered the field of schizophrenia research by staking his claim to its phenomenological origins marked by core self disturbance (Hafner & Maurer, 2006; Nelson, Yung, Bechdoff, & McGorry, 2008), a difficult to measure symptomology to say the least. Ever since, it seems, a tension has raged between the biological model favored among the medical and psychiatric establishments, and models that

emphasize a holistic understanding, namely environmental and psychosocial stressors, in the etiology of psychosis.

A relatively new body of research in the broad scope of schizophrenia research, the “prodromal” or clinical high-risk paradigm has been manifestly plagued by inconsistent methods and terminology (Bota and Ricci, 2007; Keshavan and Schooler, 1992; Yung, Phillips, Yuen, and McGorry, 2004). A debate still rages about the predictive reliability of the term, which means that it is still unclear and unresolved whether or not one can accurately diagnose prospectively (Hafner and Maurer, 2006; Thompson, Nelson & Yung, 2011). At any rate, the definition of a prodrome as “an early or premonitory manifestation of impending disease, before specific symptoms begin,” (Gennaro, Gould & Blakiston, 1979, as cited in Woods et al., 2009, p.1) betrays an important limitation in the way in which it is understood: at the basis of this conceptualization lies the assumption that a prodrome for schizophrenia can be identified only in retrospect.

Terminology is further complicated by the unspecific symptoms of the prodrome phase. They vary, from the occurrence of concentration and attention difficulties, to sleep disturbances, depression, anxiety, derealization and depersonalization. It is not clear that such a constellation of symptoms can be definitively construed as early signs of incipient psychosis (Bota et al., 2008; McGlashan et al., 2007; Woods et al., 2009). Other researchers argue that non-specific symptoms could be the marker of an array of affective disorders such as depression and substance abuse (Hafner and Maurer, 2006; Yung et al., 2003; Yung et al., 2004) and unclear onset markers of psychosis (Yung et al., 2010). Critics of studies in prodrome cite conceptual and strategic obstacles including false-positive issue, potential stigma, and lack of predictive specificity (McGorry, Yung, & Phillips, 2003; Yung & Nelson, 2011; Yung et al., 1998). To

compete with this pervasive poor construct validity, the term At-risk Mental State (ARMS) has recently come into more frequent use, where in language emphasizes the fact that progression to psychosis is not inevitable (McGorry and Singh, 1995; Yung, 2006). Inaccurate assessment is problematic because it can bring a statistically high yield of false positives, which can bring painful distress, stigma, and increased insurance premiums (Hafner and Maurer, 2006; Niendam et al., 2009; Yang, Wonpat-Borja, Opler & Corcoran, 2010). The fear is that research and practice founded on a less than reliable diagnostic tool may risk people without psychosis being subjected to medical interventions unnecessarily. Public health ramifications of inaccurate assessment are complicated by the uncertain direction of causality of schizophrenia with poverty and social marginalization, including obstetric complications, illicit drug use and childhood trauma. “It may be that those who experience psychotic illness drift down through society via unemployment, unstable relationships, social isolation and withdrawal; on the other hand, lower socio-economic status is associated with greater stress, which may increase risk for psychosis” (Yung et al., 2007, p. 634). That risk factors for schizophrenia, including low social capital, difficulty with relationships, and increased stress from exclusion and discrimination, are readily mistaken as diagnostic symptoms has confounded preexistent research.

To be sure, criteria for the term have been reliably tested over the last 15 years, and “have been found to predict onset of first episode psychosis at rates several hundred-fold above that of the general population” (Yung & Nelson, 2011). Conversion studies find that subthreshold positive symptoms meeting prodromal criteria signify conversion rates to psychosis of 40 to 50% within one to two years (Corcoran et al., 2003). It follows that early findings in conversion studies are promising; nonetheless, the approach is simultaneously met with short- and long-term associated risks and ethical dilemmas involving interventions with individuals with unspecified

diagnosis. For these reasons, there is currently a question of whether to include ultra high risk (UHR) criteria as a transitional diagnosis in the forthcoming publication of the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (Yung & Nelson, 2011). The inclusion of UHR criteria in the DSM V, either as a disorder in its own right or as an onset specifier for psychosis, would present an important means of emphasizing the need for better recognition as well as the possibility of mandatory routine screening for this disorder. It would also pave the way for better education of health professionals in non-traditional mental health settings.

Among methodological limitations in the literature reviewed the salient features are: relatively small sample sizes, omission of a control group, and assessment criteria variability (Yung et al., 2003). Authors Woods et al., (2009) report that in only half of the studies reviewed are sample sizes larger than 50. Further epidemiological confounding issues arise in the use of ultra high risk (UHR) criteria as its predictive validity is highly susceptible to variables in any given sample and recruitment area. The specificity of target groups are compromised by interlocking factors, such as the availability and accessibility of mental health services from one area to the next, and the domain and strategies of recruitment. Understandably, UHR criteria has weak transferability across studies (Yung & Nelson, 2011; Yung et al., 2003). Moreover, UHR criteria were applied to a help-seeking population and have not been evaluated in a non-help-seeking population (Yung & McGorry, 1996).

Remarkably, qualitative research is noticeably lacking in this area despite the fact of its unique ability to describe subjective phenomenon. One exception was a qualitative research study which set out to explore the development of symptoms in individuals identified as prodromal to psychosis (Corcoran et al., 2003). Open-ended interviews were conducted with 20

parents of prodromal adolescents to describe changes observed. Findings revealed that a trajectory of change in personality, relationships, and behavior from an essentially normal baseline may be consistent with increased risk for psychosis among prodromal adolescents (Corcoran et al., 2003). This is one of the first studies to characterize adolescents and young adults who are imminently at risk of developing non-affective psychosis. Though the sample size of this study was relatively small, the strategy employed eliminates retrospective bias differentiating itself from preceding and problematic first-episode studies.

As a whole, the literature reviewed uniformly suggests that prodromal individuals are symptomatic and at high and imminent risk for psychosis, have impaired functioning, and are help-seeking. Despite many methodological limitations, research about this population provides significant data useful for minimizing the negative outcomes of acute psychosis. The next section will discuss research within the last decade that focuses on understanding barriers to access and to appropriate intervention, both significant areas for study for their potential to reduce the period of untreated illness.

Pathways to Care

As public health concern. The rationale for the focus in research on early intervention in prodromal psychosis, in part, stems from the reported relationship between the duration of untreated illness (DUI) and poor outcomes in psychotic disorders, poor vocational and social functioning, and impairments in subjective and objective measures of quality of life, such as damage to social networks, educational and vocational outlets (Addington, van Mastrigt, Hutchinson, and Addington, 2002; Norman & Malla, 2001; Yung et al., 2007) and also sustained disability and premature death (McGorry & Yung, 2003; Yung et al., 2007). Structural brain abnormalities and gray matter loss (Keshavan et al., 2003) have also been observed with

prolonged untreated illness. Treatment delay during prodrome is a modifiable factor in outcomes. Yet longer duration of untreated psychosis was associated with poor response to antipsychotic treatment (Norman & Malla, 2001; Norman, Malla, Verdi, Hassall, & Fazekas, 2004). Such unexpected findings might indicate methodological limitations excluding contextual factors which may play a more significant role in the course of illness than previously believed. Understanding the psychological and social service impediments to early intervention is a worthwhile and necessary public health concern (Hafner and Maurer, 2006; Lincoln & McGorry, 1999; McGorry et al., 2009).

Pathways to care vs. help-seeking behavior. Throughout the literature reviewed, the term *pathways to care* is frequently defined as “the sequence of contacts with individuals and organizations prompted by the distressed person’s efforts, and those of his or her significant others, to seek help as well as the help that is supplied in response of these efforts” (Rogler & Cortes, 2008; Singh & Grange, 2006, p.76). Though the phrases are indeed inter-related, “pathways to care” are differentiated from “help-seeking.” The latter phrase is specifically understood as a three part process beginning with problem definition, followed by the decision to seek help and finally the selection of a treatment provider (Cauce et al., 2002). Help-seeking behavior, as it is commonly understood, stems out of the behavioral health model of health services use initially developed over half a century ago to define and measure attitudes, access, and need for care (Andersen, 1995). For the majority of empirical research into health services utilization, the model has been useful in examining help-seeking pathways because it acknowledges societal factors, health services system factors, and individual factors. Yet, the Andersen model has been criticized (Bradley et al, 2002) for not fully exploring how these domains are interrelated, for minimizing the role of psychosocial factors and oversimplifying the

impact of race and ethnicity. The model and subsequent research falling within this paradigm has failed to comprehensively explore attitudes, expectations, and self-determination and contextual factors like discrimination and stigma. Systematic reviews by Singh and Grange (2006) and Anderson, Fuhrer and Malla (2010) report a persistent focus on individual determinants contributing to mental health care utilization, including demographic predictors, diagnoses and severity of symptoms in the majority of studies examined. Contextual factors, such as relationship functioning and intersecting systemic dynamics that predict service utilization, are still largely understudied. This highlights the underlying ideological tension between models that emphasize biological factors over environmental and psychosocial stressors in the etiology and pathology of psychosis. Furthermore, this points to a much-needed area of social work research inclusive of a social-constructivist approach to mental health help-seeking behavior.

Determinants of pathways to care. Although pathways to care among psychiatric patients in general have been an area of empirical examination for over a decade (Amaddeo et al., 2001; Linden, Gothe, & Ormel, 2003), it is only recently that empirical studies have included people experiencing a first episode of psychosis (Lincoln & McGorry 1995, 1999) and a systematic review of studies of pathways to care in first-episode psychosis concluded simply that pathways are diverse and varied (Singh & Grange, 2006). Moreover, little is known about pathways to care among patients with first-episode psychosis in the United States (Addington et al., 2002; Compton, Esterberg, Druss, Walker & Kaslow, 2006; Skeate, Jackson, Birchwood, & Jones, 2002). Even fewer studies have examined contacts made during the prodromal phase (Anderson, et al., 2010; Norman et al., 2004). Clearly the small number of studies limits drawing any decisive conclusions.

There is agreement that the following barriers are salient among help-seeking psychotic individuals and their families: lack of caregiver involvement; poor literacy; substance abuse and homelessness (Lincoln, Harrigan, & McGorry, 1998); severity of the problem; propensity and attitudes about seeking help; accessibility of services; availability of alternative resources; family attitudes and coping styles (Addington et al., 2002; Bechard-Evans et al., 2007; Skeate, Jackson, Birchwood, & Jones, 2002). Demographic descriptors impeding pathways include “being single being unemployed, living alone, living in public housing and ethnic minority status” (Morgan et al., 2005; Singh and Grange, 2006, p. 81).

Privatized health care. A systematic review of pathways to mental health care of first episode psychosis patients (Anderson et al., 2010) examined articles published between 1985 and 2009, and found that among the 30 total, only two studies examined mental health care in the U.S. The focus of the review was the nature and determinants of pathways to care of patients experiencing first episode psychosis found that, while the most commonly cited first contact was a physician in the European studies, in the U.S. emergency services was widely the first contact. This nascent body of literature derives from diverse countries, including Australia, Belgium, Canada, Dominica, France, Germany, Norway, Trinidad, and the United Kingdom (Addington et al., 2002; Morgan et al., 2005; Norman et al., 2004; Skeate et al., 2002). The preponderance of European study locales presents severe limitations on transferability of findings across study groups because of differences in access, public health policy, insurance, etc. Hence, findings are more applicable to countries with nationalized healthcare systems and therefore even less is known about pathways to care in privatized mental health care.

Given the paucity of studies based in the United States, a deeper exploration of barriers and pathways to care in the U.S. should not overlook a specifically political reality, such as the

influence of state policies and market-driven insurance coverage plans. In addition, personal financial status, insurance costs and free-care options are subject to the influences of socio-demographic characteristics (Sturm & Ringel, 2003) and are significant determinants of segregated healthcare in a privately funded healthcare system (Archie et al., 2010; Snowden & Yamada, 2005). One fact is clear: disparities of insurance coverage are pronounced. It is hardly disputed that in comparison to Whites and individuals of higher socio-economic status (SES), ethnic minority and low SES individuals report experiencing more instrumental barriers to using services, such as lack of insurance and transportation (Clark & Anderson, 1999). Researchers have found that even among diverse populations with equivalent levels of private insurance, ethnic minorities utilize treatment less than Whites (Thomas & Snowden, 2002). African Americans are almost twice as likely as Whites, and Hispanics almost three times as likely as Whites, to be uninsured (Smedley et al., 2003).

A review of the literature identified barriers to mental health care in the U.S. generally as follows:

First, failure among patients, families, law enforcement, mental health providers to recognize the presence or seriousness of symptoms; second, . . . uncertainty where to seek help . . . ; third was a lack of financial resources, insurance, or transportation . . . Less reported were: lack of insight, embarrassment around seeking psychiatric care, cultural and language barriers . . . ” (Judge, Perkins, Nieri, and Penn, 2005, p. 268).

The authors (Judge et al., 2005) argued that reliability of this investigation is enhanced by a “‘topographical approach’ which emphasizes perspective of clients” (Lincoln et al., 1998; Lincoln & McGorry, 1999, as cited in Judge, 2005, p. 466). Furthermore, under-recognition of

symptoms as a primary barrier to care is endorsed globally and documented by Singh and Grange (2005) in a systematic review of worldwide research in first-episode psychosis.

Referral pathways. The international focus of recent research also functions to highlight the role played by referral systems integral to pathways to care because of such variables as sample site and timing of the referral along the course of illness. In the UK, general practitioners serve a primary function as gatekeepers to secondary services (Compton et al., 2006; Morgan et al., 2005). Referral pathways involving general practitioners showed similarity across other high-income countries (Skeate et al., 2002). Addington et al., (2002) elucidated three phases of prodrome stage in which different referral paths of help seeking are observable. In the pre-psychotic phase, marked by negative symptoms of schizophrenia, family physicians were more common than teachers or psychologists as referral sources for clients. Once positive psychotic symptoms were readily observable, the most frequent contact was between the patient and emergency services (Anderson et al., 2010; Norman et al., 2004). Third, in the psychotic phase, most often contact was initiated by the patient and the patient's family. Research investigating referral pathways are susceptible, by definition, to variables including poor assessment skills by primary care and family practitioners to identify the signs and symptoms of mental illness (Lincoln et al., 1995; Lincoln et al., 1998; Skeate et al., 2002). Finally, early intervention via a general practitioner or family primary care physician is more prevalent among African Americans than Whites, while referrals for psychiatric care are less prevalent (Addington et al., 2002; Merritt-Davis & Keshavan, 2006). These findings highlight disparities in assessment, detection and diagnosis of mental illness among African Americans, a phenomenon that will be explored in further detail later in this literature review.

In summary, studies of initial treatment seeking by affected patients and pathways to care have faced conceptual and methodological problems and have received little attention in the U.S. The fact that the most commonly cited barrier to care was a lack of understanding about psychosis is an area that this research intends to explore. Nonetheless, there is general agreement in the field regarding the complexity of pathways, which can include general practitioners, psychiatric services, social services, police, and school counselors.

Ethnicity and Access to Care

Prior studies into severe mental illness research on the whole have shown that immigrants and refugees are more susceptible to mental illness because of potential mental health stressors, such as: pre-migration experience, migration trauma, acculturation, unemployment, and structural characteristics of the new society that oppress or limit opportunities for newcomers (Morgan et al., 2008; O'Mahony & Donnelly, 2010; Snowden and Hu, 1997). In addition, Asian immigrant families are likely to encounter challenges like language, work, racism and discrimination, and acculturative stress (Shea, Yang and Leong, 2010). Nevertheless, empirical research on pathways to mental health care among specific racial populations and ethnic minorities remains extremely limited (Merritt-Davis & Keshavan, 2006; Morgan et al., 2005), and is especially lacking in comparisons between prodrome populations from different ethnic groups. This points to a much-needed area of research into the social determinants of help-seeking behavior.

According to a systematic review of studies investigating pathways to mental health care of first episode psychosis patients (Anderson et al., 2010), five reports of thirty examined contacts made in the prodromal period; and seven included ethnicity as a covariate and only one assessed the African American population exclusively. Three of the four studies reporting ethnic

differences in the pathway to care also found evidence of differences in compulsory admissions for ethno-racial minority patients (Archie et al., 2010; Morgan et al., 2005). Canadian and British studies found that African-Caribbean and Black African patients were less likely to be referred by a general practitioner and more likely to have police involvement on their pathway to care when compared to White patients (Anderson et al., 2010; Compton et al., 2006; Morgan et al., 2005). A study from Canada found that Asians and patients of other ethnic backgrounds (not including African-Canadian) were three to four times more likely to make first contact with emergency services than White patients (Archie et al., 2010). This is supported in research findings by Merritt-Davis and Keshavan (2006), that found higher rates of involuntary civil commitment and police involvement for African Americans. A study evaluating help-seeking among African American, Latino and Caucasian youth, discovered that African American families, when compared to Caucasian families, are less likely to seek help from agencies and professionals, and more likely to contact family and community sources (Brawner & Waite, 2009).

A study was found noteworthy because it explores cultural differences in access to care in the U.S. health care system (Compton et al., 2009). This study contributed important findings about health services-level factors as determinants of treatment delay among urban, socio-economically disadvantaged African-American patients with a first episode of non-affective psychosis. Effects of three health service-level predictors - namely, presence or lack of insurance coverage, of financial problems, and of other barriers (for example, transportation problems, not knowing where to go for help, and having difficulty getting time off from work) as reported by family members were measured. The intent and methodology were unique as a

means by which to explore demographic, socio-economic, and ethnic variables as the primary objective rather than only a mediating factor for other analyses.

Insight and Explanatory Models

Culturally diverse conceptualizations of the highly subjective phenomenology of psychotic illness, and in particular relative to early stages of psychosis in schizophrenia, are fundamental to appropriate recognition and treatment (Bowers, 1977; Lysaker, Tsai, Maulucci, & Stanghellini, 2008). Race, ethnicity, acculturation, and social stressors of immigration impact the symptomology and significance of psychiatric disorders within a social context (Shea & Yang, 2010). Explanatory models of illness can in turn influence treatment satisfaction and compliance (Kleinman, 1988), such that socio-cultural differences may impact help-seeking and may account for non-compliance (Constantine & Sue, 2005). A study comparing explanatory models of illness in schizophrenia (McCabe & Priebe, 2004) found that Whites cited biological causes more frequently than non-White groups, who cited supernatural causes of illness more often. A biological explanatory model was related to enhanced treatment satisfaction and therapeutic relationships but not necessarily treatment compliance. Further evidence was detailed in a single case study examining the psychiatric experiences of a Korean-American immigrant man. Analysis led authors to conclude that in collectivist cultures, which emphasize group conformity, deference to authority, indirect communication, emotional restraint and repressed expressiveness, interpersonal style and avoidant coping behaviors may appear an anomaly in traditional Western settings (Shea, et al., 2010). That culture shapes the experience and expression of mental illness is worth note.

The concept of insight into psychosis is surely a difficult object of standardized measure for clinical usage. The phenomenon has been given shape by three disparate and coinciding parts:

namely, the subjective recognition of mental illness, compliance with treatment, and the capacity to fathom unusual cognitions as pathological (David, 1990). Insight in psychosis has disputably come to be understood as a socio-cultural construct (Amador, Strauss, Yale, & Gorman, 1991). This notion assumes congruence between the patient and clinician and is the outcome of an interactive process of self-understanding and social context. In a qualitative study comparing insight in patient-family-clinician triads among immigrants with schizophrenia, there was a strong correlation between patient and family but not between patient and clinician (Tranulis, Kirmayer & Corin, 2008). These findings suggest that insight can be understood as the meaning given to psychotic experience and that the process of making meaning is a context-dependent adaptation reflecting particular life experiences and other social determinants. This is consistent with a cultural constructivist view of insight that has been, since the inception of psychiatry, in opposition to the notion of an empirical measure based on the clinician's judgment as a gold standard. That cultural psychiatry (Kirmayer, Corin, & Jarvis, 2004) has been deemed a distinct branch of psychiatry reinforces the dichotomy and would require a paradigmatic shift in research and clinical practice.

Young Adulthood as Risk Factor

A particularly vulnerable population that has not been given large focus in early schizophrenia literature includes at-risk youth and young adults. Research indicates that most adolescents and young adults with serious mental health problems do not receive adequate treatment (Cauce, 2002). Psychosis is a particularly relevant topic for Transition Age Youth (TAY), being that the typical onset of schizophrenia is between the ages of 16 and 25, and the incidence of schizophrenia increases for individuals ages 15-18 (TAY Resource Guide, 2007). This age bracket represents a distinctive transition to adulthood leaving many somewhere

between child and adult mental health services to “fall through the cracks” (Pelosi & Birchwood, 2003). Research into help-seeking behavior is especially vital for patients in adolescence because this is a period where lifelong patterns of coping can be established. Psychosis can be a life-changing experience, so that this might be the first time an individual is concerned with his/her own health. Thus the population represents a unique opportunity to nurture more informed consumers of health care.

As a target demographic, youth experiences of early psychotic symptoms are often hidden and ignored (Boydell, Gladstone, & Volpe, 2006; Cauce, 2002; Corcoran et al., 2007) and difficult to discern, as adolescence is a stage of behavioral changes and evolving ego identity development. Difficult to describe and not always noticeable at first, symptoms are easily mistaken by family members and school teachers for teen angst and rebelliousness, drug use, and the stress of hormonal fluctuations (Corcoran et al., 2007). Likewise, isolation and social withdrawal is commonly mistaken for the marked need for privacy and self-reliance indicative of an age-appropriate quest for mastery (Cauce, 2002). Clearly, then, there are diagnostic impediments inherent to the age group that can interfere between the onset of symptoms and the decision to seek help. Emerging empirical data into racial and ethnic differences in clinical diagnosis of young adults has shown that African American youth received more externalizing diagnoses than did European American youth. “Potential explanations for these findings include biopsychosocial origin, clinician bias, discordant normative behavioral expectations between parents and service providers and interaction between differential expression of underlying pathology and tolerance for such expressions” (Minsky et al., 2006, p.558).

Alternative routes to mental health treatment such as social services are an overlooked aspect when considering adolescents’ help-seeking behavior (Addington et al., 2002; Cauce et al., 2002;

Snowden and Yamada, 2005). Services like the child welfare system, primary and non-primary care clinics, and the juvenile justice system are not equipped to provide adequate clinical care for the level of mental health problems which they encounter. Compared to White adolescents, African American adolescents with social and emotional disorders are more likely to end up in the juvenile justice system (Cauce et al., 2002). Furthermore, ethnic and racial minority children and adolescents are referred for mental health treatment from involuntary sources more often than are White youths (Cauce et al., 2002; Yeh et al., 2002). The reality of such racially disparate pathways to care underscores the inescapable socio-cultural influences impinging on adolescents and their families at all stages of responding to the onset of illness.

Role of the Family and Social Network

Many studies attest to the crucial role played by significant others in the patient's social network in seeking help for emerging symptoms often because relatives and friends were more likely than individuals themselves to notice changes in behavior (Boydell et al., 2006; Corcoran et al., 2007; Judge et al., 2005). In addition, understanding the role families play in early decision making is important because families are often the initiator of first treatment, despite their report not knowing how to access appropriate services (Amaddeo et al., 2001; Compton, 2006). Yet, the paucity of available data in research on families facing first and pre-psychosis has been acknowledged (Addington et al., 2002; Amaddeo et al., 2001; Compton et al., 2006).

Cross-cultural concepts of social network. By buffering individuals from the ill effects of stressful events and by influencing attitudes about using mental health services, social networks may have a protective effect on people's mental health. And while it is widely accepted that social networks can serve a protective function for individuals with impaired mental health,

social networks may inhibit help seeking and service selection, depending on the socio-cultural norms (Cauce et al., 2002).

In the field of cross-cultural psychology, literature concerning cultural differences in collectivist and individualist ideologies is well documented (Koydemir, 2010; Sue, Zane, Hall, and Berger, 2009). As we understand it, culture helps shape one's orientation toward self and others and one's values of interdependence or independence. When comparing Asian Americans to European Americans, the authors theorize that "individuals with interdependent self-construal may avoid the experience and expression of strong emotions - especially negative ones - and decide against seeking professional help as such behaviors may bring shame to the family and disrupt in-group harmony," (Shea et al., 2010, p. 213). Kumar and Browne (2008), studied mental health service use by Maori and European people of New Zealand and found that despite having a larger and presumably more supportive social network, Maori were more likely to obtain mental health services. The authors found that ethnic differences existed based on valuation given to kinship or individualism by each culture interacting with the receptivity or prejudice of the host community. These studies indicate that culture impacts the individual's perceived causes, meaning and severity of symptoms, and that help-seeking behavior and attitudes about expected outcomes vary in relation to specific cultural norms as well as to the context in which they are experienced.

Family systems. Research within the framework of a family systems model has concentrated on both how the family tolerates symptomatic behavior in addition to affecting help-seeking behavior. Yung and McGorry (1996) coined a "hybrid/interactive model" to describe how family interactional patterns impact the symptom presentation of the prodrome illness. In this model, a feedback loop exists in which symptoms manifest and at the same time the family responds in

certain ways, which in turn affects the individual, and so forth. Furthermore, literature suggests that family systems can collude with racial and ethnic characteristics. Namely, differences have been found in parental decisions around where their children should get help, such that White parents are more likely to have contacted mental health professionals than African Americans or Latinos (Cauce et al., 2002). In a sample of 34 urban, low-income, African Americans in the first-episode psychosis, an inverse correlation was found between family strengths (such as loyalty, respect, shared values, and trust) and delayed help-seeking in a public health care system (Goulding et al., 2008). That a short term of untreated psychosis was associated with greater family strengths indicates that the involvement of family and kinship support is a protective factor for managing symptoms before involving the medical establishment.

An additional aspect of the psychosocial impact of the family systems dynamics on the help-seeking behavior of prodromal individuals is measurement of their response to symptoms. Family interaction with a first episode of psychosis often reveals an avoidant strategy of ignoring and hiding of early symptoms, marked by excusing, secrecy and denial. As noted earlier (Norman, et al., 2007), withdrawal/social isolation and avoiding help are prevalent mediators in help-seeking behavior of patients and their families in early psychosis, especially among parents who fear that minority children will end up institutionalized.

In the review of the literature, only one study was found that focuses specifically on families of clinical high-risk and recent-onset psychosis. The aim of the study (Wong et al., 2008) was to explore the extent of perceived family burden and its impact for intervention strategies. Family burden is measured as both an objective and subjective concept:

Objective burden includes financial expenditures, assistance in daily living, supervision of problematic behaviors and negative impact on daily routines. Subjective burden

involves the psychological consequences of an individual's illness for the family, such as an increase in worry and displeasure. (p. 257)

The finding showed that in the early illness stages, with less symptom severity, involvement by family was achieved without significant disruption in their lives. The authors conclude that increased worry may in fact help to motivate families to seek help.

Emotional expressiveness. The emotional economy within a family opens up and illuminates another facet: the interaction of family systems dynamics and individual help-seeking behavior is impacted by the family's style of emotional expressiveness. In a study involving twenty-six adolescent patients at imminent risk for conversion to psychosis, findings showed a relationship in which caregivers' emotional over-involvement and positive communication at baseline was associated with an improvement in social functioning, negative and disorganized symptoms and enhanced social functioning at subsequent follow-up (O'Brien et al., 2006).

Several factors influencing pathways have been investigated, including demographic, cultural, institutional and economic factors that affect the availability and accessibility of services. However, even when access to services is similar across racial and ethnic groups, differences in usage are still apparent. The source of racial disparities in mental health utilization is not well understood. The next section of this literature review will review studies exploring the impact of stigma and race-based discrimination on help-seeking behavior among the mentally ill.

Stigma, Mental Illness and Mental Health Service Use

As has become abundantly clear, this research aims to understand the factors that keep people from seeking psychological services when they are experiencing problematic symptoms. People with mental illness and their caregivers often point to the apprehension of stigma as a mark of blemish, which acts as a major barrier to treatment seeking, treatment adherence, and

overall well-being (Browner & Waite, 2009; Corrigan, 2004; Franz et al., 2010; Kirkwood & Stamm, 2006). By definition, stigma occurs as the interplay of social and power dynamics of one entity over another and results in the loss of perceived social status (Birchwood, et al., 2007; Corrigan, 1998). Beyond individual level psychosocial facets of stigma and its influence on help-seeking behavior, it is of vital importance to consider the larger socio-political context in which these interact. Structural factors can also include the influence of the media as a social, economic, and political power entity which shapes the stigmatizing process.

Public stigma. According to Corrigan (2004), two types of stigma exist: public stigma and self-stigma. Public stigma is the perception held by a group or society that an individual is socially unacceptable and often leads to negative reactions toward them. These perceptions are often harmful because they lead to stereotyping, prejudice, and discrimination of individuals who seek psychological care (Corrigan, 2004). Culturally constructed stigma marginalizes people with mental illness and other disabilities and may restrict the individual's participation in the community. "For example, stigma may result in education and housing discrimination, a lack of public services and jobs, and other restricted opportunities. In turn, these barriers may prevent people with mental illness from living full and productive lives" (Charlton, 1998, as cited in Kirkwood & Stamm, 2006, p. 472).

Self-stigma. On the other hand, self-stigma, or internalized stigma, is the reduction of an individual's self-esteem or self-worth caused by the individual internalizing a perceived negative self-concept. Self-stigma comes forth as a complex process affecting identity transformation. In such a process, the individual renounces his/her former sense of self to a stigmatized view of oneself (Thornicroft, 2008). Help seeking in this context is a concept that may pose a potential threat to an individual's self-esteem because it may signify inferiority. Therefore, a person may

renounce help from others, even when they are experiencing personal and emotional pain, because it would acknowledge weakness, inadequacy or failure.

Self-stigma has been associated with a reduction in protective psychological variables including hope for recovery, self-esteem, and positive thinking (Lysaker et al., 2007). In a European study examining self-stigma and perceived discrimination among mental health users as a barrier to recovery from schizophrenia, results showed a correlation between level of perceived stigma with lower quality of life, the attribution of personal responsibility to the cause of illness, and avoidant coping strategies specifically withdrawal and secrecy (Brohan, Elgie, Sartorius & Thornicroft, 2010). Clearly, there are varying personal responses to internalized stigma and negative attitudes affect treatment seeking behavior.

Associative stigma. The psychosocial effects of individual stigma can also be understood in terms of social group theory whereby an individual may be more likely to avoid treatment if it is believed that his/her family members endorsed the belief that mental illness is a disgrace to the family or signifies incompetence (Corrigan, 1998; Vogel et al., 2006). Within the theory of collective self-esteem, an individual's perceptions of stigma as indicated by his/her particular social network may affect his/her attitude toward seeking mental health services, and eventually the likelihood of actually doing so. A closer examination of the relationship between family as social group and the role of stigma indicates family systems level coping strategies. "Stigma is pervasive among families of individuals with psychotic disorders and includes both general and 'associative' stigma – that is, the process by which a person is stigmatized by virtue of association with another stigmatized individual" (Wong, et al., 2008, p. 2). In Wong's study, stigma in families of individuals in the early stages of psychotic illness was low and only ethnic minority families of individuals with recent-onset psychosis endorsed a sense of shame and need

to conceal the patient's illness. However, non-White families of individuals in the prodrome to psychosis did not endorse associative stigma. This finding is confounded by the stage of illness and its potential impact on stigma reports by families of youth in pre-psychosis.

Research concerning the deleterious effects of stigma is wide (Birchwood et al., 2010; (Brohan, Elgie, Sartorius & Thornicroft, 2010; Lysaker, Davis, Warman, Strasburger, & Beattie, 2007) and suggest that coping mechanisms can include: negative emotional reactions, harmful behavioral coping strategies, and structural discrimination. In a study comparing coping strategies used by adolescents with and without subclinical psychotic symptoms, findings revealed that the adolescents with subclinical psychotic symptoms used avoidance-type coping strategies more frequently and positive-type coping strategies less frequently in comparison to the control group (Fonseca-Pedrero, et al., 2010). Birchwood et al., (2007) presented empirical research that explored the emotional aspects of the experience of stigma associated with social anxiety and found that participants felt that the diagnosis caused social marginalization. Aversion to treatment because of label avoidance has been linked to a decrease in help seeking of professional psychiatric services in a sample of U.S. college students (Vogel, Wade, & Hackler, 2007). Therefore, not only is the presence of a disorder but also seeking psychological services is stigmatized by the public.

Composite stigma. The composite effects of stigma are, thus, various and compounded by multiple aspects of social rank theory and discrimination. Corrigan and colleagues (2003) reported that 50% of subjects with severe mental illness experienced stigma related to their illness. Among these, African Americans, Asian Americans, and gay and lesbian participants also reported high rates of discrimination due to their race or sexual orientation, thereby indicating that one source of stigma does not displace the other. People of Color may experience

the stigma of psychiatric pathology as yet another form of prejudice along with housing, education, and employment discrimination (Corrigan et al., 2003), to the extent that the cumulative effect of the experience of stigma among People of Color in the mental health system, more than for White people, is well-documented (Wong, et al., 2009; Richman, Kohn-Wood, & Williams, 2007; Yang, 2010).

Differential rates of utilization of the mental healthcare system by ethnic minority populations in comparison to Whites may be related to greater stigma in the African-American community, in which mental illness can connote the idea that the individual is morally inferior (Browner & Waite, 2009; Merritt-Davis & Keshavan, 2006), contaminated or dangerous (Wong, et al., 2009). In a study examining cognitive factors in cross-racial mental health help-seeking behaviors among college students, perceived stigma for seeking help was more evident among African American students than for Caucasian students, and that having a positive attitude toward service use was the only significant predictor of help-seeking intentions (Bagley, 2010).

Clearly, stigma is a complex phenomenon for which we can surmise that these varying constructs of stigma function together within an interacting system and social context which in turn exert influence over help-seeking behavior, attitudes towards and access to services. These may pose barriers to appropriate care, however, little is known about stigma in the early stages of evolving psychotic disorder.

Racial Discrimination

Racism is a malady that persists within the U.S. and research efforts continue to investigate the role of racism on the mental health of African Americans (Brondolo, Brady ver Halen, Pencille, Beatty & Contrada, 2008). Research indicates that the incidence of schizophrenia in ethnic groups was higher when these groups perceived more discrimination (Veling, Hoek &

Mackenbach, 2008). Race-based health disparities have been consistently linked to the cumulative effects of racism itself in collaboration with the environmental conditions that help to sustain it, such as limited access to coping resources, low socio-economic status, limited opportunities and housing segregation (Clark & Anderson, 1999), which in turn can have psychological ramifications such as depression, low self-esteem and humiliation and social defeat (Veling et al., 2008). Finally the mere awareness of prevailing negative cultural stereotypes has been associated with poor mental health and academic underachievement (Veling et al., 2008).

Disparities in help-seeking behavior exist between Whites and People of Color. The relationship of race-based discrimination and help-seeking behavior are inconsistently correlated co-determinants. The stress of discrimination could increase the need for services and social support as a buffer of the effects of racism (Brondolo, et al., 2008). Alternately, mistrust based on past research abuses and experiences of systemic racism and discrimination by the U.S. health care system (Brawner & Waite, 2009; Merritt-Davis & Keshavan, 2006) may also pose significant barriers to service utilization.

In a community sample of 1,000 White and Black Americans in a Midwestern metropolitan area, findings of an investigation into individual factors influencing mental health service utilization showed that for Black Americans, past discrimination and identity markers were more important than structural variables such as education or income. Feelings of affinity to other Black Americans (Identity 1: “Regard”) were related to increased utilization, while high levels of racial self-concept (Identity 2: “Centrality”) were associated with decreased utilization. For Whites, only psychological distress and gender were significantly associated with service utilization. Results suggested that for Black Americans, the extent to which prior exposure to

discrimination affects help-seeking behavior depends on one's racial identity. These differences suggest that socio-cultural experiences, such as discrimination and group identity, are more prominent variables explaining race disparities in service use, and that different variables help explain service use among White respondents (Richman et al., 2007). Furthermore, the authors' hypothesis that past experiences with discrimination would be related to lower treatment seeking, particularly among those who are highly identified with their race, was not supported in their results. That this relationship was not found may suggest that discrimination for Blacks may be better conceptualized as a type of cumulative stressor. Such stress would increase rather than decrease the likelihood that people would seek care, especially when racial identity is low (Richman et al., 2007).

The findings of this study were consistent with findings of a study examining the relationships of self-reported psychological distress, social support, and willingness to seek mental health counseling among Black and Latino college students. Data enumerated reasons to avoid accessing formal mental health resources, such as college or university counseling centers, including potential stigma, strong level of affiliation to their culture; cultural values prioritizing inter-dependence and distrust of a White mental health counselor (Constantine et al., 2003).

While few empirical studies have considered the relationship between particular types of racism and specific emotional and psychological reactions, Carter and Forsyth (2010) collected and coded participants' descriptions of remembered instances of racial micro-aggressions against a scale measuring their help-seeking reactions such as levels of intrusion, hyper-vigilance, avoidance, et cetera. Patterns of help seeking in response to racism were remarkably similar for all racial groups that included Latinos, Asians, and African Americans. The outcomes found only 12% of participants sought help from psychologists and other mental health professionals and

instead were more likely to seek out friends and family. These findings are consistent with previously mentioned literature regarding the relationship of self-stigma associated with professional help-seeking as an inhibiting factor in an individual's decision to seek mental health services. On account of "healthy paranoia" and "cultural mistrust" (Browner & Waite, 2009), African American adolescents are less likely than Caucasian counterparts to acknowledge the need for mental health services when they believe they may be stigmatized by their healthcare provider.

In conclusion, acknowledgement of need and utilization of formal mental health services by African American young adults experiencing prodromal psychosis are influenced by a variety of factors. Racial disparities are evident in barriers to care including accessibility, such as insurance coverage thus financial ability to pay for services; subjective perceived need and stress thresholds; and trust towards culturally competent providers. Help-seeking behavior is a complex phenomena existing within a network of interacting dynamics in the social environment that have myriad psychological and behavioral consequences.

Summary

Social theorists have long contested the reductionist viewpoint that human behavior is simply a matter of personal choice or simply a reflection of cultural differences. Help-seeking behavior is a composite of psychosocial and cultural forces that are the consequence of dynamic interplay between individual and family, cultural values and beliefs, and social systems level factors. Few studies however have closely studied the effects of culture, its impact on help-seeking behavior and its interaction with other environmental dynamics in psychopathology. Essentially the underpinnings of this investigation uphold that collective cultural competency is an oft overlooked area of medical and psychiatric research and that a cultural collision exists between

the culture of the mental health profession and that of marginalized patient populations. Barriers in access to services are often explained as cultural differences rather than the social structures and psychological interactions that may limit full participation by non-Whites with norms, values, and beliefs that differ from the mainstream mental health system (Bhui and Singh, 2004).

The literature review illuminates some gaps existing in what is known about ethnic and racial differences in help-seeking behavior for prodrome psychosis. There is limited research available that has examined non-White, prodromal patients' perspectives about their needs, access to and experiences of the mental health care system. The aim of this article is therefore to describe what prodrome to psychosis patients perceive to be the barriers to seeking mental health services, and how these compare between White and non-White participants.

CHAPTER THREE

Methodology

Research Design

The purpose of this study was to identify psychosocial barriers influencing the behavior of help seeking for mental health services among a population of individuals in the prodrome to psychosis. The primary aim was to describe how the perspectives of the prodrome individuals of Color compare to those of White individuals on their perceived needs, barriers and attitudes relating to mental health services. The design of this thesis research brings focus to a few research questions stated succinctly as follows:

Is there a measurable difference between barriers most commonly cited by People of Color (POC) and by White-identified people? Is there a measurable difference between stigma as a barrier to services for POC compared to White people? Second, is there a correlation between severity of experienced discrimination and the quality of experiences and attitudes towards mental health services?

This descriptive investigation utilized mixed-methods to assess help-seeking behavior by a semi-structured questionnaire (Appendix A). This investigation is based on a secondary analysis of existent data. The questionnaire used predominantly closed-ended questions to ascertain first demographic information, and then to describe specific pathways to care and decisions of early help-seeking behavior. The questions and answers were created to measure behaviors conforming to the rubric of the traditional medical setting in which the research protocol was designed, recruited and evaluated.

The questionnaire also employed open-ended questions asking participants to use their own words to describe the first concerns about their behavior, and to explore their decisions of when and where to seek help, as well as rate their experience obtaining mental health services. Questions were designed to help individuals recall retrospective information about pathways to care. Phrasing of the question and answers can be seen in the addendum.

The rationale for using a mixed methods approach, in which both qualitative and quantitative data are measured is advantageous because as a legitimization tool, it triangulates the sources of information and enhances validity (Andrew & Halcomb, 2006). This approach has the potential to corroborate findings or reveal paradoxes that may otherwise have not been discovered. This is an appropriate choice of method for this study that endeavors to understand psychosocial factors, that are more complex social phenomena, and improves the credibility and representativeness of a small sample size. To be sure, such an approach has been used in related studies (Yeh et al., 2003). As will be described in the following section, the mixed method approach was also used to analyze findings.

Sample

Recruitment. The sample was drawn from the Supplemental Diversity Project of a larger National Institute of Mental Health funded research grant under the Center for Intervention Development and Applied Research (CIDAR) administered through the Commonwealth Research Center of the Beth Israel Deaconess Medical Center (BIDMC) Public Psychiatry Division of Massachusetts Mental Health Center (MMHC). The aim of that ongoing study, entitled “Vulnerability to Progression in Schizophrenia,” is to study subjects who are at various stages of progression of the disorder, “prodromal” (clinical high risk), first episode and chronic, to provide

a broad perspective and database on phenotypic markers and predictors of progression as well as normal controls.

Participants were recruited from the metropolitan Boston area, and included both males and females: 75 persons in the prodrome (PRO). Inclusion criteria required that participants were fluent English speakers and that one family member was available for interview. Among those meeting prodrome criteria, participants' age ranged from 13-35 years. Subjects were given informed consent and paid for their participation. The only exclusion criteria were substance abuse, an inability to speak English and/or inability to give consent. This study had approval from the Institutional Review Boards at the BIDMC. The clinical high-risk group of patients was identified as 'prodromal' to psychosis using diagnostic criteria for a prodromal syndrome according to the DSM IV. The sample included subjects under the age of 19 if the participant met diagnostic criteria for Schizotypal Personality Disorder or the diagnostic criteria called the Criteria for Prodromal Syndromes (COPS).

From the recruited population meeting prodrome criteria, a selection of prodromal participants were selected based on whether he/she and an immediate family member agreed to participate in the Mental Health Services Interview. Selection of patients was not random and represented a sample of convenience. The sample for this study ($N=15$) included 9 Caucasian; 4 Hispanic; 1 African American and 1 Multi-Racial participant.

Data security. Provisions for maintaining confidentiality were met at the outset of the original study and anonymity was maintained by assigning an ID number to participant data. All information was de-identified to protect participants' confidentiality. Electronic data was been stored on a password-protected computer on a secure firewall server at the MMHC. Patient files were locked in a cabinet, accessible to only study staff members. For the purposes of this

secondary data analysis, data shared were limited and were not representative of the entire questionnaire (Appendix).

Possible risks and benefits. There was no immediate benefit for participation. It is hope of this researcher that enrollment as part of the long-term NIMH research study may bring benefits to participants in the future by virtue of consistent and close monitoring of symptoms. On-going participation with the research staff and clinicians increases the likelihood of early detection of emerging symptoms of psychosis and early intervention has been linked to improved outcomes in the course of schizophrenia. Finally, especially for young adults and patients in the first onset, there is invested interest in contributing to further research in an impoverished body of knowledge about early psychosis.

The questionnaire presented minimal risk to participants beyond potential mild frustration or discomfort. The consent procedures permitted that subjects could decline to respond to particular questions or could withdraw their overall participation at any point. Implicitly, the consent procedure is an empowering part of research whereby the participant is more actively involved in the joint process and increases his/her own sense of investment, personal responsibility and choice.

The potentially distressful or harmful effects of participation were minimized as a function of the chosen method of secondary analysis. Qualitative secondary analysis (QSA) is portrayed in recent literature on methodological studies as an “invisible enterprise” for which there is a “notable silence” (Boydell and Gladstone, 2006). It is a useful method of capturing nuanced subjective phenomenon. In addition, data sharing minimizes patient contact with the research community, such as repeated, lengthy and invasive interviews and bureaucratic procedures. As a

graduate student in-training, the decision to employ this approach was to decrease any likelihood of exploiting an interview with a high-risk client population (Roth, 2005).

However, one aspect of the study potentially exposed the prodromal individual to greater than minimal risks: that they may have learned for the first time that they have a psychiatric disorder. The potential risk that both the adolescent and family member may have had an emotionally upsetting reaction to this information was a sensitive issue. Another significant risk was the risk of false positive detection of psychosis and increase likelihood of the deleterious effects of stigma related to early diagnosis (Bota & Ricci, 2007). Efforts were taken to minimize potential risk through the provision of honest information about the nature of the study and about generally accepted notions of psychosis, schizophrenia and risk for families. In addition, the research team explained to the participant and his/her family that no more specific information would be available to them concerning specific risk estimates. That is, the purpose of the research, to explore the unknown link for any prodrome about the risk of schizophrenia, was explained in written and verbal communication with the participant.

Data Collection

The Mental Health Service Questionnaire was administered to PRO cases and controls, as well as their parents, at baseline or another convenient time during the course of the study.

Estimated interviewing time is 10 to 11 hours over three days. The interview was focused on a semi-structured questionnaire measuring participants' experiences with mental health services involving predominantly closed-ended questions with multiple choice answers and fewer open-ended. When no response was given, a numerical value was given to closed-ended questions.

When no response was given to open-ended questions, the data was omitted. Of the data shared (30 multi-part questions total), ten were open-ended, exploratory questions.

Responses were recorded close-to-verbatim by one of two female interviewers of similar non-White ethnic background. Data was transcribed by a co-investigator into an itemized Excel spreadsheet. Cooperative work with research investigators was constrained because data had already been collected and transcribed and this researcher was only granted partial access to the results of the questionnaire. It is unclear whether the interviewer pursued answers to qualitative questions or to what degree she elicited further elaboration by the participant.

Data Analysis

First, to examine the effects for ethnicity, race information was sorted into two categories – *White* and *People of Color* – because limitations of the sample size prevented a significant quotient of subgroups within the minority sample (e.g., African American, Hispanic, and other). Combining all ethnic groups into a singular *People of Color* category was a valid approach because for the purposes of this study, any effect of race-based barriers to mental health services may signify the experiences of being a member of a minority ethnic group.

In order to examine the most commonly cited barriers to care, statistical analysis using frequency and sum total of barriers (Q21) was performed using Excel software. Percentages of agreement were calculated within each race category to determine strength of agreement for comparison purposes.

For the second part of the research question [is there a correlation between severity of experienced discrimination and the quality of subjective experiences and attitudes about mental health services?] a two-part correlation analysis was employed. First, frequency of the discrimination data (Q5Aa-Bk) was measured according to severity scale and type. Possible responses about type of discrimination experiences were based on the following choices: *skin*

color, ethnicity, gender, age, appearance, disability, sexual orientation, religion, income, accent. *Other* was offered but no responses were provided by either group.

Data was then compared to data generated by the question “How would you describe your first experience obtaining mental health services?” (Q25B). Responses were scaled as follows: 0 (*neutral*), 1 (*very bad*), 2 (*bad*), 3 (*good*), 4 (*very good*). Correlation analyses were run on the discrimination data and ratings which had been coded as positive or negative.

Finally, a content analysis from a phenomenological perspective was performed on the qualitative responses to questions relating to attitudes and experiences of obtaining mental health services. The responses were thematically coded and quantified to measure whether ratings were positive or negative. Direct quotes were used to minimize researcher bias and to increase reliability and validity in data interpretation. Codes revealed patterns which extrapolated recurrent themes of meaning, ideas, and feelings. Here themes identified will explicate the role of ethnicity and race in meaning-making of symptoms, mental health literacy, attitudes and other factors that promote concordance or discordance between patient and provider. Themes regarding subjective experiences and attitudes about mental health services were examined under the framework of grounded theory and interpretive phenomenological analysis. These models were utilized because they privilege participants’ experiences and first-hand perspective and support the social constructivist view that person and world are mutually constitutive.

The first hypothesis predicts that lack of awareness of illness will be the most common barrier for both groups, and that for other barriers, race disparities will be revealed: Among prodromal People of Color, we will find greater occurrence of systems-level barriers compared to White prodromal people. The second hypothesis is that there will be a negative correlation between levels of discrimination experienced and favorable ratings. That is, the higher the

discrimination level, the lower the concordance between patient and provider. It is not expected that there will be significant variance of barriers as measured across racial categories.

Limitations of these findings will be hindered by the small sample size which prevents the generalization of findings. Replicability is constrained by the effect of state-specific infrastructures that define pathways to mental health care. In addition, recruitment bias is predicated on a clinician's assessment of suitability and is subject to diagnostic bias. Attrition rates may be affected by aversion to a stigmatizing label confounding poor recruitment and high refusal during the screening phase. Reliability and validity are subject to retrospective bias, a methodological confound in prodrome studies (Yung, 2010). Furthermore, qualitative data analysis is limited by researcher bias and professional allegiance to the NASW Code of Ethics. Findings of this study are limited further by a coarsely hewn category according to a racial binary system, which by no means suggests that one ethnic group is like the other or that no variability exists within each ethnic group (Cauce, et al., 2002). Given these limitations, findings of qualitative data will focus on meaning rather than causal relationships.

CHAPTER FOUR

Findings

The purpose of this study was to examine the mental health help-seeking behaviors of prodrome to psychosis individuals. The research question sought to describe the perceived psychosocial barriers to care using a mixed-methods design to explore the experience-near data of the participants ($N=15$). This research project focused on:

(1) What are the barriers to care most often cited? (1b) Are there measurable differences in the most commonly cited barriers to care as cited by White people and by People of Color (POC)? (2) Among the barriers, is there a measurable difference in stigma-related barriers according to race? (3) Among prodromal participants who cite past experiences of discrimination, is there a correlation between the severity of the experiences of discrimination and the quality of the attitudes and the experiences obtaining mental health services? The hypothesis was that there would be a negative correlation between severity of discrimination experienced and favorable ratings. That is, the higher the discrimination level, the lower the concordance between patient and provider.

Results indicated that several variables were important to the help-seeking behaviors of all participants and that race disparities were evident in the working alliance with mental health providers. The most commonly cited barrier across racial categories was worry about affordability. Participants of Color had more systems-level barriers to mental health services than their White prodrome counterparts. White participants in comparison to People of Color more frequently endorsed stigma-related barriers; People of Color reported a greater magnitude and

content of discrimination experiences. From qualitative data emerged themes indicating that racial disparities are evident in the attitudes, perceptions, and experiences of the client-provider relationship.

The results of this study are presented in the following four subsections. The first section details the demographic data of the participants. The second section identifies the perceived barriers to care with a special focus on stigma related barriers. The third section presents the discrimination data and looks at the correlation between experiences of discrimination and of obtaining mental health services. The final section presents the qualitative findings on experiences of obtaining mental health services.

Demographics

Overall sample characteristics. The sample for this study ($N=15$) included mixed socio-demographics. The median age of respondents in the sample was 19.7 years with the maximum age being 25 and the minimum 13 years of age. Of the total number of respondents ($N=15$), 5 were female and 10 were male. Respondents answered an open-ended question asking to describe oneself in terms of country of origin, culture and/or ethnic group. Responses included 9 Caucasian; 4 Hispanic; 1 African American/Black and 1 Multi-Racial respondents. The percentages of total sample breaks down as follows: 6.7% “African American” or “Black”; 26.7% “Hispanic”; 6.7% “Multi-Racial”; and 60.0% “White or “Caucasian.” After grouping into race binary categories, 40% of total sample were coded as “People of Color” and 60% as “White.” The average age of the Caucasian respondents was 19.4 years, similar to the average age of POC respondents at 20 years of age.

Quantitative Findings

Barriers to obtaining mental health services. Participants were asked to identify their level of concordance with 13 statements citing reasons for *not* seeking help from mental health professionals (Q21). Responses were scored using a common scale of agreement where 1 = *not at all true*, 2 = *somewhat true*, 3 = *true*, and 4 = *very true*. Percentages were calculated using the possible sum total strength of agreement in each racial group against the actual value. Then, cumulative percentages were calculated in order to rank the most commonly cited barriers. The table below presents the five most frequently cited barriers for each group.

Table 1

Most Commonly Cited Barriers to Seeking Mental Health Services

Statement: It would be hard for me to see a mental health professional because	Person of Color		White respondents		Cumulative Score of Agreement
	n = 6	% true	n = 9	% true	
I would not afford to	12	50%	17	47%	97%
I would refuse to go	10	42%	14	39%	81%
I do not know where to go/who to ask	10	42%	15	42%	84%
I know people who have had bad experiences	10	42%	11	31%	73%
I would be afraid I would be told I am a bad person	8	33%	15	42%	75%
I don't believe the mental health professional can understand my needs	11	49%	12	33%	82%
I would be ashamed of my illness	8	33%	14	39%	72%

As Table 1 illustrates, for both groups the most strongly endorsed statement was “affordability” concerns, followed by “know[ing] where to go/who to ask.” Among these seven barriers, the

least endorsed statements among Participants of Color were tied at 33%. Each of these concerns was related to avoidance of stigma: “I would be afraid I would be told I am a bad person” and “I would be ashamed of my illness.” On the other hand, for White participants the least endorsed of these seven statements was (at 31%) “I know people who have had bad experiences.” The standard deviation between responses was 0.07 for POC and 0.06 for Whites. The average strength of agreement was 42% for POC and 39% for Whites. A comparison of agreement ratings shows that POC scored higher in all statements except fear of being a bad person and being ashamed of the illness. Furthermore, comparisons between racial groupings showed that the largest discrepancy in level of accord was a difference of 16%, with People of Color more in support of the statement “I don’t believe the mental health professional can understand my needs.”

Stigma-related barriers to obtaining mental health services. Pursuant to the above table (Q21), a more specific focus on additional barriers characteristically stigma-related were examined. Additional stigma-related statements were identified from among these as: “I am afraid they would not understand me because of my cultural background,” (signifying internalized stigma and discrimination), and “I am afraid people at the mental health agency would tell other people about my illness,” (signifying concerns about confidentiality, privacy, and fear of public stigma). Respective to the former statement, findings showed that agreement scores were 7 (29% endorsement) by POC and 9 (25% endorsement) by Whites. For the latter statement, findings showed agreement scores were 6 (25% endorsement) by POC and 2 (36% endorsement) by Whites. These findings indicate that for People of Color, both of these statements fell below the statistical mean of the most commonly cited barriers. On the other

hand, among White respondents, fear relating to confidentiality concerns was less than one standard deviation from the mean, signifying a greater level of endorsement.

Discrimination data. Respondents were asked to identify whether or not they had ever experienced discrimination and to rate its severity. Discrimination was itemized according to the following qualifiers: *skin color, race, gender, age, appearance, disability, sexual orientation, religion, income and accent or other*. Three of the total respondents reported never having experienced discrimination of any sort; 2 were identified POC and 1 as White. A -0.47 correlation exists between having ever been discriminated against related to perceived skin color-based discrimination. And -0.53 correlation was found between having had an experience of discrimination and race/ethnicity specific discrimination.

The following table depicts the ratings of degree of severity of the discrimination data and percent of total for each race group, for comparison purposes. Responses were scored using a common scale of degree of severity, where 1 = *not at all*, 2 = *a little*, 3 = *a fair amount*, and 4 = *quite a lot*. Ratings on “income”, “accent”, and “other,” were not included in this table because of empty results. Percentages were calculated using the possible sum total degree of severity in each racial group against the actual value. Then, cumulative percentages were calculated in order to rank the most severely perceived discriminations.

Table 2

Severity of Prior Experiences of Discrimination

Characteristic of Discrimination	Severity Ratings			
	Person of Color (n=6)	%	White (n=9)	%
Skin color	13	54%	11	31%
Ethnicity	13	54%	12	33%
Gender	9	38%	13	36%
Age	7	29%	16	45%
Appearance	11	46%	14	39%
Disability	8	33%	10	28%
Sexual orientation	10	42%	9	25%
Religion	6	25%	11	31%

In Table 2, the statistical mean of severity ratings was 40% among POC and 32% among Whites. The standard deviation of severity level was 11% in ratings by POC and 6% in ratings by Whites. The most strongly rated discrimination characteristic was tied evenly at 54% between skin color-based discrimination and ethnicity-based discrimination by respondents of Color. The least severe experience of discrimination among POC was religion-based. For White respondents, the most strongly rated experience was age-based discrimination and the least severe was sexual orientation-based discrimination. A comparison of severity ratings shows that POC scored higher in all categories except age-based and religion-based discrimination.

Obtaining mental health services. Respondents were asked to rate their level of satisfaction with first experiences obtaining mental health services. Responses were scaled as

follows: 0 = *neutral*, 1 = *very bad*, 2 = *bad*, 3 = *good*, and 4 = *very good*. Among participants of Color, four responded that the experience was “good,” one responded that it was “bad” and one responded that it was “very good.” Among White participants, four reported “good” experiences; one responded “bad”, one responded “neutral”, and one responded “very good.” In all, two White participants did not respond.

Table 3

Quality of First Experience Using Mental Health Services

Race Group	Ratings					
	Neutral	Very bad	Bad	Good	Very good	No response
PoC			1 (17%)	4 (67%)	1 (17%)	
White	1 (12%)		1 (12%)	4 (45%)	1 (12%)	2 (22%)

Based on Tables 2 and 3, in which three participants total did not report prior experiences of discrimination, the correlation coefficient for the total study sample found was -0.06 between ever having experienced discrimination and scaled ratings of satisfaction with services. Thus no statistically significant relationship was found between subjective reports of severity of prior exposure to discrimination in relation to the quality of first experiences of treatment.

Qualitative Data

Compliance with suggestions by providers. Respondents were asked whether they did or did not follow the suggestions given by providers at the first onset of stressful behaviors, and to explain why. Overall, two White participants (22%) did not respond; seven out of nine White respondents (78%) unanimously answered “yes.” Meanwhile, among the People of Color, five out of six (83%) respondents of Color reported they had followed suggestions, and one (17%)

did not follow suggestions. Qualitative responses across both racial groups reflected the desire to understand symptomatic behavior and to “get better.” Upon closer examination, subtle differences across racial groups were observed in the explanations given. Content analysis found overall themes of trust vs. mistrust, personal agency vs. disempowerment, and externalization vs. internalization.

White respondents offered explanations expressing mutual agreement with and trust in the provider to ameliorate symptoms. This is evidenced by the following answers: “It made sense, depression runs in my family”; “I trust him, I wanted to do something about it at that point”; and “they would work and resolve the conflict.”

Among reasons offered by People of Color, themes reflected a sense of disempowerment and loss of agency. The following is a salient example provided by a 16-year old Hispanic male who reported coercion as a rationale for compliance:

I wanted to go home. I stayed in the hospital for a month, got therapy, spiritual group (didn't like it) . . . I was scared and mad that police took me to hospital. I didn't know what was going to happen. Mom called the police because she thought I was going to hurt her.

His comment reflects themes of displacement from familiar contexts (home, mother, spirituality group) and powerlessness against the justice system and medical establishment. Additionally, the following statement was reported by a 19-year old Hispanic male: “His advice was trustworthy as he had worked at the college for some time.” A subtle shift in the locus of trust and expertise to an external source is discernible. In contrast to the aforementioned statements made by White participants, which privileged personal attunement, safety and feeling understood, this latter statement conveys a deferential, passive tone that may have underpinnings

in a belief system which imbue an unquestioned authority and power to another institutional hierarchy (in this case, the university).

Finally, there was one outlier among total respondents. The outlier was a 25-year old Multi-Racial male who reported “no” (*did not follow early suggestions*), and presented an exceptional instance of cultural dissonance: “My parents did not believe in Psychology . . . I do not like taking medications and did not want to try any.” Though the unequivocal sentiment is not reflected in other data, the significance is notable.

Experiences of White participants obtaining mental health services. Participants were asked to elaborate further on their ratings of their first experiences obtaining mental health services. The codes identified were related to the positive experience characterized as comfortable, respectful, open/non-judgmental, trustworthy and empathically attuned. The negative responses revolved around themes of internalization vs. externalization of blame.

Among the nine White participants, two did not respond, five had positive reviews and two had less favorable or neutral reviews. The following excerpts illustrate how White participants described positive experiences as feeling identification with the provider. A 21-year old Caucasian male state, “I felt respected. I felt I overwhelmed the Social Worker who might not be ready to hear what I had to say. The Social Worker was very helpful as she believed me.” A 16-year old White male responded, “[the] therapist was very empathic. Gave good advice and insight, worked carefully with the meds I was taking.”

A 16-year old Caucasian female responded that the clinician was “awesome, a cool person-[an] adult with a teenager mind, understood me.” Here, an ego-supportive therapeutic alliance is characterized by identification with and idealization of the clinician.

The remainder of statements by White participants expressed ambivalence or dissatisfaction attributed to external, situational factors. A 23-year old Caucasian male stated, “I didn't feel comfortable, didn't like advice, same person mom was seeing, didn't want to be there in the first place . . . My mom wanted me to.” One respondent described the experience as “decent” and offered reasons of “divorce, adjustment, mom was concerned.” This statement was coded thematically as externalization of the subjective burden of the problematic treatment experience. Similarly, another report by a 23-year old Caucasian male ascribed reasons for misattunement to misaligned treatment goals, environmental stressors and externalization of blame: [I had a] “bad roommate, they weren’t helpful; the main problem [was] with Housing Authority . . . the therapist didn’t understand the system.”

Experiences of People of Color obtaining mental health services. Building-off the themes identified above, experiences of People of Color were in contrast characterized as uncomfortable, lacking empathy and misattuned. Among the six participants of Color, one did not respond, and the remainder relayed that while they attested satisfactory experiences in the end at first each unanimously felt awkward. The following excerpts illustrate how participants of Color described their therapeutic relationships. One 18-year old Black female stated, “I didn’t know what was wrong with me. I was able to talk openly but it was hard to figure out what to say.” An 18-year old Hispanic stated, “[it was] awkward, hard to tell someone what’s bothering me, got better later.” An 19-year old Hispanic participant stated, “I felt a bit uncomfortable at first . . . I had not been to a [mental health professional] before but became much more comfortable by end of first session.” An 18-year old Hispanic male answered that the clinical experience was “awkward, [it was] hard to tell someone what's bothering me, got better later.” A 24-year old Hispanic female participant reported:

[I] figured out that it would be best to try to work things out myself . . . [I was] treated well but didn't feel it was productive or helping the situation. [They] asked a lot of questions, felt like doctor wanted me to figure out my own problem.

This latter quote raises questions relating to the respondent's possible attitudinal conflict about the experience – a sentiment of approbation and over-compliance and simultaneous self-reproach relating to the inefficacy and incompatibility with the provider. Collectively, the reported statements were coded thematically as internalizing the burden of a problematic working alliance. Challenges faced in the treatment relationship were explained in terms of self-blame, ambivalence and frustration relating to perceived ignorance, incompetence and failure to improve.

Researcher Bias and Limitations

In addition to aforementioned methodological limitations, the small sample size of this study and limited access to descriptive demographics may yield poor generalizability and transferability of findings. It is beyond the scope of this thesis to address confounding factors such as gender, living situation, and financial stressors that undoubtedly impact the multi-faceted dimensions of help-seeking behaviors. Another confounding factor is the mode of onset, as according to a study by Chien and Compton (2008), variability exists in the way in which a particular mode of onset impacts the pathways to care. Confounding factors beyond the scope of this research also include the individual's stage of illness and coping strategies, the particular degree and quality of his/her family involvement, and cultural norms that influence attitudes, stigma and health knowledge about seeking mental health services. In addition, a skewed recruiter bias may reflect particularities of a help-seeking, English-speaking, Boston-metro population rather than the prodrome and/or non-help-seeking population at-large. Potential bias

exists in the recording and transcribing of qualitative material which was subject to the Principal Investigator's editing and paraphrasing rendering secondary data near-verbatim. In addition, the qualitative secondary analysis is further subject to interpretive bias as codes were developed in isolation and may reflect this researcher's ideological and professional commitment to principles edified in the National Association of Social Worker's Code of Ethics.

Summary

Findings showed that many factors impede help-seeking behavior but the most common perceived barrier to care is affordability for both race groups. Racial disparities were evidenced in the overall quantity, intensity and characteristics of perceived barriers. Findings also showed that stigma-related barriers were statistically less significant concern for People of Color than for Whites. Results of the discrimination data showed that People of Color reported more frequency and more severity of experiences overall and that the content of the most intensely experienced discrimination was skin color and ethnicity based. Compared to White respondents, People of Color reported more severe discrimination experiences in all categories except age-based and religion-based discrimination. No statistically significant correlation was found between subjective reports of severity of prior exposure to discrimination in relation to the quality of first experiences of mental health services. However, a content analysis was performed on the qualitative responses to questions relating to attitudes and experiences of obtaining mental health services. The responses were thematically coded and quantified to measure whether ratings were positive or negative. Themes included personal agency vs. powerlessness; trust vs. mistrust; and internalization vs. externalization. Correlation analyses were used to assess whether an association could be traced between the subjective reports (dependent variable) and independent variables (race and discrimination). No statistically significant differences of race disparity were

found, however by extrapolation, thematic patterns suggested a negative correlation between levels of discrimination and qualitatively coded ratings of the treatment experience. That is, the greater the severity of experienced discrimination the less favorable the rating of the working alliance.

CHAPTER FIVE

Discussion Chapter

The purpose of this study was to describe the psychosocial factors that impact help-seeking behavior among individuals in the prodrome to psychosis. The mixed-methods study more closely examined ethnic and racial disparities in perceptions of need, access, and experiences of the mental health system. The results of this study confirmed past research on common barriers to care, and that barriers were greater for People of Color. Findings showed that Whites perceived more stigma-related barriers despite reporting more favorable experiences and attitudes about mental health service providers. Statistical correlation analysis did not support prior literature regarding race-based discrimination and help-seeking attitudes. Qualitative findings were consistent with recent literature regarding the efficacy of culturally competent care in the therapeutic dyad. A comparison of the existing literature and the current study results will be discussed in greater detail. Final sections will discuss study strengths and limitations, and implications of the findings for social work practice, policy and research.

Discussion of Literature and Findings

Descriptive findings of the most commonly cited barriers to care were congruent with findings published by Compton et al. (2009), that identified patients' financial concerns as the most cited barrier. However, this finding is inconsistent with findings reported previously by researchers (Judge et al., 2005; Singh & Grange, 2005) who noted first, the failure to recognize symptoms, followed by ignorance of where to seek help, and finally, financial resources as

barriers in descending order of importance. In this study overall, there was a greater endorsement of affordability concerns by both groups which is supported in the literature suggesting that health care, insurance and economics are significant mediators in a privately funded healthcare system (Archie et al., 2010; Smedley et al., 2003; Snowden & Yamada, 2005).

That the results of this study showed a prevalence of barriers for People of Color more than for Whites was not surprising (Clark & Anderson, 1999). A compelling finding revealed that the least significant reasons cited by People of Color for not seeking professional mental health services were related to the shame of illness and “being told I am a bad person.” Furthermore, that the only barriers to care more strongly supported by White participants than by People of Color were stigma-specific barriers corroborates the former finding. Together, these data are significant because not only does label avoidance in the context of mental illness exist regardless of race (Corrigan, 2004), but also because this racially disparate phenomenon may help to elucidate the process of self-stigma. One interpretation of these findings may suggest that minority race and stigma together function as protective factors and thus, in effect, promote professional help seeking. This may have more to do with the effects of cumulative stress as proposed by Richman et al. (2007) such that prior socio-cultural factors are prominent variables explaining race disparities in service use. The finding that People of Color in this study did not internalize negative beliefs about the “self” evidences a resiliency and adaptability that can be understood as a defensive strategy, a psychodynamic phenomenon that merits further exploration. As such, the disavowal, or refusal, of self-stigma may signal a process whereby the individual’s past exposure to discrimination in fact has functioned to increase his or her adaptive coping strategy of self-preservation. Absence of self-stigma is, in this interpretation, an act of distancing the self from the oppressive “other.” This would disprove findings by Veling et al.

(2008) that reported psychological ramifications of stigma to include depression, lowered self-esteem and social defeat. Instead, this finding may elucidate the process of self-preservation by a cyclic emotional reaction and consequent behavioral response engendering “healthy mistrust” (Brawner & Waite, 2009). In this way, systematic oppression and subjugation increases awareness and resiliency, the ability to overcome adversity, and optimism in regard to help seeking. On the contrary, White people in this study endorsed self-stigma and therefore internalized a more harmful negative self-concept despite positive experiences in treatment. This finding is consistent with the suggested theory, however additional variables, such as socioeconomic status and sexual orientation, conflate internal mechanisms of self-concept and defensive coping. Level of race- and ethnic-identity and self-esteem measures are proposed areas for further investigation into the role of self-stigma in help-seeking behavior beyond the parameters of this study.

The finding that participants’ lack of confidence that mental health services can help is consistent with prior research (O’Callaghan et al., 2010), however that this statement was found to be the most racially discrepant barrier has not been accounted for in prior literature. The race distinction between patient’s level of agreement with statements that stigma and discrimination are barriers is an important one that may increase our understanding whether help-seeking attitudes and behavior patterns are better explained by self-cognitions versus system bias. This finding may correspond to qualitative findings, to be discussed below, suggesting that People of Color were reluctant to trust providers.

Discrimination data. That the findings showed that People of Color experienced the most frequent and severe experiences of discrimination is consistent with literature (Anderson et al., 1989; Brondolo et al., 2008; Clark & Anderson, 1999; Richman et al., 2007; Veling et al., 2008).

And that the most commonly endured types of discrimination were tied evenly as skin color-based and ethnicity-based is hardly surprising (ibid). Furthermore, the non-significant correlation between levels of discrimination and satisfaction with services disproved the hypothesis of this study and was inconsistent with Constantine et al. (2003). These findings are conflated by the highly subjective nature of the question and the inherent bias at the time of the interview. That is, a participant may not feel comfortable admitting past experiences of discrimination as a means of self-preservation in a moment when he or she is already feeling vulnerable. This interpretation is supported in literature suggesting that African American adolescents are less likely than Caucasian counterparts to acknowledge the need for mental health services when they believe they may be stigmatized by their healthcare provider (Brawner & Waite, 2009).

Qualitative data. Findings showed that “trust” was a strong predictor of compliance with suggested treatment by mental health providers for both groups. When participants trusted their mental health provider they were more likely to follow suggestions for treatment and follow-up. A closer examination of racial disparities using content analysis yielded divergent themes of trust vs. mistrust, personal agency vs. disempowerment, and externalization vs. internalization among White and Non-White participants, respectively. This suggests that the perceived lack of concordance with mental health care providers by People of Color impedes attitudes towards seeking professional mental health help services. Literature describing “healthy paranoia” and “cultural mistrust” (Brawner & Waite, 2009) among African American adolescents is consistent with these thematic findings of the qualitative data. Furthermore, the affective sentiments described are supported in social work literature that defines the tenets of the therapeutic process, including: empathy, mutuality, the dynamics of power and authority, the use of self, and the process of communication (Shonfeld-Ringel, 2001). Qualitative findings did support recent

literature regarding culturally competent care in the therapeutic dyad (Comas-Díaz & Jacobsen, 1991), relational theories and multicultural conceptual sources (Shonfeld-Ringel, 2001), and social constructivist views on illness narratives (Kirmayer, et al, 2004). Still it is plausible that the lack of concordance between providers and clients of Color may be indicative of methodological limitations and variables beyond our parameters.

Given the small sample size, limited qualitative data, and binary categorization of race groups, the risk of generalization prohibits decisive conclusions to be drawn. Still, the added detail provided by the qualitative data warrants some interpretation. First, that emergency service use was found to be a contact along a Person of Color's pathway to care was perhaps more indicative of the efficacy and potential of qualitative methodology to gather more information rather than an indication of a dominant theme. Nonetheless, the inequitable finding is consistent with literature indicating higher rates of involuntary civil commitment, emergency services and police involvement among non-Whites (Anderson, Fuhrer, & Malla, 2010; Archie et al., 2009; Compton, et al., 2006; Merritt-Davis & Keshavan, 2006; Morgan et al., 2005).

An unexpected finding regarding the role of family involvement and health literacy revealed contrasting perspectives in each race group. “[Suggestions made by the service provider] made sense, depression runs in my family,” responded a White participant, while “my parents did not believe in psychology” was the response given by a Person of Color. These viewpoints demonstrate ethnic differences in health literacy, which, it can be speculated, may relate to the participant's knowledge of his or her family history of mental illness as well as the degree of family involvement. These qualitative responses are augmented by literature suggesting that the presence of a positive family history of a psychotic disorder (Norman et al., 2007) can influence service use decision-making. In addition, it can be extrapolated that these illustrate cultural

differences in explanatory models of illness which can account for a discordant client-provider communication. Finally, the racially discrepant results support literature suggesting that the question of whether the family facilitates or inhibits help-seeking and service selection is dependent on socio-cultural norms (Cauce et al., 2002).

The real and perceived lack of culturally concordant mental health care that is readily accessible, as well as perceived to be both affordable and of good quality, influences attitudes and may impede access to care. In order to deliver effective treatment, we must focus on modifiable barriers and means for addressing them in partnership between the consumer, provider and advocates in the mental health field.

Strengths and Limitations

Strengths of this study include the mixed-methods approach whereby quantitative data was enriched by qualitative. Namely, the subjective details which lent contextual evidence would not have been garnered if barriers were strictly measured by conventional means. This proved to be a worthwhile method for a hard to reach population and a relatively new field of research. In addition, findings contribute data to a sorely needed area of analysis focusing on U.S. mental health care pathways.

However, given the small sample size and nature of secondary data, whereby only part of the questionnaire and only partial data was disseminated, results of this study are neither generalizable nor representative. Generalizability is also limited by the effects of the variability of the duration and quality of the prodromal phase among participants. A larger, more diverse sample size may have allowed for omission of the binary racial grouping and an exploration of intra-ethnic characteristics. Further, a critical analysis of current diagnostic trends is also not included, despite the fact that diagnostic trends and biases greatly influence the population

addressed in this study. Construct validity of subjective experiences of discrimination and stigma is hindered by lack of standardized measure of cultural equivalence within and between the racial binary manufactured for the purposes of this investigation. Additional data, such as insurance status, socio-economic status and level of family cohesion would have allowed more conclusions to be drawn about the interaction of cost, insurance, and attitudes in seeking care and how barriers relate to actual behavior.

The instrument used to collect data articulated an ideological bias. The method and means in which participants were recruited, interviewed, and examined was redolent of a psychiatric institutional hierarchy – one which historically has held different meanings for Whites and People of Color in relation to racism, discrimination and stigma. Assumptions of normative behavior were conveyed in the chosen language and suggested pathways that relegate certain practices as alternative and reifies others within the medical praxis. Furthermore, the curtailed field of questioning risks diminishing the capacity for response and telegraph style transcription conveys apathy rather than subtleties of rich narrative. The clear behavioral leanings and outcome-oriented questions emphasize access over attitudes and reveal a positivist ideology.

On the other hand, the way the central question of this investigation is phrased in effect severs the participant from the present and past and detaches his or her frame of judgment and realm of experience. This is in part due to the retrospective bias, also known as the “telescopic effect” in research. The inflection of the question [*It would be hard for me to see a mental health professional because...I would not afford to do so*] is particularly curious given that it departs in tense, mood, and voice from the language used in preceding questions. This *barriers question* employs the third-person inactive voice and is posed in the conditional tense but without indication of the hypothetical boundaries of the clause from the point of view of the speaker. The

subordinate clause, in the subjunctive mood, has psychodynamic implications that express a wish, emotion, possibility, judgment, opinion, necessity, or action that has not yet occurred. This may have been a conscious strategy to increase respondent rate and generate more data.

The evidence-based emphasis of the data collection instrument favors measurable evidence-based rather than relationship-based practices. Given the power differential inherent to the interview process, the emphasis may risk pressuring participants to behave differently, rather than addressing the psychosocial barriers found in the deficient health care infrastructure. This presents a familiar challenge to the social work professional confronted with the demands of managed care. No interpretations of causality have been claimed, however, and interpretations are subject to bias.

Implications for Social Work Practice, Policy and Research

Theory development. The phenomenology of prodrome to psychosis is a relatively new area in mental health theory and practice. Arguably, modern psychiatry has long neglected the subjective experiences of mental illness survivors, at the cost of understanding how larger social systems shape the experience of mental health (Kleinman, 1988). Theoretical development of the etiology of the illness through a cultural constructivist framework would have the potential to challenge the way treatment is conceptualized. A new conception of the constellation of psychosis symptoms would have implications for a preventive model of care that incorporates both psychosocial and pharmacological interventions.

Social work practice. This thesis supports improvements in early detection strategies, early intervention and engagement in outpatient services. Implications of this study for social work practice underscore the primacy of the basic tenets of the profession, namely, the person-in-situation perspective and a relational framework. Mentalization-based psychodynamic

psychotherapy with an individual in the prodrome to psychosis may facilitate engagement in treatment (Brent, 2009). Cognitive-Behavioral Therapy is an appropriate intervention in the prodrome stage for management of negative and positive symptoms of psychosis, and is supported in related literature (Evans-Jones, Peters, & Barker, 2009). Psychosocial treatments aimed at improving cognition have been increasingly found to be effective. Recent evidence supports that people with early-stage schizophrenia show healthy response to a form of cognitive rehabilitation called cognitive enhancement therapy (CET) compared to supportive therapy (Lewandowski, Eack, Hogarty, Greenwald, & Keshavan, 2011). In addition, that family involvement in help-seeking behavior has been established as a modifiable determinant points to the need for more research focused on socially oriented interventions. Wider community organizing efforts can include stigma-reducing campaigns targeting media that reinforces negative stereotypes that impair an individual's sense of self-efficacy. Finally, early intervention efforts should include readily accessible and affordable information, support, and counseling services targeted at youth and young adults.

Social work research. Findings of this project support new directions of schizophrenia research. In response to a deficits-based medical model of discourse, a recovery-orientation has been identified as a new guiding principle of mental health policy and clinical care, and is characterized by patient self-determination, interventions to promote empowerment and hope (Amering, 2010; Carpenter, 2002). It has been termed the “recovery movement” and shares a commitment to social work values by bridging the gap between consumer/survivors of mental illness and their health care providers. An analogous area is the field of participatory-action research whereby mutual collaboration between the client and practitioner at all phases of research design and implementation is an innovative approach giving expert voice to the

survivors themselves by overcoming power imbalances (Ochocka, Janzen, & Nelson, 2002). Benefits of such an enterprise would lend validity to the controversial question of whether to include prodrome criteria in the forthcoming publication of the DSM-V, the occasion of which would present an important means of emphasizing the need for better recognition by mental health practitioners.

Policy implications. Finally, the finding that fears of paying for health care services were the most commonly cited barrier to care is indicative of a flawed system of health care delivery and calls for radical change of governmental policy. Health care reform would need to address not only insurance companies and mental health parity, but also the social architecture that can help foster the individual's capacity to thrive. These include referral systems of care, the implementation of mandatory routine screenings, and professional training improvements that can help to educate mental health professionals in non-traditional mental health settings.

Conclusion

In spite of its unavoidable limitations, this study has portrayed a gamut of disparate behaviors among a population that has not been the object of rigorous examination. This study has focused on the problematic link between minority concerns and ideological, political, and societal engagement. It has argued for the necessity of an intercultural awareness not because "culture" should be held in esteem in and of itself. Rather, culture at best provides the basis for a genuine encounter between social workers and clients who find themselves at the margins of society and outside the structure of care-giving system. It was my intent to place the "encounter" at the center, which amounts to my way of understanding the responsibilities and limitations of our profession.

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Mental Health Service Questionnaire

[Patients/Healthy Controls]

CIDAR Subject: 0 = No 1 = Yes ___

If yes, CIDAR Subject #: ___ / ___ / ___

Date of Interview: ___ / ___ / ___

Interviewer: _____

Note: Interviewer writes as close to verbatim as possible for all open-ended questions

First, thank you for agreeing to participate in our study. I know that the study was explained to you, but do you have any other questions before we get started?

I. Information

1. What was the first language you learned to speak as a child? ___ 1

- 01 = English 04 = Portuguese 07 = Creole 10 = Japanese
02 = Spanish 05 = German 08 = Somalian 11 = Korean
03 = French 06 = Russian 09 = Chinese 12 = Other

2. A. Where were your parents born (town, state/province, country)? _____

1= US 2 = Other (specify):

2A1. Mother ___ 2A1

2A2. Father ___ 2A2

B. Where were your grandparents born? _____

1= US 2 = Other (specify):

2B1. Grandmother (dad side) ___ 2B1

2B2. Grandfather (dad side) ___ 2B2

2B3 Grandmother (mom side) ___ 2B23

2B4 Grandfather (dad side) ___ 2B24

3. As you know, people who live in the US come from many different countries, cultures, and ethnic groups; and some people chose to describe themselves in reference to their backgrounds. It is common to hear someone say that they are, for example, Hispanic or Latino, Black or African American, Asian American, Chinese, American Indian, Caucasian, Italian American, or multiracial.

- e. Appearance __5Ae __5Be
- f. Disability __5Af __5Bf
- g. Sexual Orientation __5Ag __5Bg
- h. Religion __5Ah __5Bh
- i. Income __5Ai __5Bi
- j. Accent __5Aj __5Bj
- k. Other [specify] __5k __5Bk

II. First Concerns

During our life time it often happens that we, or other people around us, become concerned about our behavior (For healthy controls, here is an example of a behavior of concern—“strong reaction to a loss that you care”).

6. A. Was there a time when you or somebody around you became concerned about your behavior (pattern of behavior)?

0 = No *[Go To Section III]* 1 = Yes __ __6A

B. Who was the person that first became concerned about your behavior? __ __6B

- 01 = self 05 = a friend 08 = spiritual advisor
- 02 = mother 06 = grandparents 09 = school counselor
- 03 = father 06 = doctor 10 = school psychologist
- 04 = sibling 07 = school teacher (specify which grade)

C. How old were you at that time? __ __6C

7. What was it that concerned _____? *[Use same code as 6B]* __ __7

8. *[Use italicized part if the answer to 6B is not self]*

A. When did you *[the person mentioned in 6B]* start to be concerned about your behavior? __ __8A

B. What were you *[the person mentioned in 6B]* concerned about?

C. How old were you at that time? _____ 8C

D. *[If the answer to 6B is not self.]* Was it : _____ 8D

1 = before you first became concerned or 2 = after you became concerned?

Some people use culturally specific words and some people use slang to describe a person who is acting or thinking in an unusual way or who has problems with their behavior.

9. A. Are there words *[in your culture]* that you or your family used to describe your problem that you or other people were first concerned about? 0 = No 1 = Yes _____ 9A

B. [If yes] what are those words/expressions/phrases? _____

C. What do these words mean? _____

III. Early Help-Seeking

10. How soon after you or other people first became concerned did you start to talk with someone about your problem/worries/stress?

1 = _____ weeks 2 = _____ months 3 = _____ years [specify] _____ 10

11. With whom did you first speak? [open-ended] _____

12. How often did you talk with her/him?

1= once or twice 2= weekly 3= almost every day _____ 12

13. What did they suggest that you do?

14. A. Did you follow their suggestions? 0 = No 1 = Yes ___ 14A

B. Why? _____

18. At that time, did you **also** talk with any of the following people about your concerns? *[For interviewer, I will read you a list of people, please be patient, it'll be fast]* 0 = No 1 = Yes

- a. acupuncturist ___ 18a
- b. Chiropractor ___ 18b
- c. Nutritionist ___ 18c
- d. herbalist ___ 18d
- e. counselor or social worker ___ 18e
- f. family doctor or pediatrician ___ 18f
- g. family members living in other countries ___ 18g
- h. friends ___ 18h
- i. friend of parents ___ 18i
- j. healer, such as a doctor of oriental medicine ___ 18j
- k. parents or other immediate family members ___ 18k
- l. internet support/chat group ___ 18l
- m. medical specialist such as cardiologist, gynecologist, ___ 18m
- n. neighbors, church members, self-help group ___ 18n
- o. nurse, occupational therapist, physical therapist ___ 18o
- p. school teacher, child care provider, or guidance counselor ___ 18p
- q. psychiatrist, psychologist or psychotherapist ___ 18q
- r. spiritualist such as a Santero, Buddha, Shaman, Hujan ___ 18r
- s. other [Specify] _____ ___ 18s

19. Who was most helpful to you? *(use same code as 18 and choose as many as apply)*

_____ 19

20. How did they help you? _____

IV. Obtaining Mental Health Services

Next, I am going to read you some statements that people give as reasons for NOT seeking help from mental health professionals. I would like you to tell me if each statement was:

1 = Not true at all 2 = Somewhat true 3 = True 4 = Very true

21. It would be hard for me to see a mental health professional because:

- a. I would not afford to do so. ___ 21a
- b. My family would not want me to do so. ___ 21b

- c. I would refuse to go. __21c
- d. I don't know where to go or who to ask about mental health services. __21d
- e. I am afraid they would not understand me because of my cultural background. __21e
- f. I would not have time because I have too many family responsibilities. __21f
- g. I would be ashamed of my illness. __21g
- h. I would be afraid I would be told I am a bad person. __21h
- i. My parents couldn't take off work to take me to see someone. __21i
- j. I couldn't take off work/school to see someone. __21j
- k. I know people who have had bad experiences with mental health professionals. __21k
- l. The places where I get services are far away. __21l
- m. I don't know anyone who has seen a mental health professional to tell me what to expect. __21m
- n. I am in poor health. __21n
- o. I don't think that I have a mental health problem. __21o
- p. I do not know when I need to see a doctor. __21p
- q. I have no transportation available. __21q
- r. I don't believe the mental health professional can understand my needs. __21r
- s. My spiritual leaders indicate that I don't need to see a mental health professional. __21s
- t. I am afraid people at the mental health agency would tell other people about my illness. __21t

22. A. Have you sought help from a mental health professional (such as counselors, psychologists, psychiatrists, social workers, etc) before? 0 = No 1 = Yes __ __22A

B. How old were you when you were first seen by mental health professional? __ __22B

23. What was the most important reason that made you seek professional help at that time?

24. Where did you go? _____

25. A. How would you describe your experience there?
 1= very bad 2= bad 3= good 4= very good __ __25A

B. Please tell me more about your experience. _____

26. What kind of help/treatment did you receive at that **FIRST** visit? [open-ended] _____

27. Were any of the following treatments recommended at that time? 0 = N 1= Yes
- a. medication ___ 27a
 - b. group counseling /psychotherapy ___ 27b
 - c. family counseling/therapy ___ 27c
 - d. individual counseling/psychotherapy ___ 27d
 - e. career support/counseling ___ 27e
 - f. social skills training ___ 27f
 - g. cognitive behavioral therapy ___ 27g
 - h. behavior modification ___ 27h
 - i. other treatments (such as physical treatments like ECT) ___ 27i
28. A. Did you follow their advice? 0 = N 1= Yes ___ 28A
- B. If yes.....how long did you try the treatment? _____ ___ 28B
- C. How often? _____ ___ 28C
- D. If not, why? _____
-
29. How helpful do you think the treatment was for you? ___ 29
- 1= not at all 2= somewhat 3= very 4= extremely
30. Since the first time you sought help from a mental health agency/professional, how many different agencies or mental health professionals have you gone to?
- 1= No other 2= one to three 4= four to six 5= seven or more ___ 30
31. *[IF different providers]* Did any of the following reasons at any time contribute to changing your health care provider (s): 0 = No 1= Yes
- a. dissatisfaction/not helping ___ 31a
 - b. moved ___ 31b
 - c. family objected ___ 31c
 - d. I refused to continue ___ 31d
 - e. other treatment [e.g. acupuncture, spiritual healing] was more helpful ___ 31e
 - f. couldn't afford to continue ___ 31f
 - g. transportation became a problem ___ 31g

h. Other [specify]_____ 31h

32. While you were receiving professional mental health services, were you also seeing any of the following:

0 = No 1 = Yes

a. religious advisor such as a minister, priest, pastor, or rabbi 32a

b. acupuncturist, nutritionist, herbalist or chiropractor 32b

c. healer, such as a Doctor of Oriental medicine 32c

d. spiritualist such as Santero, Buddha, Shaman, Hagan (specify_____) 32d

33. How helpful do you think they were? 33

1= Not at all 2= Somewhat 3= Very 4= Extremely



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January 19, 2011

Laura H. Wyman
Administrative Assistant/Research Sequence
Smith College School for Social Work
Lilly Hall
Northampton, MA 01063
(413) 585-7974

Dear Ms. Wyman,

This letter hereby confirms that Paula Mazzotta from the Smith College School for Social Work is granted provisional permission to use data collected from Dr. Huijun Li's investigation in the CIDAR study for Ms. Mazzotta's qualitative research in partial fulfillment of the requirements for the degree of Master of Social Work. A completed application for amendment to the IRB has been submitted and we are presently awaiting official authorization.

Thank you.
Sincerely,

Robert W. McCarley, M.D.
Professor and Head,
Harvard Department of Psychiatry,
Associate Director, Mental Health Services,
VA Boston Healthcare System

Amendment: Notification of IRB Approval/Activation**Protocol #: 2007P-000135; BIDMC****Legacy #: East HMS DMH****Grant number: 3P50MH080272-03S2 (Robert. McCarley, Huijun Li)**

To: Robert McCarley, MD

Title of Protocol: **Longitudinal Assessment and Monitoring of Clinical Status and Brain Function in Adolescents and Adults**

Sponsor Amendment #: N/A

IRB Amendment #:49

Approval Date:01/26/2011

Approval Expiration Date: 03/21/2011

This certifies that the research study referenced was reviewed by the Committee on Clinical Investigations (CCI), the appropriately authorized Institutional Review Board (IRB) and Privacy Board appointed to review research involving human subjects. This action was reviewed via Expedited review.

This amendment was eligible for expedited review and is approved as follows:

- **Addition of five study staff (not co-investigators): Stephanie Dalsheim, Gabriella Mangarella, Paula Mazzotta, and Alexandra Oldershaw.**

The following documents were reviewed and approved:

- **Study Description (Part B) revised 1/24/11**

No change in the currently approved consent documents is required.

Please note that approval for this study expires 03/21/2011, and will require continuing review prior to this date. It is the responsibility of the investigator to complete the necessary requirements to secure this approval.

Direct any questions, correspondence and forms (e.g., continuing reviews, amendments, adverse events, or safety reports) to the Committee on Clinical Investigations (CCI) at E/FN 201, or call (617) 667-0476. Additional information can be found on the CCI website:

<http://research.bidmc.harvard.edu/OST/CCI/CCIHome.asp>

Alan Lisbon, M.D.
Chairman, Committee on Clinical Investigations

2/7/2011
Date of Correspondence