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AN EXAMINATION OF MEXICAN DESCENT CAREGIVERS' REASONS FOR SEEKING
TREATMENT FOR RELATIVES WITH SEVERE AND PERSISTENT MENTAL ILLNESS

BY

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DISSERTATION

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ABSTRACT

Examining how Latino caregivers of relatives with Serious and Persistent Mental Illness (SPMI) conceptualize their relative's problems and how their relatives engage and disengage with services is a critical undertaking in light of (a) evidence showing that Latino caregivers have high levels of involvement in the care of their diagnosed relatives, and (b) consistent reports of low usage of mental health services by Latinos. Mental illness conceptualizations and experiences with seeking treatment were examined with a sample of Latino caregivers (n = 17) who were users of services at the National Alliance on Mental Illness (NAMI). We conducted a stability check of the findings with a second sample of caregivers from community venues (n = 15). Following caregivers' self-reports in standardized measures, the combined sample had elevated levels of depression and comparable levels of *familismo* (high), stigma (low), and enculturation (high) when compared to samples of Latino adults and/or caregivers. Qualitative analyses indicated that caregivers played key roles in the initiation and retention of mental health services by their relatives. A large portion of caregivers reported that psychiatric crises, family caregiver support, and early positive experiences with services played an important role in successfully engaging Latinos in services. Findings are particularly significant because: (a) they provide empirical data which are scarce in the literature on service usage processes among Latinos, and (b) qualify the degree to which common explanations, such as *familismo* and folk beliefs, might be influential in Latinos' low service usage.

*Dedicated to the family members with a loved one struggling
with mental illness. May your self-less
dedication and strength help overcome the difficult times.*

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CHAPTER 1: BACKGROUND AND SIGNIFICANCE

Serious and Persistent Mental Illness

Individuals with “serious and persistent mental illness”, or SPMI, typically suffer from a variety of mental health problems that lead to severe and chronic disability (Schinnar, Rothbard, Kanter, & Jung, 1990). The term SPMI can include various psychiatric diagnoses such as schizophrenia, bipolar disorder, severe depression, among others. However, more than just a difference of diagnoses, there is a difference in culture when individuals refer to SPMI. The concept of SPMI includes an understanding that SPMI is about a population of severely and chronically ill people and not about a DSM diagnosis, that it should include multidisciplinary treatment methods rather than just a medical physician, that a biopsychosocial rather than a purely medical approach is often used, and that functional outcomes, especially social and occupational, are often more important than symptomatic outcomes (Schinnar et al., 1990).

In the late 20th century, deinstitutionalization and significant improvements in psychotropic medication for SPMI, along with shifts in financial reimbursement policies for care, enabled many persons with SMPI to reside outside of hospitals and return to the community to pursue life goals such as a career or higher education (Brown, 1985). However, individuals with SPMI face strong deficits in psychosocial functioning thus their success in community adjustment depends on a number of factors such as utilization of mental health services, psychiatric medication usage, and strong social support networks (Kopelowicz et al., 2007; Jenkins, 1997). In fact the high levels of disability place schizophrenia alongside cardiovascular disease, diabetes, and alcohol use in terms of the high burden and costs to society (Michaud et al., 2006).

The existent data on Latino help-seeking behaviors suggests that Latinos begin the process of mental health treatment with medical health providers (Peifer, Hu, & Vega, 2000) and may under-utilize mental health services due to problems related to lack of knowledge about existing services or to other barriers to care such as lack of health insurance. Insurance is a barrier to all but can be expected to be an even more influential barrier for Latinos because: (a) undocumented and/low income Latinos are less likely to have any and/or robust health insurance (due to undocumented status and/or low skill labor), and (b) even among the insured, insurance copayments or deductibles are often unaffordable to many Latinos in low-wage jobs (Bledsoe, 2008).

Latino adults with SPMI are known to use mental health services at a low rate compared to national averages; moreover severity of problems and course of illness are worse for individuals who do not use adequate mental health services (Vega et al., 2007; Barrio et al., 2003; Kopelowicz et al., 2007). Low usage of mental health services among Latino adults with SPMI follows trends in the Latino population at-large. Rates of mental health service use for any mental illness is lower among Latinos compared to other ethnic groups (Lopez et al., 2002; Vega et al., 2007). Based on data from the National Comorbidity Study (NCS), among individuals diagnosed with a psychological disorder Latinos (5.9%) had the lowest rates of specialty care for mental health disorders when compared to non-Latino Whites (11.8%) and African Americans (7.2%) (Alegria et al., 2002). Among Mexican Americans, Vega and colleagues found that the overall 12 month rate of utilization for any medical and mental health provider was 28.2% (Vega, Kolody, Aguilar-Gaxiola, & Catalano, 1999). This same study reported that utilization rate of mental health services was 8.8% with proportionately more mental health services used in urban areas than in rural areas, primarily by U.S. born Mexican Americans and that respondents

with the least amount of education tended to turn to informal providers (e.g. family) for help with a mental illness problem (Vega, et al., 1999). Another study reported that Latinos diagnosed with schizophrenia were less likely than European Americans with schizophrenia to receive services from specialized outpatient case management (Barrio et al., 2003).

Notably, family caregivers of Latino adults with SPMI are likely to play a crucial role in engaging this population in services. First, among Latinos in the U.S. up to 70% of individuals with SPMI live with family (Guarnaccia & Parra, 1996; Ramírez García et al., 2004). Second, prosocial family caregiver behaviors among Mexican Americans are predictive of positive mental health outcomes for the affected individual (Lopez et al., 2004). Third, family caregiver behaviors have been found to predict their diagnosed relatives' medication usage and the application of social skills following an intervention (Ramirez Garcia et al., 2006; Kopelowicz et al., 2007). Taken together, this set of evidence suggests that Latino family caregivers can be influential in the course of illness and treatment processes. However, to date caregivers' role in treatment engagement and retention of their relatives remains largely unexamined. Consequently, we draw from hypotheses and literature on service usage among the Latino population at-large.

Latinos' Service Usage and the Alternative Resource Hypothesis

The alternative resource hypothesis states that low usage rates of formal services by Latinos in the population at-large are in part due to help-seeking from alternative sources including family or other spiritual/religious sources such as folk healers (Loera et al., 2009). Reliance on family members, as suggested by this hypothesis, is consistent with the notion of high *familismo* among Latinos, which refers to a high sense of obligation to, and connectedness with, one's immediate and extended family (Cuellar, Arnold, & Gonzalez, 1995). Accordingly,

research suggests that Latino caregivers tend to turn to family for support and advice when dealing with a disabled relative (Guarnaccia et al., 1992). However, empirical data that would illuminate the degree to which treatment use by Latino adults with SPMI is linked with family support are scarce. In a notable exception, Weisman (2003) found that Latino caregivers assisted relatives by reminding them to keep medical or psychiatric appointments. This isolated but notable finding suggests that family supportive behaviors may catalyze rather than deter service usage, as one might interpret with a strict application of the alternative resource hypothesis.

Religion, spirituality, and the use of folk treatments have been noted as other alternative sources of treatment often used by Latinos (Leong, Wagner, & Tata, 1995). Folk treatments or *curanderismo*, generally refer to a traditional method of healing typically by an unlicensed person who practices the art of healing of the mind, body, and spirit through traditional practices such as herbal remedies, body cleanses, and the power of suggestion (Loera et al, 2009). One study reported that just 5% of 141 Latino patients with depression sought treatment from a *curandero* compared to 34% of the patients that sought treatment from a counselor and 40% that sought treatment from a general medical provider (Sleath & Williams, 2004). Other studies have suggested that although Mexican Americans believe in folk healing, they generally under use *curanderos* and prefer to consult medical providers or resort to home remedies or self-medication (Anderson et al., 1981; Trotter, 1982; Applewhite, 1995). Taken together, the scarce data on this topic show that Latinos use alternative treatments; however the data so far do not provide conclusive evidence to suggest that alternative treatments are a major reason for low usage of mental health services in this population.

Alternative Conceptualization Hypothesis

Studies have indicated that help-seeking behaviors for mental health issues are partly influenced by how individuals perceive illness symptoms and the knowledge and attitudes they have about treatments (Cabassa, Lester, & Zayas, 2007; Lewis-Fernandez, Das, Alfonso, Weissman, & Olfson, 2005). Notably, researchers have reported qualitative data showing that some Latinos conceptualize mental illness as being a problem with *nervios* (or “nerves” in English) and as a *fallo mental*, or a “mental failure” (Guarnaccia et al., 1992). The *nervios* conceptualization of mental illness refers to describing mental illness problems as somatic problems and/or low levels of anxiety rather than acute psychotic symptomatology. Other studies have reported that Latinos have perceived mental illness as a problem caused by social factors rather than genetic or biological factors (Cabassa, Hansen, Palinkas, & Eli, 2008; Cabassa, Lester, & Zayas, 2007). Even if the assumption that such alternative beliefs interfere with formal service treatment seeking and usage, there are minimal data that show to what degree Latinos adhere to alternative beliefs. The key question of how cultural and/or alternative beliefs interfere with formal treatment use remains unanswered.

Cultural beliefs and Stigma

Cultural beliefs and attitudes may also impact mental illness views and help seeking. For example, research suggests that Latinos may have *verguenza*, or shame, in disclosing a mental illness in the family and therefore may be less likely to seek treatment (Rogler, Malgady, & Rodriguez, 1989). Research has also shown that stigma associated with mental illness is a pervasive barrier to mental health treatment, leading to negative attitudes towards treatment and preventing appropriate help by families (Conner, Koeske, & Brown, 2009). There is some evidence that suggests that Latinos view mental health conditions more stigmatizing than non-

Latino peers (Keyes et al. 2010). It may be that individuals choose not to pursue or continue formal services to avoid the stereotype, prejudice, and discrimination associated with the label of mental illness (Corrigan & Watson, 2002).

Gateways to treatment

Despite the value of understanding the forces that may pull Latinos away from mental health services (e.g., alternative resources and conceptualizations), it is also crucial to understand how contact with formal services occurs. For example, family members have reported seeking help from mental health professionals when the behaviors of their affected relatives became more alarming and treatment often begins with emergency services such as inpatient hospitalization (Corcoran et al., 2007). Notably studies have shown that Latino samples underutilize mental health services but were more likely to be admitted to *state* and *county* mental hospitals than European-Americans (Rosenstein et al., 1987). Taken together, these findings suggest that inpatient services might be a crucial point of entry to formal services when symptoms erupt despite cultural forces that pull Latinos away from mental health services. More importantly the possibility that hospitalizations are a major point of entry to services for Latinos highlights the need to understand gateways or paths to service initiation, a topic that is understudied in the literature.

Study Overview

The goal of the research is to inform policy makers and public mental health services on the family caregivers' potential role in treatment engagement and retention of Latino adults with SPMI. A qualitative inquiry was utilized for two key reasons. First, it is critical for service providers and stakeholders to understand family caregivers' perspective of treatment initiation and engagement so that any policies or services aimed at engaging caregivers take into account

their views and are more in tune with their socio-cultural lenses (Lakes, Lopez, & Garro, 2006). Second, even though the literature offers hypotheses for low usage of services such as Alternative Resources and Cultural Beliefs, treatment usage processes are likely multifaceted. Given the dearth of research on this topic among Latinos with SPMI and their family caregivers, an open perspective about this phenomenon seems warranted and is well fitting with qualitative methods that emphasize breadth of perspectives during interrogation.

The specific aims of this study were to examine Latino (Mexican) descent caregivers' : 1) explanatory models of their relative's mental health problems, and 2) their narratives of mental health treatment usage by their relative with SPMI including a) reasons for initiating formal treatment, b) reasons for continuing formal treatment and c) barriers to continuing formal treatment. Qualitative research methods have a strong emphasis on understanding the lived reality and perspectives of participants within their own social contexts (Kral, Burkhardt, & Kidd, 2002; Polkinghorne, 2005) and to capture with high fidelity the experiences of their informants (Miller, Hengst, & Wang, 2003). Therefore, we expect that qualitative methods' contributions to develop a clear understanding of help-seeking among Mexican descent families across different illness management stages (e.g., treatment initiation, retention, stoppage) will be useful in intervention development and implementation. Self-report measures were also utilized to assess key constructs related to cultural orientations and family caregiving in order to understand better the nature of the sample.

CHAPTER 2: METHOD

The total sample of 32 caregivers was recruited in two phases with different recruiting methods. First, 17 Latino caregivers who were users of services at the National Alliance on Mental Illness (NAMI) were recruited. Given that NAMI offers psychoeducation about mental illness and informs caregivers of existing resources, it is possible that caregivers who attend NAMI adhere to a psychiatric view and know of more services (and be more likely to use them) than non-NAMI attenders. For this purpose we sought a community sample to represent the experiences of caregivers who were not exposed to NAMI services. Thus, 15 Latino caregivers who did *not* have a history of receiving services from NAMI were recruited at various community venues. The research site was a major metropolitan area in the southwest with a large Latino population; at the time of the study the area had a Latino population of 80.7% and a White, non-Latino population of 14.2%. The median household income was \$37,428 with 24.1% of individuals living below poverty level.

Participant Recruitment and Procedures

NAMI Sample. Seventeen family caregivers who were receiving services by NAMI participated. Caregivers were recruited through flyers posted in NAMI offices. Caregivers that responded to the flyer were screened through phone interviews for the following inclusion criteria: a) having an adult relative with mental health problems and b) identifying themselves as the family member with the most responsibility caring for their relative. Interviews were held in private offices and were conducted by one bilingual interviewer (the first author of this study). The mean age of the caregivers was 57.6 ($SD = 8.6$). Caregivers were greeted in Spanish and asked if they preferred to conduct the interview in Spanish or English. Twelve interviews (71%) were conducted in Spanish and five interviews (30%) were conducted in English. Twelve

caregivers were born in Mexico (71%) and five in the US (29%). Informed consent was reviewed with caregivers first. Then the caregivers were interviewed on demographic and family composition information in order to ease interviewees before the in-depth interview. Caregivers filled out quantitative questionnaires and were compensated \$40.00 at the end of the interview session. All interviews were audio-recorded by the interviewer and transcribed prior to analysis.

Community Sample. Fifteen family caregivers were recruited through health fairs in the community (n=7; 47%), churches (n=2; 13%), and the waiting room of a psychiatric hospital (n=4; 27%). Two caregivers (13%) who were seeking services from NAMI for the first time, but had not received services at the time of their participation in this study, were also included. Interviews took place in the homes of the caregivers (n=1) or in private NAMI offices (n=14). The same research procedures were used as in the NAMI sample to screen for eligibility and to collect data. The mean age of the caregivers was 52.1 ($SD = 9.7$). Ten interviews (67%) were conducted in Spanish and five interviews (33%) were conducted in English. Eleven caregivers (73%) were born in Mexico and four were born in the US (4%).

Demographic Description of Caregivers and of Adult relatives with mental health problems

The NAMI caregiver sample had more years caring for their relative compared to the Community caregiver sample. The samples did not differ significantly in country of birth, language spoken during interview, and education and income level. Overall caregivers of both samples were predominantly female, born in Mexico, Spanish speakers and of low income status. Relatives' SPMI ranged from a recent onset (e.g., one to three years, n=9; 28%) to more chronic (e.g., four to seventeen years, n=23, 72%). The NAMI and Community samples of relatives with mental health problems did not significantly differ on age, number of prior hospitalizations, and country of birth (most were born in the United States). However, based on caregiver reports, the

NAMI relatives had significantly more years being ill compared to the Community relatives (see Table 1 and Table 2 in Appendix A for demographics of caregivers and adult relatives).

Qualitative Interview Protocol and Analyses

NAMI Sample interview protocol. Caregivers participated in a one-on-one 1 to 2 hour interview (administered in the language of the participant's choice) designed to elicit narratives by caregivers on the following topics: a) conceptualizations of their relative's problems, b) factors that have promoted their use of formal mental health treatment for their relative with SPMI, and c) barriers and challenges encountered while trying to use formal treatment for their relative with SPMI. The module on illness conceptualization was constructed to minimize the likelihood that questions would bias the caregivers to a psychiatric view of their relative's condition. For example, there was no mention of psychiatric terminology (e.g., "diagnosis", "mental illness", "symptoms") by the interviewer in early stages of the interview and they were only utilized once the caregiver mentioned a diagnosis or similar psychiatric terminology. The *conceptualization* module of the interview covered topics such as the worldviews of the mental health problems as well as their onset and history. The *experiences with help-seeking* module of the interview covered topics such as experiences initiating treatment for their relative, the types of formal and informal treatments the caregivers have sought for themselves and their relatives and the challenges families have faced in seeking formal services for their relative (please refer to the Appendix B for NAMI caregiver qualitative interview).

NAMI Sample qualitative data analysis. The transcripts (170 pages) of the seventeen NAMI caregiver interviews were analyzed by the research team with the Consensual Qualitative Research (CQR; Hill, Thompson, & Williams, 1997) methodology to identify major themes or topics regarding the caregivers' experiences with seeking mental health services for their

relatives with mental health problems. The CQR method involves the use of multiple researchers to reach consensus on findings across cases to enhance the reliability and validity of the results (Fuertes, et al., 2002; Hill, Nutt-Williams, Heaton, Thompson, and Rhodes, 1996). The coding team, which consisted of research assistants with little familiarity with the caregiving literature, was not informed about the specific goals of the study to minimize biased themes. The primary researcher instructed the coding team to look for thematic contents related to 1) the caregiver's conceptualization of their relative's behaviors and concerns (i.e., mental illness), and 2) experiences that influence the initiation and retention of treatment use.

The coding team consisted of eight individuals (6 female and 3 male) from diverse backgrounds. Three of the research team members were of Mexican descent and six were European American. Five of the coders were Bilingual (English and Spanish speakers) and analyzed the entire set of Spanish and English interviews. The other three coders were non-Spanish speakers; therefore they coded the five English interviews. The coding team conducted three steps to code each interview transcript: (1) assign narratives to broad domains (or themes), (2) identify sub-themes under each broad domain, and (3) identify core ideas (specific examples) from the narratives that exemplify each sub-theme for the domains. The coding team members completed the three steps independently; the independent results of the interview coding were then discussed during weekly group meetings to reach consensus on a final list of domains and sub-themes. Both Spanish and English speaking coders were present during all the group meetings in order to minimize possible biases by language of the interview or language dominance of the coders. In the next CQR step, two auditors (the authors of the paper) checked for accuracy of created themes within the protocols for each coder and across coders. Once the auditors finalized the list of domains and subthemes, the coding team generated narrative

examples (See Tables 6-9 in Appendix A for list of Domains, Subthemes, and Core Ideas/Narrative Examples).

Community Sample interview protocol. Community caregivers were interviewed using a slightly modified version of the qualitative interview used with the NAMI caregivers in phase 1. The interview was slightly modified to reflect a more open-ended interview to further minimize the possibility of respondent biases to over-report psychiatric conceptualizations and treatments and under-report beliefs in folk conceptualizations and use of alternative treatments. The length of the protocol was also shortened in order to lower respondent fatigue (See Appendix C for qualitative interview protocols).

Community Sample qualitative data analysis. The transcripts (roughly 150 pages) of the total fifteen caregiver interviews were analyzed by the research team with the Consensual Qualitative Research (CQR; Hill, Thompson, & Williams, 1997) approach. CQR methods were utilized to build upon the results obtained with the NAMI sample. More specifically, the Community Sample served as a stability check of the results obtained with NAMI caregivers. Stability check refers to the process of examining if initial obtained results explain the phenomenon accurately (Hill et al., 1997). In the present study, we examined if additional data from caregivers who have not been exposed to the programs and services offered by NAMI would reveal different aspects of mental illness conceptualization and / or service usage than those reported by the NAMI sample (e.g., new domains, categories, or relations among the categories). For this purpose, a new coding team, consisting of a team of four new coders (3 Bilingual speakers, 1 English speaker) not involved in the Phase 1 and two returning (Bilingual speaking) coders, was utilized to analyze the community caregiver data.

CQR analyses by the new coding team resulted in new sub-categories and narrative examples that emerged in Phase 1. One final audit was conducted between the authors of the paper to examine the stability of the final domains and categories. The auditors concluded that the results were stable and data analysis was concluded (See Tables 6-9 in Appendix A for list of Domains, Categories, and Core Ideas/Narrative Examples).

Caregiving and Family Measures

Quantitative measures of important constructs that have been examined in the caregiving literature, such as caregiver distress and burden, criticisms, family functioning, and levels of *familismo* (familism) were administered to both NAMI and Community caregivers in order to 1) compare the two sub-samples of caregivers, 2) situate the combined caregiver sample among larger samples of caregivers and Latino adults from studies found in the literature, and 3) better understand caregiving from a multi-method approach.

NAMI and Community Caregiver Variables

Familismo. The cultural value of *familismo* was measured with the Familism Scale (Lugo Steidel & Contreras, 2003). This is an 18-item self-report measure regarding the extent to which one values family and the role family plays in one's life. Responses are on a 10-point Likert scale ranging from 1 (strongly disagree) to 10 (strongly agree). An example item is “*a person should always support members of the extended family if they are in need even if it is a big sacrifice*”. The scale was shown to have adequate convergent and discriminate validity with a sample of 125 low-SES Latino adults, as demonstrated by its correlations with measures of acculturation (Lugo Steidel & Contreras, 2003). The developers of the scale reported Cronbach's α for the overall scale to be .83 (Lugo Steidel & Contreras, 2003) for their sample.

Behavioral Acculturation. The Bidimensional Acculturation Scale (BAS; Marin & Gamba, 1996) was used to measure linguistic and behavioral acculturation and enculturation among Latina/o caregivers. Items measure language usage, linguistic proficiency, and language preference for media in English or American culture (acculturation) and in Spanish or Hispanic culture (enculturation) with 24 items for each culture. The possible ranges for the scale are 1 to 4; higher scores indicate higher levels of acculturation. An example item is “*how often do you speak English/Spanish?*” The BAS was validated by its developers with a sample of 254 Mexican and Central American adults (74% completed the questionnaire in Spanish). The developers of the scale reported the Cronbach’s α for the acculturation subscale (English) to be .94 and .87 for the enculturation subscale (Spanish) among Mexican American respondents (Marin & Gamba, 1996).

NAMI and Community Caregiver Mental Health

Psychological Distress. Depressive symptomatology was measured with the Center for Epidemiologic Studies Depression Scale (CES-D Scale), a 20 item self-report questionnaire that assesses the caregiver’s level of distress. The respondent rates their level of distress on a 4-point scale ranging from 1 (indicating rarely or none of the time) to 4 (indicating mostly or almost all the time). An example item is “*I felt sad*”. The scale has high construct validity among Latino respondents (Liang, Van Tran, Krause, & Markrides, 1989) and among the general population (Radloff, 1977). The internal consistency of the scale was satisfactory (Cronbach’s $\alpha = 0.89$) based on a sample of non-psychiatric Spanish speakers (Vasquez, Blanco & Lopez, 2005).

Caregiver Burden. Caregiver burden was measured with the Burden Assessment Scale (Reinhard, Gubman, Horwitz, & Minsky, 1994). Burden refers to the problems that are perceived by the caregiver about his or her psychological well-being, health, finances, social life,

and relationships that are due to the changes and demands that occur as they give help and support to their ill relative (Magaña et al., 2007). The Burden Assessment Scale (Reinhard et al., 1994) is a 19-item scale that is scored using a 4-point scale ranging from 1 (indicating not at all) to 4 (indicating a lot). Responses are summed, with higher scores indicating greater levels of caregiver burden. An example item is “*I felt trapped by my caregiving role.*” The scale’s validity has been supported in studies that have differentiated between family samples with different levels of burden (Reinhard et al., 1994; Matias-Carrelo et al., 2003) and has shown to have high internal consistency (Cronbach’s $\alpha = 0.91$; Ivarsson, Sidenvall, & Carlsson, 2004).

Stigma. Stigma was measured with an adaptation of a scale by Greenberg and colleagues (1993), comprised of five items that are rated on a 5-point scale ranging from 1 (never) to 5 (always). The items ask about the extent to which family members avoided interacting and talking about a relative’s illness with family and friends for fear of what others may think of them. An example item is “*I am careful about telling people about my son/daughter because of what they might think of me*”. Evidence for validity comes from evidence that the scale is significantly correlated with co-residence between caregivers and ill relatives, greater psychiatric symptomatology of ill relatives, and a measure of caregiver burden (Link, Yang, Phelan, & Collins, 2004). The scale had satisfactory internal consistency with a sample of 85 Latino caregivers of adult family members with schizophrenia (Cronbach’s $\alpha = 0.84$; Magaña et al., 2007).

NAMI and Community Family-level Variables

Family Predictors of Psychiatric Relapse. The caregiver’s level of criticism and negative affect toward their ill relative was measured by the Family Attitude Scale (FAS; Kavanagh et al., 1997). The FAS is a 30-item questionnaire in which caregivers reported how often each

statement was true at the moment, on a scale from 0 (never) to 4 (every day). Responses are summed to give a score ranging from 0 to 120, with higher scores indicating higher levels of criticism. A cutoff of >50 correctly identified 71% of high-criticism environments and 62% of low criticism homes in the original study (Kavanagh et al., 1997). An example item is “*I feel very frustrated with him/her*”. The FAS has been shown to be a valid measure of the criticisms subcomponent of Expressed Emotion; it correlates with EE as measured with the Camberwell Family Interview (CFI) and predicts relapse in patients with schizophrenia (Hooley et al., 2006). Overall, the FAS appears to be a reliable and valid indicator of relative relationship stress and expressed anger (Kavanagh et al., 2007). There are no studies to the author’s knowledge that have utilized the FAS with a Latino sample. The FAS has been shown to have good internal consistency (Cronbach’s $\alpha = 0.95$) administered to caregivers (Manchester, 1990).

Family Cohesion. Levels of family cohesion were measured by utilizing a 9-item subscale of the 90-item Family Environment Scale (FES; Moss & Moos, 1994). The 9-items of the FES Cohesion subscale are true-false items that measure perceptions of family unity, commitment, help, and support. An example item is “there is a feeling of togetherness in our family”. Scores are coded such that lower scores for the sum of the nine items indicate greater family cohesion. The validity of the FES cohesion scale among Latinos has been empirically supported (Santisteban et al., 2003; Ramirez Garcia et al., 2010). Cronbach’s alpha for family cohesion has been reported to be .75 among a sample of Hispanic parents (Santisteban et al., 2003).

Mental Health Service Use Variables of NAMI and Community Caregivers

A service use rating scale (please refer to Appendix B, pgs.65-72), adapted from the World Health Organization (WHO) Composite International Diagnostic Interview (CIDI), was

developed to measure formal mental health service use in the qualitative narratives of the caregivers. The research team identified specific service use variables related to the affected relative's a) time of using services (past 3 months and past 12 months), b) who they saw for services, and c) current medication usage. Furthermore, caregivers' own mental health service use was measured and consisted of caregivers' a) time of using services (past 3 months and past 12 months) and b) who they saw for treatment. For the NAMI caregivers, service use was measured through the qualitative interview portion of data collection. For the Community caregivers, service use was measured using a close-ended direct questionnaire that was administered after the qualitative interview in efforts to further minimize bias to psychiatric responses by caregivers. Chi square analyses demonstrated that NAMI caregivers were significantly more likely to have their relative use services in the past three months ($\chi^2 = 3.64$, $df = 1$, $p = 0.05$) compared to the community caregivers. There were no other significant differences between the two caregiving samples (see Table 3 in Appendix A for Service Use data).

CHAPTER 3: RESULTS

Clinical Description of Adult Relatives with Mental Health Problems

NAMI Relatives' Psychiatric Variables. NAMI caregivers were probed to report their relatives' diagnosed disorder (only after extensive probing on conceptualization of the problem). Caregivers reported the clinical diagnosis made by a formal mental health service provider who provided care for their relative. The affected relatives had a caregiver-reported diagnosis of schizophrenia (n=8; 47%), bipolar disorder (n =6; 35%), and schizoaffective disorder (n=3; 18%). Furthermore, caregivers also responded to questions about their relative's psychiatric history such as age of onset for relative's illness, symptomatology, and history of psychiatric hospitalizations and treatment.

Interviews were examined to verify for the presence of symptoms that were consistent with the diagnoses reported by the caregivers. The dissertation author and supervisor, who are both trained administrators of the Structural Clinical Interview for DSM-IV Disorders (SCID; First, Spitzer, Gibbon, & Williams, 2002), reviewed each interview for reported symptoms of schizophrenia spectrum and/or bipolar disorders. The interview symptom analysis found that all 17 caregivers reported psychotic and/or manic symptoms consistent with schizophrenia spectrum and bipolar diagnoses.

Community Relatives' Psychiatric Variables. The same method to probe for NAMI relatives' psychiatric variables was used. Initially, the Community relatives with SPMI had a caregiver-reported diagnosis of schizophrenia (n=3; 17%), bipolar disorder (n =10; 56%), ADHD (n=3; 17%), and two (10%) did not have a diagnosis but were reported to have psychotic symptoms by the caregiver. Interviews were checked for symptom verification by the same procedure used with NAMI relatives. The interview symptom analysis found that 15 of 18

caregivers reported psychotic and/or manic symptoms consistent with schizophrenia spectrum and bipolar diagnoses. Therefore, the three ADHD cases were excluded from the final Community sample because they did not report symptoms of SPMI.

Furthermore, a 29-item standardized measure of psychiatric symptoms (Lehman et al., 2003) was administered to assess further the relatives' symptoms. Caregivers reported the frequency of relative's symptoms of the last 6 months on a 4-point scale ranging from 0 (not at all) to 3 (a great deal). Results from the standardized measure verified that the Community relatives had moderate (score of 2) to high levels (a score of 3) on a combination of SPMI symptoms (e.g., rated 2 or 3: hallucinations n = 10, delusions n = 13, bizarre behaviors n = 8, paranoia n = 12, racing thoughts n = 8, social withdrawal n = 14, angry outbursts n = 15, harmful behaviors towards others n = 9, offensive and disruptive behaviors n =9).

Taken together the relatives' serious mental illness ranged from a recent onset (e.g., one to three years, n=9) to more chronic (e.g., four to seventeen years, n=23). It is worth noting that there were more relatives with a reported diagnosis of schizophrenia or schizoaffective disorder (n=11; 65%) in the NAMI sample and there were more relatives with a reported diagnosis of bipolar disorder (n=10; 67%) in the Community Sample. Overall both the NAMI and Community relative samples did not significantly differ on age, number of prior psychiatric hospitalizations, and country of birth (most were born in the United States). However, the NAMI caregiver sample consisted of relatives with significantly longer years being ill compared to the Community sample (Please see Table 4: Clinical Description of Adult Relatives with Mental Health Problems in Appendix A).

Clinical Description of Caregivers

Comparison between Caregiving Samples. Tests of mean differences (t-tests) were conducted to examine differences between the two samples on the standardized measures. As seen in Table 6, the community caregivers had significantly higher levels of distress (measured by the CES-D; $M=28.8$, $SD=10.2$) compared to NAMI caregivers ($M=19.3$, $SD=9.3$; $t(30) = 2.5$, $p = .017$). The two caregiver samples did not differ in all of the other variables.

Total Caregiver Sample Variables. Table 5 shows descriptive statistics on key constructs of the 17 NAMI caregivers, the 15 Community caregivers, and the total combined sample of 32 caregivers. The Mean CES-D score for the total caregiver sample was 23.8 ($SD = 11.5$; possible scores range from 0 to 60, with higher scores indicating greater levels of depressive symptoms) based on a 4-point scale ranging from 1 (indicating rarely or none of the time) to 4 (indicating mostly or almost all the time). Notably, 22 caregivers (69%) in the study presented here met the standard CES-D cutoff score of 16 or higher, which classifies individuals as having elevated levels of depressive symptoms (Cuffel et al., 1997). This percentage of depressed caregivers is higher than the percentage (40%) reported in another study with Latino caregivers (Magaña et al., 2007, $M = 19.5$, $SD = 9.8$). The mean CES-D score for the current sample also indicates higher levels of depressive symptoms than the mean CES-D score of 10.8 observed in a non-clinical sample of 3,012 Mexican American adults surveyed in California in the Mexican American Prevalence and Service Survey (MAPSS; Vega et al., 1998).

The burden score for the total sample was 45.4 ($SD = 12.5$; possible scores range from 19 to 76, with higher scores indicating greater levels of burden), which was lower than the mean burden score ($M = 55.3$) of a sample of 94 family caregivers of relatives with severe mental disorders (Reinhard et al., 1994). The caregivers had a mean stigma score of 1.8 (1.2) based on

5-point scale ranging from 1 (never) to 5 (always), which is similar to the level of stigma reported by Latino caregivers in other studies (Magaña et al., 2007, $M = 1.9$, $SD = 1.6$). Overall caregivers reported little to no stigma through the quantitative measure of stigma.

The caregiver's level of criticism and negative affect toward their ill relative was 38.3 ($SD = 29.0$) based on possible scores ranging from 0 to 120, with higher scores indicating higher levels of criticism as measured by the FAS (Kavanagh et al., 1997). There are no known published studies that have utilized the FAS with Latino samples in the U.S. This score is lower than the FAS mean score of 55.0 ($SD = 53.8$) in a sample of 54 family caregivers of a relative with psychosis (Kavanagh et al., 2008). However, lower levels of criticism by Mexican American caregivers compared to European caregivers have been reported in the literature (López et al. 2009)

Caregiver Cultural and Family Variables. Caregivers had a moderately high mean score of 7.4 ($SD = 1.3$) on a familism scale (Lugo Steidel & Contreras, 2003) ranging from 1 (strongly disagree) to 10 (strongly agree) which is similar to the mean ($M = 7.4$, $SD = 1.2$) reported in a sample of 129 adult Latinos (Lugo Steidel & Contreras, 2003). Caregivers from the total sample had a moderately high mean score of 2.8 ($SD = 2.8$) on a scale of family cohesion (FES; Moos & Moos, 1994) based on 9 true or false items (scores are coded such that lower scores for the sum of the nine items indicate greater family cohesion). This score is similar to the family cohesion reported by 21 Latino family members of a relative with schizophrenia from another study (Weisman et al., 2005; $M = 2.2$, $SD = 1.7$). Finally, caregivers from the total sample had a higher score on Mexican enculturation ($M = 3.5$, $SD = 0.7$) than U.S. acculturation ($M = 2.6$, $SD = 0.8$) based on a scale that ranges from 1 (low) to 4 (high) (Marin & Gamba, 1996). Caregivers from the current study did not differ on level of U.S. acculturation but had higher scores on Mexican

enculturation compared to caregivers from a study of 60 Mexican American caregivers (Aguilera et al., 2010; acculturation: $M = 2.8$, $SD = 1.0$, enculturation: $M = 2.6$, $SD = 0.9$).

Overall, the combined sample had a higher percentage of caregivers that met cutoff for depression compared to other studies with Latino caregivers. Furthermore, the combined sample had moderately high levels of burden, lower levels of criticisms toward their relative, and endorsed higher levels of familismo, family cohesion, and enculturation to Mexican culture similar to caregiver samples from the literature (see table 5 in Appendix A).

Qualitative Results

Domain I: Mental Illness Conceptualizations. CQR analysis revealed a domain that focuses on the worldviews and attitudes caregivers hold regarding the illness and behaviors of their ill relative including two main categories: 1) psychiatric and 2) spiritual/supernatural. Table 6 shows narrative examples of these categories along with the percentages of the caregivers that held these conceptualizations. Compared to NAMI caregivers, Community caregivers were significantly more likely to report folk (i.e., religious/spiritual) conceptualizations and less likely to report psychiatric conceptualizations ($p < 0.05$, Fisher's exact test). It is important to note that most Community caregivers ($n=11$, 73%) and half of the total caregivers (47%) held more than one conceptualization of their relative's mental illness.

Psychiatric Conceptualizations. One major finding is that all NAMI caregivers (100%) and a large portion of Community caregivers (60%) reported a psychiatric explanation for their ill relative's illness. In other words, the caregivers either stated that they agreed with the diagnosis that was given to their relative by service providers or they explained their relative's problems in psychiatric terms (e.g., "he has a brain disorder", "he hears voices due to the illness", "a psychological problem is the cause of his behavior". For example, caregiver EP029

offered a psychiatric conceptualization of her relative's illness. EP029 is a 72-year old single mother of a 42-year old daughter who was diagnosed with Bipolar Disorder and who was reported to have experienced symptoms of mania, delusions, and bizarre behaviors during her most severe manic episodes. The mother stated that she "bought into" the notion of a mental disorder because throughout the years she observed how the medication and the hospitalization would stabilize her daughter's psychotic and manic behaviors. She stated, "*my daughter has bipolar disorder, she does not have any signs of depression, she is just very hyper and anxious...also the doctor said she was missing lithium in her brain so they gave her medication.*"

Spiritual Conceptualizations. In contrast to the mostly psychiatric-conceptualizations reported by NAMI caregivers, Community caregivers' second most reported mental illness conceptualization was a spiritual/supernatural based explanation. Out of the 15 community caregivers, six caregivers (40%) reported a spiritual/supernatural conceptualization. Conceptualizations were considered to be religious/spiritual by the coding team if the content and nature of the conceptualization dealt with religious themes such as "God's direct influence", demonic possessions, or other views that required treatment by religious or spiritual means. For example, caregiver EP023 is a 53-year old mother of a 20-year old son who had been recently diagnosed with Schizophrenia, had an onset of psychotic symptoms two years prior, and was reported to have experienced hallucinations, paranoid delusions, and aggressive outbursts at the time of the interview. Caregiver EP023 reported that although she did agree with the Schizophrenia diagnosis and was attempting to learn more about it, she mainly conceptualized her son's problem as a spiritual possession. She stated: "*Esquizofrenia (Spanish term for Schizophrenia) is not only the illness he has, it is also the enemy...it is the bad spirit taking over*

his mind in his head and his whole body. So I'll speak to Esquizofrenia and yell at her to leave him. I've learned that it's a woman spirit."

A supernatural conceptualization referred to explanations dealing with curses or spells placed on the affected family member or entire family by others with intent to harm the affected person. For example, Caregiver EP030 explained that she sought a *curandera* (folk healer) to address her son's aggressive and bizarre (i.e., hallucinations and delusions) behaviors and was explained by the *curandera* that a former partner of her son's father had placed a curse on the caregiver but had affected her son in place of her. Caregiver EP030 explained that this was one of the first conceptualizations she held and believed in because she sought the *curandera* for treatment multiple times with positive results (e.g., periods of symptom stabilization), despite having been informed by medical staff about a possible mental illness years prior during a hospitalization. Caregiver EP030 explained that although she was told about mental illness, she did not seek information about it at the time (10 years prior to the interview) and ignored the medical staff's advice to follow-up with mental health professionals.

Multiple Worldviews. As stated earlier most Community caregivers (n=11, 73%) and half of the total caregivers (47%) held multiple conceptualizations of their relative's mental illness. That is, they held more than one view regarding their relative's illness and did not just subscribe to one major explanation. For example caregivers conceptualized their relative's mental health problems as stemming from drug use (28%) and trauma (21%) in adolescence in addition to the previously mentioned spiritual explanations. Community caregivers did not report one single explanation for their relative's illness and held multiple explanations of the nature of their relative's problems and behaviors. Overall it appeared that the multiple conceptualizations held by community caregivers leaves them unsure about the nature of their relative's illness.

Domain II: Navigating of formal treatment for relatives with SPMI. CQR analysis revealed a domain that focuses on a caregiver's experiences with seeking help to address their relative's SPMI. This domain was broken-down into three main categories: A) reasons for treatment initiation, B) reasons that promote treatment retention and C) treatment barriers.

Category A: Reasons for Relatives' Initiation of Formal Treatment Use

CQR analysis led to the identification of five main sub-categories of treatment initiation factors: 1) psychiatric crisis, 2) encouragement from health professionals, 3) school referrals, and 4) treatment of a comorbid condition (See table 7 for narrative examples and percentages of reported reasons for initiating formal treatment use). Statistical analysis (two-sided Fisher's exact test) did not indicate significant differences between Community and NAMI caregivers' reasons for their relatives' initiating formal treatment use. Half of the total caregiver sample (50%) reported that the main factor that "pushed" them to pursue formal treatment was a "crisis" or "emergency" such as dangerous episodes of aggressive, violent, paranoid, or "strange" behaviors. Others reported being encouraged by a general/health practitioner (28%) or a school counselor (19%). Overall, it appears that notable to extreme disruptions in social functioning promote the treatment initiation.

Half of the total caregiver sample (50%) reported that the main factor that "pushed" them to pursue formal treatment was a "crisis" or "emergency". In other words, this factor refers to instances in which caregivers had to turn to formal treatment to address impairing or dangerous episodes of aggressive, violent, paranoid, or "strange" behaviors. For example, caregiver EP036 and EP037 reported that they had to call 911 in order to receive help for uncontrollable violent and aggressive outbursts that were suddenly occurring to their ill relative. In both of these cases, their ill relative was taken to a psychiatric hospital and remained hospitalized for the first time in

their lives. Caregiver EP024 stated that although the family began to notice strange behaviors (e.g., dressing unusual, placing kitchen utensils in inappropriate places throughout the house) on the part of the ill relative nothing was done to immediately seek any type of treatment to address the relative's changes in functioning. However, once the relative became hostile and began screaming at her family members when they tried to reason her out of delusional thinking (e.g., she believed she had been hired as an executive for a computer company and spent the entire night preparing for her non-existent job) they had to call 911. Caregiver EP023 reported that they were afraid her behavior would put the affected relative's young children in danger so they felt calling the police was the right decision. Caregiver EP023 also described a similar, scary onset of psychotic symptoms, "...my son got very paranoid and said he heard voices. He bought a rifle and would go to the roof of the house and point it at people to make sure "they" wouldn't get him. That's when we decided we had to take him to the hospital." Overall, the *Psychiatric Crisis* reason appears to leave family caregivers and members with no choice but to seek formal services given that the behaviors that characterize severe psychotic disorders are too much to handle by family members alone.

Other Treatment Initiation Reasons. Another commonly reported reason by NAMI and community caregivers to impact treatment initiation for their relative was *encouragement from health professionals*. A total of nine caregivers (28%) from both caregiver samples were encouraged from health professionals to seek mental health services for their relative. In contrast to psychiatric crises, these cases involved problems that were reported to not be severe enough to require calling emergency services such as the police. For example, two caregivers had health providers in the family who advised and urged them to seek formal treatment when their relative was demonstrating unusual behaviors such as social withdrawal and "hysterical crying". Another

important treatment initiation reason reported by 19% of the total caregivers was the *referral to services by school officials*. For example, Caregiver EP028, a 44-year old mother of an ill 26-year old son, reported that her son was first referred to a mental health provider at age 10 when he was having conduct problems in school. This led to a diagnosis of ADHD at the time but the caregiver reported that treatment was never effective because her son was always resistant to treatments. She reported that as her son grew older, he developed substance use problems and got into trouble for breaking laws. She stated that at the time of the interview he was struggling with symptoms of paranoia, aggressive and violent behavior, mania, and substance dependence.

Category B - Reasons for Treatment Retention

This category focuses on the reasons that impact retention *after* treatment was sought for their relative's mental illness problem. CQR analysis led to six major sub-categories of reasons for treatment *retention*: 1) previous positive experiences with formal service treatments, 2) caregiver/family support, 3) NAMI support, 4) treatment of comorbid conditions, 5) encouragement from religious/spiritual sources, and 6) relapse of psychotic symptoms. Statistical analysis (two-sided Fisher's exact test) demonstrated significant differences between the percentages of reported NAMI support ($p < 0.05$, Fisher's exact test) between NAMI and Community caregivers. (Please see Table 8 for narrative examples and percentages of reasons for treatment retention reported by caregivers).

Prior Positive Experiences with Services. This was the most commonly reported reason (72%) among total caregivers that enabled affected relatives to remain or return to formal services according to the caregivers. "Positive experiences" refers to the many types of interactions that caregivers reported such as effectiveness of medication to address SPMI symptoms, satisfaction with service providers and case management to address social

functioning, and culturally congruent ingredients such as the inclusion of family in the treatment plan. Seven community caregivers (47%) reported satisfaction with the stabilizing effects of psychiatric medication which led the caregivers to continuously support, monitor, and at times, administer the medication to their ill relatives. Three community caregivers (20%) mentioned being satisfied with the case management given to their ill relatives and one especially emphasized the importance of service providers who made home visits and helped the relative with social and vocational rehabilitation in keeping the relative interested in continuing services.

One “culturally congruent” positive interaction reported was the acceptance and willingness of service providers to involve the family in treatment. This was reported in only a few cases (n=3; 9%) of the total sample but played an important role in having caregivers satisfied with engaging and encouraging their relatives to pursue formal mental health services. Caregivers reported being consulted and informed of their relative’s treatment plan and were willing to support their relatives with medication monitoring and assistance to psychiatric appointments. Another culturally congruent factor was the availability of bicultural and bilingual service providers in the city. None (0%) of the Spanish speaking caregivers (n=10) reported experiencing any difficulties in finding a Spanish speaking provider. When probed about language barriers the ten caregivers stated that throughout the course of their relative’s illness they were always able to find treatment resources in Spanish.

Encouragement from Family. Community caregiver reported less encouragement from family members when compared to NAMI caregivers (33% vs. 59%, n.s.). For example, caregivers EP034 and EP035, parents to a 26-year old daughter struggling with symptoms of mania and paranoid delusions, were strongly urged and supported by their immediate family members to pursue formal mental health treatment. Caregiver EP034 noted that it was her sister,

a registered nurse, who strongly suggested their daughter be seen by a mental health specialist when the daughter was exhibiting “odd behaviors” in public places. Caregiver EP034 stated, “We went to the Thanksgiving parade and it was overwhelming for her during that day. She told me she didn’t want to be there so we went back to the car... and in the car, she just started crying hysterically. So I called my husband and my sister-in-law, who is a nurse practitioner. So that’s the first place we ran to. And she told me let’s go take her to the hospital. So we first went to the hospital.”

NAMI Encouragement of Relative’s Treatment. One major finding reported only by NAMI caregivers (76% of NAMI sample) was that NAMI support and encouragement was a major factor in continuing formal mental health treatment for their relative with SPMI. For example, Caregiver EP015 stated that through the NAMI psychoeducation classes she heard about the benefits of formal treatments, namely medication, through other caregivers’ stories. She stated that hearing other caregivers’ testimonials helped normalize the problems associated with the mental illness and helped gain confidence in using formal services. Caregiver EP013 stated that through NAMI she learned about the benefits (and shortcomings) of formal treatments. She stated, “the doctors would tell me that he will be cured if he is seen for treatment but in NAMI I learned that the medicine would help stabilize him but unfortunately not cure him...I learned that he would never be his old self again”.

Furthermore, NAMI was instrumental in providing direct emotional support to the family caregivers. Caregivers in the study reported that NAMI resources helped with understanding their relative’s problems and symptoms, learning how to cope with their relative’s behaviors more effectively, developing empathy and more effective communication skills with their relative, and normalizing the illness and caregiving experience through contact with other family

caregivers. For example, caregiver EP006 stated, “*my gosh the [NAMI] classes are phenomenal; knowing what my brother is thinking, and how he is feeling. I never knew what his feelings were before taking the classes. My gosh, when I found out then, I reacted differently toward him. And so did my husband because he’s read up on the illness*”. None of the Community caregivers had ever used NAMI or similar mental health advocacy resources, and therefore did not report gaining benefits and awareness from any other form of support. Overall it appears that community mental advocacy organizations like NAMI are instrumental in a) bridging families to formal mental health services and b) providing emotional and psychological support for the caregivers.

Category C: Barriers to Seeking Formal Services for the Relative with SPMI

CQR analysis revealed a final category that focuses on the barriers and challenges to directly obtaining or continuing mental health treatment for their relative with SPMI. Even though resistance to treatment by some affected relatives (53%) and use of alternative resources (50%) were confirmed by caregivers as influential barriers, lack of family support and cultural beliefs also stand out. Statistical analysis (two-sided Fisher’s exact test) demonstrated significant differences between the percentages of reported resistance to services by affected relatives and use of alternative treatments ($p < 0.05$, Fisher’s exact test) between NAMI and Community caregivers. Compared to NAMI caregivers, Community caregivers were significantly more likely to report the use of alternative treatment and less likely to report resistance by affected relatives than NAMI caregivers ($p < 0.05$, Fisher’s exact test). Overall a substantial portion of caregivers identified the influence of certain Latino beliefs and the lack of family support, both from affected relatives and extended family members, as challenges to long term service use. Furthermore 44% of the caregivers reported cost of services or lack of insurance as a barrier to

continuous treatment use (please see Table 9 for narrative examples and percentages reported of barriers to treatment by caregivers).

Role of Cultural Beliefs. Caregivers were probed about their views on cultural factors that act as barriers to *other* Mexican descent families trying to address SPMI. This probe was added because caregivers from both samples would not report, or perhaps admit, to any direct experience with cultural barriers beyond the cultural explanation of *verguenza* (shame). One example common of “cultural barriers” reported by 28% of the caregivers includes the spiritual/supernatural conceptualizations of illness discussed in Domain I. For example, caregiver EP025, the 37-year old husband of the 27-year old wife with delusions and mania, stated that Mexicans seem to think that people are bewitched and possessed by the devil when mental illness problems begin and when they see changes in their relative’s behaviors.

Verguenza (Shame), Negacion (Denial) & Stigma. In addition to alternative conceptualizations, about half of the caregivers across both samples (63%) reported that Latino individuals might not seek formal mental health services due to beliefs of *verguenza* (shame), *negacion* (denial) & stigma. For example, Caregiver EP025 mentioned that *negacion* (denial) still exists in his family one year into dealing with his wife’s illness and having gone through a psychiatric hospitalization. He stated that although his ill wife’s grandmother appeared to have mental illness issues, his wife’s mother denied or did not accept the possibility of her daughter having mental illness. He stated, “...*her mother denies it I guess because she’s her mother and does not want to admit it. Or maybe they didn’t realize it or instead saw it as she was hexed rather than admitting she was really ill*”.

Five caregivers (16%) that made reference to Latino cultural beliefs, referred to *verguenza* or the “*el que diran?*” (translates into “what will others say?”) phrase as a reason to

not seek services. Caregivers stated that other Latino individuals are hesitant to seek services because they have *verguenza* (shame) about the illness and therefore are preoccupied with worrying about what others around them will think of their family. For example Caregiver EP030, a 50-year-old mother of a 25-year old son struggling with psychotic and aggressive behaviors, stated that Latinos have a lot of “*verguenza*” and do not seek treatment for fear of other’s opinions/views. She mentioned the “*el que diran*” explanation as well as a lack of support and understanding from other’s around them as reasons to hide a mental illness from the public. She discussed how her landlord has threatened to evict her and her son out of their apartment if he has another relapse and causes destruction to property so she tries to hide her son’s psychotic behaviors from others as much as possible by isolating themselves.

Caregiver EP030 also mentioned that she believes the lack of knowledge, awareness, and education about mental illness in the Latino population creates a barrier to seek formal treatment. However, other caregivers mentioned that older generations of Mexicans tend to believe more of the folk conceptualizations and therefore still utilize folk treatments but that younger generations tend to be more acculturated and more willing to seek formal treatment. For example, Caregiver EP032 stated he believes Latinos do seek treatment and that the generations differ. He stated that the first generation immigrants are more fixated on the belief that with family love or folk treatments they will cure their relative but the second generation family members are more educated and more acculturated to seek proper formal treatments. Overall it appears that caregivers believe that other Latinos worry about the stigma of mental illness and it is therefore exhibited through cultural notions of shame (*verguenza*) and denial (*negacion*).

Resistance by Relatives with SPMI. A large number of NAMI caregivers (65%) and almost half of the Community caregivers (40%) admitted that a major challenge to utilizing

formal services (and for some even utilizing folk treatments) was a belief on the part of their relatives that they did not have a mental illness or related problem or a strong refusal by their relative to attend treatment. These caregivers reported that there was a strong resistance to pursue individual, family, and group therapy on the part of the ill relative. Relatives struggling with paranoid delusions had added resistance to medication and were reported to have had more relapses and subsequent hospitalizations. Another similarity among relatives that resisted formal treatment was that they were characterized as being more aggressive and paranoid than ill relatives who were more open to using formal services.

Use of Alternative Treatments. Community caregivers were more likely to report use of alternative treatments as a barrier (73%) when compared to NAMI caregivers (24%). It is important to note that community caregivers reported that folk/spiritual treatments acted as barriers early in the relative's illness trajectory and that, at the time of the interview, they either no longer sought folk treatments or they utilized them in conjunction with formal treatments. For example, caregiver EP025, a 37-year old husband of a 27-year old wife struggling with psychotic symptoms, reported that his wife's family continuously chose to take his wife to a *curandera* (folk healer) in Mexico for *limpias* (cleanses). He stated that despite their insistence on turning to folk healers, he has come to realize that the *limpias* have not had any effect on her symptoms while the psychiatric medication has. At the same time, he sees no harm in the *limpias* and therefore does not mind his wife's family taking her to the *curandera* in Mexico.

Most of the community caregivers also held multiple conceptualizations (87%) of their ill relative's problems and therefore were not fully invested in one view (i.e., psychiatric conceptualization) or another (i.e., folk/spiritual conceptualization). This results in not fully committing to one type of treatment because not enough time has passed to observe the

effectiveness of their treatment choices. Caregivers with multiple illness conceptualizations and uncertainty of best treatment choice will likely give equal, if not more, weight to spiritual or folk treatments creating a significant barrier to the utilization of formal mental health services.

Lack of Family Support. Another barrier to the use of formal services is the lack of support and encouragement given to the ill relative and the caregiver to seek formal mental health treatment for the relative. About half of the community caregivers (53%) and NAMI caregivers (41%) reported a lack of support or resistance from other family members in seeking services. For example, community caregiver EP028, the 44-year-old mother of a 26-year old son stated that she does not turn to family for help because she receives criticism, rather than support, for addressing her son's problems. She stated, "...my mother criticizes me because she tells me "well throw him out. Why do you have to put up with this? Look at his age." But that's my son. How am I going to throw him out? Where is he going to go? He only has me. If I can't help them and support their treatment, who's going to help?"

Cost of Treatment. One final barrier that will be presented was cost of services and/or lack of insurance. About half of the NAMI caregivers (47%) and half of the community caregivers (40%) reported that they had difficulties continuing formal treatments (e.g., psychiatric medication or psychotherapy) due to not having insurance or the financial means to pay for services. One caregiver stated that financial struggles might lead a caregiver to seek folk treatments rather than seek formal treatments. Caregiver EP027 stated herbs and vitamins are much cheaper than medication so "if I don't have enough money to go to the doctor I'm going to go get the herbs".

CHAPTER 4: DISCUSSION

Although researchers have found that families play a key role in the course of SPMI (Hooley, 2007) as well as that cultural background plays an important role in the link between family relationships and SPMI (Jenkins, 1997; Lopez et al., 2004; Lopez, Ramírez García et al., 2009), little is known about how family caregivers may link their relatives to mental health services. In this study we addressed this critical gap in the literature by examining Latino caregivers' narratives of how their relatives initiated, stayed, and turned away from treatment.

We examined two different caregiving groups: one group utilized psychoeducation services from the National Alliance on Mental Illness (NAMI) and the other group did not have a history of using NAMI services (Community group). Results indicated that Community caregivers had less years caregiving and were significantly more distressed compared to NAMI caregivers. Furthermore, NAMI caregivers more commonly ascribed to a psychiatric model of mental illness (i.e., described their relative's problems as a mental disorder) compared to Community caregivers suggesting that family members who participate in NAMI or similar psychoeducation services and/or who have had many years of caregiving experience are more likely to have psychiatric views. Overall, the combined sample of caregivers had a high percentage of caregivers that met cutoff for depression and endorsed similar levels of *familismo*, stigma, and acculturation when compared to national samples of Latino adults and caregivers found in the literature.

Role of Family Caregiving in Help Seeking

In terms of family level characteristics, we found that the sampled Mexican descent caregivers had high levels of *familismo* in a self-report measure, and that they played key roles in their relatives' usage of mental health services. For example, they were instrumental in initiating

treatment during psychiatric crises and/ or by following the recommendations of others such as health care providers or school officials. Likewise, they were instrumental in keeping their relatives in treatment by providing direct instrumental support to have their relatives meet their appointments, interacting with service providers, and/or following up recommendations from people whom they trusted such as NAMI peers or spiritual/religious leaders. Family and caregiver support was reported to be an important treatment retention factor (53% of total sample, 59% of NAMI sample, 27% of Community sample). These findings are consistent with other studies that have highlighted the importance of caregiver support in treatment processes (Kopelowicz et al., 2012; Marquez & Ramirez Garcia, 2011; Weisman, 2005).

Despite the high levels of reported *familismo*, our findings do not provide straightforward support for the Alternative Resource Hypothesis, that is, the notion that Latinos' low usage of services can be attributed largely to the rich support systems available in the extended family (Leong, Wagner, & Tata, 1995). For example, caregivers' responses to their relatives' problem behaviors were *not* limited to assisting them in ways that would largely eliminate the need for mental health services. Rather caregivers were very willing to promote mental health service usage as a means to cope with problem behaviors.

We also found evidence for instances of *isolated single-family caregiving*. A barrier to services reported by half of the total sample was *not* having support from extended family members (41% NAMI, 53% Community). Other researchers have found substantial percentages of Latino caregivers who were largely the sole providers of caregiving duties in the family (Marquez & Ramirez Garcia, 2011; Herrera, Lee, Palos & Torres-Vigil, 2008). As such, it is possible that despite the presence of a dedicated family caregiver, other family members may not be supportive and in some instances question or have conflict with the primary caregiver because

of their discordant views about the problem behaviors and responses. Accordingly intervention to address the ways to manage problem behaviors in the broader family unit might be needed.

The tension between family supportive behaviors and isolation between a particular caregiver and the rest of the family is illustrative of the need to examine family caregiving with holistic views that do not exclusively focus on either the supportive role or the stress-risk for relapse role that families may play. That is, the latter topic has primarily focused on the link between patients' risk for relapse and caregivers' criticisms, hostility, and/or emotional overinvolvement; these different caregiver behaviors may amount to stress-producing states which interact with cognitive vulnerabilities in patients and trigger symptomatic relapse (Hooley, 2007). However, the degree to which family supportive behaviors may coexist and interact with such stress-producing caregiver behaviors is largely unknown. Following our results we advocate for further in-depth study of these family caregiver supportive behaviors in general, and for treatment engagement processes in particular. Notably, some researchers have stipulated ways in which families' behaviors tied to relapse protection and service usage may interact with EE and/or distress caregiving states (see Nuechterlein et al., 1994; Kuipers, Onwumere, & Bebbington, 2010); however, empirical research on this topic is scarce.

Alternative Resources and Conceptualizations

Families are embedded in their cultural context (Szapocznik & Kurtines, 1993) and so is family caregiving for persons with SPMI (Jenkins & Karno, 1992). Accordingly the family caregiving context has been suggested to be related to caregiver views of illness- specifically beliefs that problem behaviors have a somatic nature or spiritual basis and contrast with biomedical explanations. For example, the use of folk healers is also cited as a target of help-

seeking that may deter usage of mental health services by Latinos according to the “Alternative Resource Hypothesis”.

In this study, we found that a substantial portion of caregivers reported use of folk healers was a barrier to service usage (73% Community vs. 24% NAMI), and that they conceptualized their relatives’ problems as having a spiritual, religious or supernatural explanation (47% Community vs. 18% NAMI). However, we also found data that suggest researchers and clinicians should be cautious in interpreting the weight of folk healing as an explanation for low usage of services. Use of folk healers was only one of four major barriers reported by nearly half of the total caregivers indicating that there are other reasons deterring individuals from services. Moreover, 84% of the caregivers conceptualized the problem behaviors as psychiatric and 59% held multiple, coexisting conceptualizations (spiritual/religious *and* psychiatric). Thus conceptualizations that are consistent with folk healing practices may coexist with psychiatric views which are consistent with mainstream mental health services. Results indicated that NAMI caregivers were significantly less likely to report folk conceptualizations and use of folk treatments compared to Community caregivers suggesting that caregivers exposed to psychoeducation services are more likely to have psychiatric views.

Cultural beliefs commonly held by Latinos, such as *verguenza* (shame) and *negacion* (denial), were also offered as an explanation for low usage of services. Latino cultural beliefs were more commonly reported by Community caregivers (63% of combined sample, 47% of NAMI sample, 80% of Community sample) suggesting that cultural beliefs may have a stronger influence on the help-seeking behaviors of less experienced and less knowledgeable caregivers. For example, caregivers commonly reported that Latino individuals might not seek mental health services due to feelings of *verguenza* (shame) and *negacion* (denial), or in broader terms due to

stigma. According to the caregivers, Latinos' shame about mental illness, their denial to admit the existence of mental illness, and their resulting preoccupation about what others around them will think of their family (stigma) keeps them from seeking formal services.

Interestingly, caregivers reported low scores on a quantitative stigma scale and did not admit to experiencing stigma or *verguenza* personally as barriers but referenced them as barriers to "other Latinos". These findings have at least two implications. First, the discrepancy in quantitative and qualitative findings suggests the importance of utilizing multiple methods to assess the accuracy of cultural beliefs given that multiple methods yield convergent or divergent findings. Second, the discrepancy in findings suggests that caregivers with more experience and with exposure to psychoeducation may be more likely to adhere to a psychiatric model of illness conceptualization and personally reject folk beliefs. Although the majority of caregivers denied being influenced by cultural beliefs, all caregivers noted that cultural beliefs impact help-seeking in the at-large Latino population. This suggests that the study of cultural beliefs and stigma must be approached from a sensitive and non-judgmental manner with multiple methods of assessment in order to produce a comprehensive understanding of culture's impact on help-seeking.

Overall cultural beliefs, such as *verguenza*, have long been hypothesized to be a reason for the documented underutilization of mental health care among Latinos in the U.S. (Leong, Wagner, & Tata, 1995) but we did not find empirical studies that would indicate whether Latinos have higher or lower levels of stigma compared to other ethno-cultural groups. As research on this topic takes place, we posit that policy makers consider implementing initiatives to reduce stigma among Latinos through public awareness, psychoeducation, and other culturally relevant mediums, such as music, movies, and art (e.g., Lopez, Lara, et al., 2009).

Treatment Initiation and Retention

Notably our study findings also shed light on processes related to treatment initiation and retention, rather than focusing only on what impedes usage of services. Results suggest that regardless of views of mental illness held by caregivers, points of entry into mental health services involve emergency psychiatric hospitalizations (50% of combined sample) and early identification of a problem from other sources such as medical providers (28% of combined sample) and school officials (19% of combined sample). Findings from other studies have indicated that family members seek help when the behaviors of their relatives became more alarming in the context of overt psychotic symptoms and often begin with emergency services and hospitalization (Corcoran et al., 2007). The lack of insurance (as reported by 44% of the total sample) by Latino individuals may also play a major role in first turning to emergency services given that the low socioeconomic status and lack of insurance lessens the likelihood of using private providers for mental health care (Vega & Lopez, 2001). These findings suggest that mental health providers should work closely with agencies that serve Latino populations such as general health care providers or public schools to create important pathways to mental health treatment use in a timely manner (Bledsoe, 2008).

With respect to treatment engagement more than half (73%) of the caregivers reported that positive experiences, which included observed effectiveness from treatments, positive interactions with service providers, and cultural congruency of treatments, was a major factor in continuing formal treatment use. Other studies have shown that patients' positive attitudes toward treatments and providers' interpersonal skills may be shaped by early positive experiences with primary care providers (Cabassa, Lester, & Zayas, 2007). Taken together these

findings illustrate that in addition to barriers to treatment, there are pathways to treatment initiation and retention of adults with SPMI according to the narrated views of these family caregivers. We posit that policy makers, researchers, and clinicians should also spend resources in understanding and promoting treatment engagement processes rather than to focus exclusively on barriers to treatment.

Limitations and Conclusions

The themes extracted utilizing CQR methods are bound by the characteristics of the sample so they may not generalize to the entire Latino population (our sample was primarily Mexican descent and of low socio-economic status). For example, our study involved families that had a relative with a history of treatment in clinical settings such as inpatient and outpatient clinics. Caution should be made when trying to generalize the findings to families that have relatives in other service settings such as prisons or homeless shelters. However, caregivers had comparable levels of distress and burden as observed in larger samples with Mexican descent caregivers; thus the sample does not appear to be out of range when compared with the extant literature. Furthermore, the study took place in an area of the U.S. with a large Spanish speaking population that had available bilingual service providers. Future studies should address service use in areas with low density of Latino populations to examine service usage processes in such community settings as well. The findings are based on caregivers' reports of their family's experiences in addressing their relatives' mental illness and did not include the data reported by the adults diagnosed with a mental illness. We also did not include actual service use data to test the link between cultural beliefs and service use. A limitation of this, other service usage studies, is that there is an implicit assumption that more use of formal services leads to the best outcomes and that lower use of services by Latinos compared to European Americans is associated with

poor outcomes for Latinos. However, there may be circumstances in which moderate to low service use may not be necessarily associated with poor mental health outcomes.

Despite its limitations, this study provides empirical data on how family caregivers play a role in the service use of Latino adults with SPMI which is missing in the literature on service usage processes among Latinos. The study provides data that qualifies the degree to which common explanations, such as *familismo*, folk beliefs, and alternative resources might be influential in Latinos' low service usage. Given the small sample size we do not claim that the results are definitive. Rather, our results suggest that the hypothesized patterns of cultural explanations, such as family support, cultural beliefs, and alternative resources, are present among Latinos but yet they do not appear to be conclusive and exhaustive explanations for low service usage. As such, engaging Latinos diagnosed with SPMI in services, and the role family plays, demands further and careful considerations by policy makers and public mental health researchers.

REFERENCES

- Aguilera, A., Lopez, S.R., Breitborde, N.J.K., Kopelowicz, A., & Zarate, R. (2010). Expressed emotion and sociocultural moderation in the course of schizophrenia. *Journal of Abnormal Psychology* 119(4), 875–885.
- Alegría, M., Canino, G., Rios, R., Vera, M., Calderon, J., Busch, D., & Ortega, A.N. (2002). Inequalities in use of specialty mental health services among Latinos, African Americans, and Non-Latino Whites. *Psychiatric Services*, 53(12), 1547-1555.
- Anderson, R., Lewis, S., Giachello, A. L., Aday, L. U., & Chiu, G. (1981). Access to medical care among the Hispanic population of the southwestern United States. *Journal of Health and Social Behavior*, 22, 78-89.
- Applewhite, S.L. (1995). Curanderismo: Demystifying the Health Beliefs and Practices of Elderly Mexican Americans. *Health & Social Work*, 20(4), 247-253.
- Barrio, C., Yamada, A.M, Hough, R.L, Hawthorne, W., Garcia, P., & Jeste, D.V. (2003). Ethnic Disparities in Use of Public Mental Health Case Management Services Among Patients With Schizophrenia. *Psychiatric Services*, 54, 1264-1270.
- Bledsoe, S. E. (2008). Barriers and Promoters of Mental Health Services Utilization in a Latino Context: A Literature Review and Recommendations from an Ecosystems Perspective. *Journal of Human Behavior in the Social Environment*, 18(2), 151-183.
- Brown, G.W. (1985). The discovery of Expressed Emotion: Induction or deduction? In J.P. Leff & C.E. Vaughn (Eds.), *Expressed Emotion in families: Its significance for mental illness* (pp. 7-25), The Guilford Press, New York.

- Cabassa, L.J., Lester, R. & Zayas L.H. (2007). It's like being in a labyrinth: Hispanic immigrants' perceptions of depression and attitudes towards treatment. *Journal of Immigrant & Minority Health*, 9(1), 1-16.
- Cabassa, L. J., Hansen, M., Palinkas, L. A., & Ell, K. (2008). *Azúcar y nervios*: Explanatory models and treatment experiences of Hispanics with diabetes and depression. *Social Science & Medicine*, 66 (12), 2413-2424.
- Conner, K. O., Koeske, G. & Brown, C. (2009). Racial Differences in Attitudes Toward Professional Mental Health Treatment: The Mediating Effect of Stigma. *Journal of Gerontological Social Work*, 52(7), 695-712.
- Corcoran, C., Gerson, R., Sills-Sharhar, R., Nickou, C., McGlashan, T., Malaspina, D., & Davidson, L. (2007). Trajectory to a first episode of psychosis: A qualitative research study with families. *Early Intervention and Psychiatry*, 1(4), 208-315
- Corrigan, P.W. & Watson, A.C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry*, 1 (1), 16-20.
- Cuéllar, I., Arnold, B., & González, G. (1995). Cognitive referents of acculturation: Assessment of cultural constructs in mexican americans. *Journal of Community Psychology*, 23(4), 339-356.
- First, M.B., Spitzer, R.L., Gibbon, M. & Williams, J.B.W. (1996). Structured clinical interview for DSM-IV axis I disorders, clinician version (SCID-IV). American Psychiatric Press, Inc., Washington, DC.
- Greenberg, J. S., Greenley, J. R., McKee, D., Brown, R., & Griffin-Francell, C. (1993). Mothers Caring for an Adult Child with Schizophrenia: The Effects of Subjective Burden on Maternal Health. *Family Relations*, 42(2), 205-211.

- Guarnaccia, P. J., & Parra, P. (1996). Ethnicity, social status and families' experiences of caring for a mentally ill family member. *Community Mental Health Journal, 32*, 243-260.
- Guarnaccia, P. J., Parra, P., Deschamps, A., Milstein, G., & Argiles, N. (1992). Si Dios quiere: Hispanic families' experiences of caring for a seriously mentally ill family member. *Culture, Medicine and Psychiatry, 16*, 187-215.
- Herrera, A. P., Lee, J., Palos, G., & Torres-Vigil, I. (2008). Cultural influences in the patterns of long-term care use among mexican american family caregivers. *Journal of Applied Gerontology, 27*(2), 141-165.
- Hill, C. E., Thompson, B. J. & Williams, E. N. (1997). A guide to conducting consensual qualitative research. *The Counseling Psychologist, 25*, 517-572.
- Hooley, J. M. (2007). Expressed Emotion and Relapse of Psychopathology. *Annual Review of Clinical Psychology, 3*, 329-352.
- Jenkins, J. H. (1991). Anthropology, Expressed Emotion, and Schizophrenia. *Ethos, 19*(4), 387-431.
- Jenkins, J. H. & Karno, M. (1992) The meaning of expressed emotion: theoretical issues raised by cross-cultural research. *American Journal of Psychiatry, 149*, 9-21.
- Jenkins, J. H. (1997). Subjective experience of persistent schizophrenia and depression among U.S. Latinos and Euro-Americans. *British Journal of Psychiatry, 171*, 20-28.

- Keyes, K.M., Martins, S.S., Hatzenbuehler, M.L., Blanco, C., Bates, L.M., & Hanson, D.S. (2012). Mental health service utilization for psychiatric disorders among Latinos living in the United States: the role of ethnic subgroup, ethnic identity, and language/social preferences. *Social Psychiatry and Psychiatric Epidemiology*, 47, 383–394
- Kopelowicz, A., Zarate, R., Gonzalez Smith, V., Mintz, J., & Liberman, R. P. (2003). Disease management in latinos with schizophrenia: A family-assisted, skills training approach. *Schizophrenia Bulletin*, 29(2), 211-227.
- Kopelowicz, A., Wallace, C.J., Liberman, R.P., Aguirre, F., Zarate, R., & Mintz, J. (2007). The use of the theory of planned behavior to predict medication adherence in schizophrenia. *Clinical Schizophrenia and Related Psychoses*, 1(3), 227-242.
- Kral, M.J., Burkhardt, K.J., & Kidd, S. (2002). The new research agenda for a Cultural Psychology. *Canadian Psychology*, 43(3), 154-162.
- Kuipers, E., Onwumere, J., & Bebbington, P. (2010). Cognitive model of caregiving in psychosis. *The British Journal of Psychiatry*, 196(4), 259-265.
- Lakes, K., Lopez, S., & Garro, L.C. (2006) Cultural Competence and Psychotherapy: Applying Anthropologically Informed Conceptions of Culture. *Psychotherapy*, 43: 380-396.
- Leong, F. T. L., Wagner, N. S., & Tata, S. P. (1995). Racial and ethnic variations in help-seeking attitudes. Thousand Oaks, CA, US: Sage Publications, Inc.
- Lewis-Fernandez, R., Das, A.K., Alfonso, C., Weissman, M.M., Olfson, M. (2005). Depression in US Hispanics: Diagnostic and management considerations in family practice. *Journal of the American Board of Family Practice*, 18(4), 282–296.

- Liang, J., Van Tran, T., Krause, N. & Markides, K. (1989) Generational differences in the structure of the CES-D scale in Mexican Americans. *Journal of Gerontology*, 44, 110–120.
- Link, B.G., Yang, L.H., Phelan, J.C. & Collins, P.Y. (2004). Measuring mental illness stigma. *Schizophrenia Bulletin*, 30, 511-541.
- Loera, S., Munoz, L.M., Nott, E. & Sandefur, B.K. (2009). Call the Curandero: improving mental health services for Mexican immigrants. *Praxis*, 9, 16-24.
- Lopez, S.R. (2002). Mental health care for Latinos: A research agenda to improve the accessibility and quality of mental health care for Latinos. *Psychiatric Services*, 53(12), 1569-1573.
- Lopez, S.R., Hipke, K.N., Polo, A.J., Jenkins, J., Karno, M., Vaughn, C. & Snyder, K.S. (2004). Ethnicity, expressed emotion, attributions, and course of schizophrenia: family warmth matters. *Journal of Abnormal Psychology*, 11, 428-239.
- Lopez, S. R., Ramirez Garcia, J. I., Ullman, J. B., Kopelowicz, A., Jenkins, J., Breitborde, N. J., Placencia, P. (2009). Cultural variability in manifestation of expressed emotion. *Family Process*, 48, 179-194.
- Lopez, S. R., Lara, M.del C., Kopelowicz, A., Solano, S., Focerrada, H., & Aguilera, A. (2009). La CLAVE to increase psychosis literacy of Spanish-speaking community residents and family caregivers. *Journal of Consulting and Clinical Psychology* 77, 763-774.
- Lugo Steidel, A. G., & Contreras, J. M. (2003). A new familism scale for use with Latino populations. *Hispanic Journal of Behavioral Sciences*, 25 (3), 312-330.

- Magaña, S. M., Ramírez García, J.I., Hernández, M.G., & Cortez, R. (2007). Psychological distress among Latino caregivers of adults with schizophrenia: the roles of burden and stigma. *Psychiatric Services, 58*, 378-384.
- Marin, G. & Gamba, R. (1996). A new measurement of acculturation for Hispanics: The bidimensional acculturation scale for hispanics (BAS). *Hispanic Journal of Behavioral Sciences, 18*, 297–316.
- Marquez, J. A., & García, J. (2011). Family Caregivers' Monitoring of Medication Usage: A Qualitative Study of Mexican-Origin Families with Serious Mental Illness. *Culture, Medicine & Psychiatry, 35*(1), 63-82.
- Masten, W. G., Caldwell-Colbert, A. T., Alcala, S. J., & Mijares, B. E. (1986). Reliability and validity of the Center for Epidemiological Studies Depression Scale *Hispanic Journal of Behavioral Sciences, 8*, 77–84.
- Michaud, C.M., McKenna, M.T., Begg, S., Tomijima, N., Majmudar, M., Bulzacchelli, M.T., Ebrahim, S., Ezzati, M., Salomon, J.A., Gaber Kreiser, J., Hogan, M., & Murray, C.J.L. (2006). The burden of disease and injury in the United States 1996. *Population Health Metrics, 4*-11.
- Miller, P. J., Hengst, J.A. & Wang, S. (2003). Ethnographic methods: Applications from Developmental Cultural Psychology. In P.M. Camic, J.E. Rhodes & L. Yardley (Eds.), *Qualitative Research in Psychology. Expanding Perspectives in Methodology* (pp. 219-242). Washington DC: American Psychological Association.
- Nuechterlein, K. H., Dawson, M. E., Ventura, J., Gitlin, M., Subotnik, K.L, Snyder, K., Mintz, J. & Bartzokis, G. (1994). The vulnerability/stress model of schizophrenic relapse: A longitudinal study. *Acta Psychiatrica Scandinavica, 89*, 58-64.

- Peifer, K.L., Hu, T. & Vega, W. (2000). Help Seeking by Persons of Mexican Origin With Functional Impairments. *Psychiatric Services, 51*(10), 1293-1298.
- Polkinghorne, D. E. (2005). Language and meaning: Data collection in qualitative research. *Journal of Counseling Psychology, 52*, 137-145.
- Radloff, L. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385-401.
- Ramirez Garcia, J.I., Wood, J.M., Hosch, H.M., & Meyer, L.D. (2004). Predicting psychiatric rehospitalizations: examining the role of Latino versus European American ethnicity. *Psychological Services, 1*(2), 147–157.
- Ramirez Garcia, J.I., Chang, C.L., Young, J.S., Lopez, S.R., & Jenkins, J.H. (2006). Family support predicts medication usage among Mexican American individuals with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology, 41*, 624-631.
- Rogler, L.H. Malgady, R.G. & Rodriguez, O. (1989). Hispanics and mental health: a framework for research. Florida: R.E. Kreiger Publishing Company.
- Rosenstein, M. J., Milazzo-Sayre, L. J., MacAskill, R. L., & Manderscheid, R. W. (1987). Use of inpatient services by special populations. In R. W. Manderscheid & S. A. Barrett (Eds.), *Mental health, United States, 1987* (DHHS ADM 87- 1518). Washington, DC: U.S. Government Printing Office.
- Schinnar, A., Rothbard, A., Kanter, R., & Jung, Y. (1990). An empirical literature review of definitions of severe and persistent mental illness. *American Journal of Psychiatry, 147*, 1602-1608.

- Sleath, B.L. & Williams, J.W. (2004). Hispanic ethnicity, language, and depression: physician-patient communication and patient use of alternative treatments. *International Journal of Psychiatry in Medicine*, 34, 235–246.
- Szapocznik, J. & Kurtines, W. (1980). Acculturation, bi-culturalism and adjustment among Cuban Americans. In A. M. Padilla (Ed.), *Psychological dimensions on the acculturation process: Theory, models, and some new findings* (pp. 139–159). Boulder, CO: Westview.
- Trotter, R. T. (1982). Contrasting models of the healer's role: South Texas case examples. *Hispanic Journal of Behavioral Sciences*, 4, 315-327.
- Vega, W. A., Kolody, B., Aguilar-Gaxiola, S., Alderete, E., Catalano, R. & Caraveo-Anduaga, J. (1998). Lifetime prevalence of DSM-II-R psychiatric disorders among urban and rural Mexican Americans in California. *Archives of General Psychiatry*, 55, 771-778.
- Vega, W. A., Kolody, B., Aguilar-Gaxiola, S., & Catalano, R. (1999). Gaps in services utilization by Mexican Americans with mental health problems. *American Journal of Psychiatry*, 156, 928– 934.
- Vega, W. & Lopez, S.R. (2001). Priority Issues in Latino Mental Health Services Research. *Mental Health Services Research*, 3(4), 189-200.
- Vega, W., Karno, M., Alegria, M., Alvidrez, J., Bernal, G., Escamilla, M., Escobar, J., Guarnaccia, P., Jenkins, J., Kopelowicz, A., Lagomasino, I., Lewis-Fernandez, R., Marin, H., Lopez, S., & Loue, S. (2007). Research issues for improving treatment of US Hispanics with persistent disorders. *Psychiatric Services* 58, 385–394.
- Weisman, A. G., Gomes, L.G & Lopez, S.R. (2003). Shifting Blame Away From Ill Relatives: Latino Families' Reactions to Schizophrenia. *The Journal of Nervous and Mental Disease*, 191(9), 574-581.

APPENDIX A – TABLES AND FIGURES

Table 1:
Demographics of Caregivers

	<i>NAMI (2010) Sample (N=17)</i>	<i>Community (2011) Sample (N=15)</i>	<i>Total Sample (N=32)</i>
Age of Caregivers	57.6 (8.6)	52.1 (9.7)*	55.0 (9.4)
Caregiver Birthplace	United States = 5 (29%) Mexico = 12 (71%)	United States = 4 (27%) Mexico = 11 (73%)	United States = 9 (28%) Mexico = 23 (72%)
Language spoken	Spanish = 12 (71%) English = 5 (30%)	Spanish = 10 (67%) English = 5 (33%)	Spanish = 22 (69%) English = 10 (31%)
Education level	Elementary = 18% Middle School = 18% High School = 35% College & Beyond = 29%	Elementary = 0% Middle School = 7% High School = 40% College & Beyond = 40%	Elementary = 3 (9%) Middle School = 4 (13%) High School = 12 (38%) College & Beyond = 11 (34%)
Income	\$5,000 - 20,000 = 53% \$20,000 – 40,000= 41%	\$5,000 - 20,000 = 60% \$20,000 – 40,000= 40%	\$5,000 - 20,000 = 18 (60%) \$20,000 – 40,000= 13 (40%)
Years of Caregiving	Less than 3 years = 2 (12%) 4 years or more = 15 (88%)	Less than 3 years = 7 (47%)* 4 years or more = 8 (53%)*	Less than 3 years = 9 (28%) 4 years or more = 23 (72%)

*p = < .05 based on t-test and chi-square analyses between NAMI and Community caregivers

Table 2:
Demographics of Adult Relatives with Mental Health Problems

<i>Adult relatives with mental health problems</i>			
	NAMI sample	Community sample	Total Sample
Age	34.3 (12.8)	28.7 (10.2)	31.6 (11.7)
Birthplace	United States = 16 (94%) Mexico = 1 (6%)	United States = 10 (67%) Mexico = 5 (33%)	United States = 26 (%) Mexico = 6 (%)
Number of years ill	15.4 (9.6)	6.9 (5.9)*	11.3 (9.0)
Number of prior hospitalizations	3.3 (2.8)	2.2 (2.5)	2.8 (2.7)

*p = < .05 based on t-test analyses between NAMI and Community caregivers

Table 3:
Service Use variables of the caregiver groups and relatives with SPMI

	17 NAMI caregivers	15 Community Caregivers	Total Caregivers
<i>Service use of relative to address mental health problems</i>			
Currently Using Services (past 3 mos.)	15 (88%)	10 (67%)	25 (78%)
Type of Service Provider Currently Seeing	13	7	20
MH Provider Only	0	1	1
Physician Only	2	2	4
MH and Physician			
Service Use in the past 12 months	16 (94%)	12 (80%)	28 (88%)
Type of Service Provider seen in past year			
MH Provider Only	12	12	24
Physician Only	0	1	1
MH and Physician	4	0	4
Currently Using Medication	11 (65%)	9 (60%)	20 (63%)
<i>Service use of caregivers to address mental health problems</i>			
Currently Using Services (last 3 months)	1 (6%)	4 (27%)	5 (16%)
Type of Service Provider Currently Seeing	1	3	4
Mental Health Provider	0	0	0
Physician Only	0	1	1
MH Provider and Physician			
Service Use in the past 12 months	6 (35%)	4 (27%)	10 (31%)
Type of Service Provider Seen in past 12 months			
Mental Health Provider	3	3	6
Physician Only	2	0	2
MH Provider and Physician	1	1	2
Utilized NAMI services in past	17 (100%)	0 (0%)	17 (0%)

Table 4:
Clinical Description of Adult Relatives with Mental Health Problems

<i>Adult relatives with mental health problems</i>			
	NAMI relatives	Community relatives	Total relatives
Age of Relative	34.3 (12.8)	28.7 (10.2)	31.6 (11.7)
Birthplace of Relative	United States = 16 (94%) Mexico = 1 (6%)	United States = 10 (67%) Mexico = 5 (33%)	United States = 26 (%) Mexico = 6 (%)
Caregiver Reported Diagnosis	Schizophrenia = 8 (47%) Bipolar Disorder = 6 (35%) Schizoaffective = 3 (18%) None = 0 (0%)	Schizophrenia = 3 (20%) Bipolar Disorder = 10 (67%) Schizoaffective = 0 (0%) None = 2 (13%)	Schizophrenia = 12 (38%) Bipolar Disorder = 16 (50%) Schizoaffective = 3 (9%) None = 2 (6%)
Number of years ill	15.4 (9.6)	6.9 (5.9)*	11.3 (9.0)
Number of prior psychiatric hospitalizations	3.3 (2.8)	2.2 (2.5)	2.8 (2.7)

*p = < .05 based on t-test analyses between NAMI and Community caregivers

Table 5:

Descriptive statistics on key constructs of the 17 NAMI caregivers, the 15 Community caregivers, and the total combined sample of 32 caregivers.

	<i>NAMI (2010) Sample (N=17)</i>	<i>Community (2011) Sample (N=15)</i>	<i>Total Sample (N=32)</i>
Psychological Distress (CES-D)	19.3 (9.3)	28.8 (10.2)*	23.8 (11.5)
Caregiver Burden	42.1 (13.2)	49.2 (10.8)	45.4 (12.5)
Stigma	1.4 (1.0)	2.1 (1.3)	1.8 (1.2)
Criticisms-EE	35.6 (27.1)	40.5 (31.9)	38.3 (29.0)
Family Cohesion	3.1 (3.1)	2.6 (2.0)	2.8 (2.8)
Familismo	7.6 (1.4)	7.2 (1.2)	7.4 (1.3)
Acculturation	2.5 (0.8)	2.6 (0.7)	2.6 (0.8)
Enculturation	3.7 (0.6)	3.4 (0.7)	3.5 (0.7)

*p = < .05 based on t-test analyses between NAMI and Community caregivers

Table 6:
 Domain I: Mental Illness Conceptualizations

Domain I: Mental Illness Conceptualization (caregivers can have multiple responses)			
Categories	17 NAMI caregivers	15 Community Caregivers	Total
Psychiatric Conceptualization <i>“my daughter has bipolar disorder, she does not have any signs of depression, she is just very hyper and anxious”</i> EP029	100%	60%*	84%
Religious/Spiritual/Supernatural <i>“Mexicans raised by older traditional generations don’t believe in mental illness. They believe in the devil and curses. They feel that a mental illness was caused by something...it is not something organic”</i> EP007	18%	47%*	28%
Caregivers that held multiple Conceptualizations <i>“Esquizofrenia (Spanish term for Schizophrenia) is not only the illness he has, it is also the enemy...it is the bad spirit taking over his mind in his head and his whole body. So I’ll speak to Ezquizofrenia and yell at her to leave him. I’ve learned that it’s a woman spirit.”</i> EP023	47%	73%	59%

*p = < .05 based on Fisher’s exact test analyses between NAMI and Community caregivers

Table 7:

Category A – Reasons for Relatives' Initiation of Formal Treatment Use

Sub-Categories	17 NAMI caregivers	15 Community Caregivers	Total
Psychotic/Violent Crisis <i>"...my son got very paranoid and said he heard voices. He bought a rifle and would go to the roof of the house and point it at people to make sure "they" wouldn't get him. That's when we decided we had to take him to the hospital."</i> EP023	41%	60%	50%
Referred by a general physician <i>"In the car she was crying hysterically. So I called my sister-in-law, she's a nurse practitioner. So that's the first place we ran to. And she told me let's go take her to the hospital. We went to the hospital."</i> EP034	29%	27%	28%
Referred by School officials <i>"The teachers told her [affected relative] father to help her by taking her to have a psychological evaluation because she was not behaving in class."</i> EP027	24%	13%	19%
Taken to treat a substance use problem	6%	0%	3%

*p = < .05 based on Fisher's exact test analyses between NAMI and Community caregivers

Table 8: Category B - Reasons for Treatment Retention

	17 NAMI caregivers	15 Community Caregivers	Total
<p>Positive experiences with service providers</p> <p><i>"The therapist was available anytime night, day, or morning when I was calling her...and to talk to my daughter...my daughter would call her at 3 o'clock in the morning...and she'd come and say I want to talk to my therapist." EP035</i></p>	71%	73%	72%
<p>Support by caregiver and family</p> <p><i>"She didn't have a car yet so she would call me and say, "I need a ride." So there I go, drop her off, and then pick her up in the afternoon and take her grocery shopping, everywhere. I know it was an inconvenience for me because then I had to kind of re-plan my day... but I never really mind doing it." EP004</i></p>	59%	27%	53%
<p>Support/Recommendation by NAMI</p> <p><i>"my gosh the [NAMI]classes are phenomenal; knowing what my brother is thinking, and how he is feeling. I never knew what his feelings were before taking the classes...when I found out then, I reacted differently toward him" EP006</i></p>	76%	0%*	41%
<p>Treatment for comorbid problem (e.g., substance use)</p> <p><i>"Well he got arrested for stealing a credit card and was tested for drugs. He tested positive for cocaine and is now in a drug rehabilitation center. So his drug problems have kept him in treatment." EP028</i></p>	29%	27%	28%
<p>Support/Encouragement by spiritual/religious sources</p> <p><i>"We asked some of our brothers and sisters at Church if they knew a doctor that could help us. And one of them said that his brother was going through schizophrenia and he took him to this doctor and that this doctor was really good. Everyone at church is very supportive of [formal]treatments" EP023</i></p>	29%	20%	22%
<p>Inpatient/Rehospitalization</p> <p><i>"[The affected relative] left with medication from [the hospital], and he was more or less okay. I'm not going to say he was great, but then he began to regress when he didn't take his meds and we had to readmit him another time, then return to readmit him another time, and another time during 2 weeks." EP013</i></p>	6%	33%	19%

*p = < .05 based on Fisher's exact test analyses between NAMI and Community caregivers

Table 9:
 Category C – Barriers to Formal Service Use

Sub-category 1: Barriers to Caregivers	17 NAMI caregivers	15 Community Caregivers	Total
Influence of Latino cultural beliefs <i>“Mexican families are afraid to look for services because they are worried about what others will say. We have been raised to have shame if there is illness in the family so we hide it.” EP030</i>	47%	80%	63%
Resistance by ill relative to engage services <i>“I’m like you need to take your medicine, it’ll help you. It won’t cure you, but it’ll help you. But she says I don’t wanna gain weight. [The medication] has a lot of side effects. But she won’t. She’s not willing to take her medicine.” EP034</i>	65%	40%*	53%
Use of alternative/folk treatments <i>“My wife’s family prefers to take her to Mexico to a curandera for limpias. At first it caused tension in the family but now it does not bother me because it doesn’t hurt that they take her. But they still oppose formal treatment” EP025</i>	24%	73%*	50%
Lack of family encouragement/support to use formal services <i>“my mother criticizes me because she tells me “well throw him out. Why do you have to put up with this? Look at his age.” But that’s my son. How am I going to throw him out? Where is he going to go? He has me. If I can’t help them and support their treatment, who’s going to help?” EP028</i>	41%	53%	50%
Cost/Lack of Insurance <i>“I think the social worker mentioned that no insurance will cover her because of her disease, and that’s not really encouraging. You know, it’s bad enough that there are young people and when they try to get insurance on their own.” EP035</i>	47%	40%	44%
Prior Negative Experiences with Service Providers <i>“they (service providers) only seek to benefit themselves and don’t really care about the well being of those hospitalized” EP032</i>	29%	13%	22%

*p = < .05 based on Fisher’s exact test analyses between NAMI and Community caregivers

APPENDIX B - NAMI CAREGIVERS' CAREGIVING AND SERVICE USE INTERVIEW

MODULE 1: Caregiving Experiences

Caregiver and Patient Interactions:

Are you the family member who provides the most support for (NAME)?

How long have you been caring for your relative?

Have you seen or talked to (NAME) in the past 3 months?

- [I want to talk about the activities that (NAME) does at home. Let's start with a typical weekday and how she/he interacts with you]. What types of things do you do together? For how long do you do these things?
- For example, has (NAME) helped you with meal preparation, shopping, cleaning, or other household chores these past 3 months?
- What types of things do you talk about?
- How often has (NAME) listened to your problems and offered advice?
- During the past 3 months, how often has (NAME) given you companionship?
- What types of things does he/she do on his/her own?
- What things does he/she do for you? What things do you do for him/her?
- Can you tell me about the things that annoy/bother you?
- What things please you the most? Make you feel proud? Admire?

Benefits and Gratification

During the past 3 months, how often has (NAME) helped you with meal preparation, shopping or other household chores?

During the past 3 months, how often has (NAME) helped you out financially?

During the past 3 months, how often has (NAME) listened to your problems and offered advice?

During the past 3 months, how often has (NAME) given you companionship?

Assistance in Daily Living Module

**It frequently happens that persons who are mentally ill need to be reminded to do everyday things. The next questions are about that. All of them may not apply to (NAME), but please try to answer them to the best of your knowledge.

During the past 3 months, did you help or remind (NAME) to do things like grooming, bathing, or dressing?

- During the past 3 months, how often did you help (NAME) with, or remind (NAME) to do things like grooming, bathing, or dressing?
- How much did you mind helping (NAME) with or reminding about these things?

MODULE 1: Caregiving Experiences Cont.

- During the past 3 months, did anyone else help or remind (NAME) to do things like grooming, bathing, or dressing? If yes, who was it? (Family, MH Service Staff, someone else, etc.).

During the past 3 months, did you help or remind (NAME) to do his/her housework or laundry?

- During the past 3 months, how often did you help (NAME) with, or remind (NAME) to do his/her housework or laundry?
- How much did you mind helping (NAME) with or reminding about these things?
- During the past 3 months, did anyone else help or remind (NAME) to do his/her housework or laundry? If yes, who was it? (Family, MH Service Staff, someone else, etc.).
-

During the past 3 months, did you give (NAME) a ride or help (him/her) to use public transportation?

- During the past 3 months, how often did you give (NAME) a ride or help (him/her) to use public transportation?
- How much did you mind helping (NAME) with his/her transportation need?
- During the past 3 months, what other persons, if any, gave (NAME) a ride or helped (him/her) to use public transportation? If yes, who was it? (Family, MH Service Staff, someone else, etc.).

During the past 3 months, did you help, remind, or urge (NAME) to make use of his time, such as going to work, or school, or aftercare, or visiting with friends?

- During the past 3 months, how often did you help, remind, or urge (NAME) to make use of his time?
- How much did you mind helping NAME make use of his/her time?
- During the past 3 months, what other persons, if any, have helped, reminded, or urged (NAME) to make use of his/her time? If yes, who was it? (Family, MH Service Staff, someone else, etc.).

Medication

Is (NAME) supposed to be taking medication for his/her condition?

- During the past 3 months, did you help, remind, or encourage NAME to take his/her medicine?
- During the past 3 months how often did you help, remind, or encourage NAME to take his/her medicine? (Every day, 3 to 6 times a week, once a week, less than once a week, etc.).
- How much did you mind helping, reminding, or encouraging NAME to take his/her medicine?
- During the past 3 months, what other persons, if any, helped, reminded, or urged NAME to take his/her medicine?

Supervision

During the past 3 months, did you try to prevent or stop (NAME) from doing something embarrassing in public or in front of others?

- During the past 3 months, how often you try to prevent or stop (NAME) from doing something embarrassing?
- How much did you mind dealing with NAME's embarrassing behavior?

MODULE 1: Caregiving Experiences Cont.

- During the past 3 months, what other persons, if any, tried to prevent or stop (NAME) from doing something embarrassing? If yes, who was it? (Family, MH Service Staff, someone else, etc.).

During the past 3 months, did you try to prevent or stop (NAME) from striking or injuring anyone, including yourself?

How about preventing or stopping NAME from threatening to strike or injure anyone, including yourself?

- During the past 3 months how often you try to prevent or stop (NAME) from injuring or threatening anyone?
- How much did you mind doing that?
- During the past 3 months, what other persons, if any, tried to prevent or stop (NAME) from injuring or threatening anyone? If yes, who was it? (Family, MH Service Staff, someone else, etc.).

During the past 3 months, did you try to prevent or stop (NAME) from:

- Talking about committing suicide?
- Making threats to commit suicide?
- Actually attempting to commit suicide?

- During the past 3 months how often you try to prevent or stop (NAME) from talking about, threatening, or attempting suicide?
- How much did you mind dealing with NAME's suicidal (talk/threats/attempts)?
- During the past 3 months, what other persons, if any, tried to prevent or stop (NAME) from talking about, threatening, or attempting suicide? If yes, who was it? (Family, MH Service Staff, someone else, etc.).

During the past 3 months, did you try to prevent or stop (NAME) from having too much to drink or using other drugs?

- During the past 3 months how often you try to prevent or stop (NAME) from having too much to drink?
- How much did you mind having to deal with his/her drinking?
- During the past 3 months, what other persons, if any, tried to prevent or stop (NAME) from drinking too much? If yes, who was it? (Family, MH Service Staff, someone else, etc.).

Impact on Daily Routines Module

During the past 3 months, did you miss or were late to work, school, or an appointment because of your involvement with NAME?

- During the past 3 months, how often did you miss, or were late to _____, because of your involvement with NAME?

During the past 3 months, were your social and leisure activities changed or disrupted because of NAME?

- During the past 3 months, how often were your social and leisure activities changed or disrupted because of NAME?

MODULE 1: Caregiving Experiences Cont.

During the past 3 months, was your usual housework or domestic routine disrupted or changed because of NAME?

- During the past 3 months, how often was your usual housework or domestic routine disrupted or changed because of NAME?

During the past 3 months, did taking care of NAME prevent you from giving (other) family members as much time and attention as they needed?

- During the past 3 months, how often did taking care of NAME prevent you from giving (other) family members as much time and attention as they needed?

Has NAME's illness caused you to make more or less permanent changes in your daily routine, work, or social life?

- If YES: How did your routine change?
Worked less/quit job _____
Retired earlier than planned _____
Have no social life _____
Have no family life _____
Lost friendships _____
Take no vacations _____

Affective Response

(Even when people have not seen each other for a period of time, sometimes they worry anyway about the other person.) I would like to ask you about concerns or worries you may have about NAME.

How much do you worry about NAME's safety?

How much do you worry about the help and treatment NAME is receiving?

How much do you worry about NAME's social life?

How much do you worry about NAME's physical health?

How much do you worry about NAME's current living arrangements?

How much do you worry about how NAME would manage financially if you were not there to help him/her?

How much do you worry about NAME's future prospects/outlook?

Thoughts on Caregiving Role:

All the things you mentioned earlier that you do for him, tell me how you feel about doing those things.

What do you think your role as a caregiver should be?

Tell me about the things that you like doing for your relative.

Tell me about the things that you don't like doing for (the relative).

- Are you ok with doing these types of things?
- What things/tasks go beyond your role as a caregiver?
- Are there any things that you do that you think are beyond your responsibility? Can you tell me about that?

How do these things make you feel about yourself?

What has been the most difficult aspect of caring your relative?

Are there any other things you do to support your relative?

MODULE 1: Caregiving Experiences Cont.

How would you describe the patient?
Does he show affection toward you?
Has your affection towards him changed?

What is the hardest thing for you about the illness?

Family and Patient Interactions

What about other family members in the house (and outside the house)? How do they interact with the ill relative (on the weekday and weekends)?

- What types of things do they do together? For how long do they do these things?
- What types of things do they talk about?
- Can you tell me about the things that he/she does that upsets (family members)?
- Can you tell me about the things family members do to upset (the ill relative)?

Other family members' caregiving

Which family member, relative, or friend provides the greatest amount of care to (NAME)?
How do your family members help out with the relative?

- What types of things do they do?
- Can you give examples?

How do your family members help you out with caring for (the relative)?

- What types of things do they do?
- Can you give examples?

Can you tell me about the family members that you struggle with in getting them to help out?
What are the things that you struggle with to get other family members to help you out with?

- How can family members help more?
- What are the things that you need help with the most?
- What do they tell you about helping him/her out?
- What do they say/believe about his/her problems/illness?

Does the patient get along with other family members?

- Which ones does he get along with?
- Which ones does he not get along with?
- Do you know why?

Satisfaction with Family Help

Why do you think that family members help you out?
Why don't the other family members help you out more?
How do you think family members can help more?
Are you satisfied with the amount of help they give you? Why or why not?
How do you try to get family members to help you out?
What would it take for you to be satisfied with the help from your family?

MODULE 2: Treatment Usage

SERVICES FOR ILL RELATIVE		
Su1.	How many hospitalizations has the ill family member had? (Circle only one response)	0 = none 1= 1-2 2 = 3-4 3 = > 5 -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
Su2.	Has the ill relative used any mental health services in the past 12 months? (this does not include any NAMI service)	1 = Yes 2 = No -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
Su3.	If yes, who have they seen in the past 12 months? (circle all that apply)	1= Mental Health Service Provider 2 = Physician 3 = Other: _____ -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
Su4.	If they have not used services in the past 12 months, when was the last time they used services?	1= 1 year ago 2 = 2 years ago 3 = 3 years ago 4 = More than 3 years ago -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
Su5.	Has the ill relative used mental health services in the past 3 months? (this does not include any NAMI service)	1 = Yes 2 = No -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)

<u>MODULE 2: Treatment Access & Utilization Cont.</u>		
Su6.	If yes, who have they seen in the past 3 months? (circle all that apply)	1= Mental Health Service Provider 2 = Physician 3 = Other: _____ -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
Su7.	What type of services have they used MORE THAN 1 YEAR AGO? (this does not include any NAMI service) (circle all that apply)	1= Mental Health Service Provider 2 = Physician 3 = Other: _____ -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
Su8.	Who first IDENTIFIED an “abnormal” problem/mental illness (that had to be addressed) for the ill relative? (Try to circle only one as best as possible, but if they mention more than one, circle them)	1= School officials/staff 2 = Police 3 = Other Family/Friend 4 = Caregiver 5 = Other _____ -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
Su9.	Who did the family/caregiver/ill relative first turn to for help to address the ill relative’s condition? (Try to circle only one as best as possible, but if they mention more than one helper, circle them)	1= Mental Health Service Provider 2 = Physician 3 = Support Groups 4 =NAMI 7 = School Counselor/Staff 8 = Religion/Spirituality 9 = Family 10 = Friends 11 = Police 12 = Other _____ -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)

<u>MODULE 2: Treatment Access & Utilization Cont.</u>		
Su10.	Who first suggested to you or your relative seek FORMAL MH SERVICES/TREATMENT for the ill relative?	1= Mental Health Service Provider 2 = Physician 3 = Support Groups 4 =NAMI 7 = School Counselor/Staff 8 = Religious/Spiritual organization or leader 9 = Family 10 = Friends 11 = Police 12 = Other _____ -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
Su11.	What are reasons for why your relative is currently using services? (circle all that apply)	1 = Observed positive results/improvements/expectations 2 = Mandated to use services 3 = Relative has not improved 4 = Relapse of symptoms 5 = Ill relative has chosen to continue in services 6 = Insurance/Financial benefits 7 = Other _____ 8 = Currently not using services -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
Su12.	What expectations do you have for the mental health treatment of your relative? (circle all that apply)	1 = Complete cure 2 = Stabilize the ill relative 3 = Alleviate stress/tension at home/family 4 = Improve ill relative's life 5 = Nothing/No change 6 = Negative effects 7 = Treatment will make them worse 8 = Other _____ -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)

<u>MODULE 2: Treatment Access & Utilization Cont.</u>		
Su13.	How satisfied are you with the mental health services for their ill relative? (circle only one response)	1 = Very satisfied 2 = Satisfied 3 = Neutral 4 = Dissatisfied 5 = Very Dissatisfied
Su14.	If the ill relative is NOT using services, has ever quit, or has not gone to treatment/appointments, what are the reasons? (circle all that apply)	1= Cost/Insurance 2 = Negative Reactions to Medication 3 = Scheduling Conflicts 4 = Negative experiences in the past. Explain _____ _____ _____ 5 = Ill relative does/did not want to go to services 6 = Stigma-related 7 = Lack of family support 8 = Transportation issues 9 = No longer mandated 10 = Thought they no longer needed services 11 = Other _____ _____ -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
Su15.	What other alternative forms of help has the caregiver turned to in order to address their relative's mental illness? (circle all that apply)	1 = Family 2 = Friends 3 = Religion/Spirituality 4 = Folk Remedies 5 = Other caregivers 6 = Education/Outreach Programs 7 = Self Help Books 8 = NAMI 9 = Other _____ -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)

<u>MODULE 2: Treatment Access & Utilization Cont.</u>		
Su16.	Is your relative currently taking their prescribed medication?	1 = Yes 2 = No -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
Su17.	If yes, who administers the medication to the ill relative or makes sure the relative is taking the med? (circle all that apply)	1 = Caregiver 2 = Other family members 3 = Service Providers 4 = The ill relative 5 = Other _____ -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
Su18.	What are the reasons for why your relative has ever stopped taking medication or for never taking medication? (circle all that apply)	1 = Cost/Insurance 2 = Side Effects 3 = Negative experiences in the past. Explain _____ _____ _____ 4 = Ill relative does/did not want to take it 5 = Stigma-related 7 = Lack of family support 8 = No longer mandated 9 = Thought they no longer needed the medication 10 = Other _____ _____ -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
SERVICES FOR CAREGIVER		
Sc1.	Has the caregiver used mental health treatment in the past 12 months? (this does not include any NAMI service)	1 = Yes 2 = No -9 = missing data (was asked but did not reply)

		N/A = Not mentioned
<u>MODULE 2: Treatment Access & Utilization Cont.</u>		
Sc2.	If yes, who have the caregiver seen in the past 12 months? (circle all that apply) (this does not include any NAMI service)	1= Mental Health Service Provider 2 = Physician 3 = Other: _____ -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
Sc3.	Has the caregiver used mental health treatment in the past 3 months? (this does not include any NAMI service)	1 = Yes 2 = No -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
Sc4.	If yes, who have they seen in the past 3 months? (circle all that apply) (this does not include any NAMI service)	1= Mental Health Service Provider 2 = Physician 3 = Other: _____ -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
Sc5.	What type of services have you used beyond the last year? (circle all that apply) (this does not include any NAMI service)	1= Mental Health Service Provider 2 = Physician 3 = Other: _____ -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
Sc6.	What are the reasons for FIRST turning to mental health services for yourself? (circle all that apply)	1= School problem/referral 2 = Court mandated/child protective services 3 = Family/Friend recommended 4 = Caregiver chose to go 5 = Work related problems 6 = NAMI recommended 7 = Other _____ -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)

<u>MODULE 2: Treatment Access & Utilization Cont.</u>		
Sc7.	What are some reasons for you CURRENTLY using services? (circle all that apply)	1 = Overwhelmed/ Burdened/Distressed 2 = Education 3 = To be a better caregiver 4 = Mandated 5 = Recommended by providers 6 = Recommended by family 7 = Recommended by ill relative 8 = Recommended by other: _____ 9 = Other _____ _____ -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
Sc8.	If the caregiver is NOT using services or has ever quit, what are the reasons? (circle all that apply)	1= Cost/Insurance 2 = Negative Reactions to Medication 3 = Scheduling Conflicts 4 = Negative experiences in the past. Explain _____ _____ _____ 5 = Ill relative does/did not want to go to services 6 = Stigma-related 7 = Lack of family support 8 = Transportation issues 9 = No longer mandated 10 = Thought they no longer needed services 11 = Other _____ _____ -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)

MODULE 2: Treatment Access & Utilization Cont.		
NAMI QUESTIONS		
N1.	Have you taken the NAMI classes or services? <i>(circle only one response)</i>	1 = Yes 2 = No -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
N2.	How did you find out about the NAMI classes? <i>(circle all that apply)</i>	1 = Service Provider 2 = Family 3 = Friends/Other caregivers 4 = Advertisements 5 = Other _____ -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
N3.	What was most valuable about the NAMI classes? <i>(circle all that apply)</i>	1 = Education 2 = Improved the caregiving experience 3 = Improved relationship between caregiver and ill relative 4 = Relieves family tension at home 5 = Normalizes caregiving experience 6 = Acceptance of mental illness 7 = Other _____ _____ -9 = missing data (was asked but did not reply) N/A = Not mentioned (not asked or did not come up in interview)
OPEN ENDED QUESTIONS		
Sr.1	What have been the most positive and helpful experiences that you have gotten from mental health service?	
Sr.2.	Studies hypothesize that Latinos have low rates seeking and using help from formal mental health services? If you believe this is true, what are some reasons for this?	
Sr.3.	What RECOMMENDATIONS do you have in order to improve access to services or the quality of services?	
Sr.4	What else have you used besides doctors and service providers to help you deal with your relative's mental illness?	

APPENDIX C: Community Caregivers Qualitative Interview

I. Caregiver – Ill Relative Relationship

- Tell me about your relationship to [relative's name].
- What are the things that stand out the most?
- What are the things you have struggled with the most?
- What are the things that have been most satisfying or rewarding?

II. Conceptualization of Mental Illness and Treatment

- You mentioned that your relative has struggled with [name symptoms]. Tell me about this issue.
- Okay so now I would like to begin asking when [relative's] troubles first began. When did you first notice something different about him/her?
- How were these issues addressed? (Probe for use of formal or alternative help).
- What do you think made [relative's name] like this?
- What do you think that [relative's name] could do more to control his/her behaviors?
- Do you think that XXX is ill? [If YES] - What kind of illness do you think he/she has?
- Has anyone told you that he is ill?
- Have you (or they) given this condition a name?
- Now I would like to talk about the past three months or so. How has he/she been doing in the past 3 months?
- Can you tell me about how you have tried to (address, improve) your relative's condition?
- *(Probe for formal services and alternative sources of help).*
- *(Probe for reasons why they have and/or have not pursued formal/alternative services).*
- Is this (the "alternative" form of help or treatment reported) something unique about Latinos?

- How do think Latinos address these issues? Who do they turn to?
- Are there other ways (treatments, doctors, etc) you have heard of or have been suggested to you that might help him/her out?
- What has been the most helpful thing to address your relative's condition? Tell me about that.
- What has been the least helpful thing to address your relative's condition? Tell me about that.

III. Thoughts on Caregiving Role

- All the things you mentioned earlier that you do for him, tell me how you feel about doing those things.
- Tell me about the things that you like doing for your relative.
- Tell me about the things that you don't like doing for (the relative).
- What things/tasks go beyond your role as a caregiver? Are there any things that you do that you think are beyond your responsibility? Can you tell me about that?
- How do these things make you feel about yourself?
- What has been the most difficult aspect of caring for your relative?
- What has been the most satisfying/rewarding aspect of caring for your relative?

IV. Family and Patient Interactions

- How do your family members help out with the relative?
- What types of things do they do?
 - Can you give examples?
- Which family member, relative, or friend provides the greatest amount of care to (NAME)?
- Can you tell me about the family members that you struggle with in getting them to help out?
- What are the things that you struggle with to get other family members to help you with?

- How can family members help more?
- What are the things that you need help with the most?
- What do they tell you about helping him/her out?
- What do they say/believe about his/her problems/illness?

- Does [Name of Relative] get along with other family members?
 - Which ones does he get along with?
 - Which ones does he not get along with?
 - Do you know why?

- Are you satisfied with the amount of help they give you? Why or why not?
- How do you try to get family members to help you out?
- What would it take for you to be satisfied with the help from your family?
- Where do you get your strength and hope to address all this?

Well thank you for your time. Before we end, is there anything you would like to add to the interview or let me know about?

APPENDIX D – DEMOGRAPHIC QUESTIONNAIRE

- A. How far did you get in school?
- 1 Elementary – 6th grade
 - 2 Middle School 7-8th
 - 3 High School 9-12th
 - 4 University or College 1-2 years
 - 5 University or College 3-4 years
 - 6 Graduated college or beyond
- B. In what country did you go to school?
- C. What is your occupation?
- D. For how long have you been working?
- E. How long have you lived in this city?
- F. Have you lived in other cities? ___ Yes ___ No
- G. Name of previous city
- H. How long did you live in this other city?
- I. What is your ethnicity? (please circle)
- 1 African American
 - 2 Asian American
 - 3 Anglo American
 - 4 Mexican American (born in US)
 - 5 Other Latino : name of country of origin
 - 6 Native American
 - 7 Other, specify
- J. Your date of birth (mm/dd/yyyy) _____ / _____ / _____
- K. Yearly Income (or Monthly Income)
- 1 \$0 – 4,999 (\$416 a month)
 - 2 \$5,000 – 9,999 (\$416-833)
 - 3 \$10,000 – 19,000 (\$833-1583)
 - 4 \$20,000 – 29,000 (\$1666-2415)
 - 5 \$30,000 – 39,000 (\$2500-3250)
 - 6 \$40,000-49,000 (\$3333-4083)
 - 7 \$50,000 or more
- L. Place of Origin
- 1 Where were you born?
 - 2 Where were your parents born?
 - 3 Where were your grandparents born?
- M. Who lives with you at home? How long have they been living at home?
- N. How old is your ill relative?
- O. Where was your ill relative born?
- P. How long has he lived in the United States?
- Q. What is the diagnosis or name of illness given to your ill relative?
- R. How many years has your ill relative been sick?
- S. How many hospitalizations has your ill relative had?

APPENDIX E - FAMILY COMPOSITION SHEET

NAME	RELATIONSHIP TO ILL RELATIVE	AGE	SEX	ON AVERAGE HOW MUCH TIME DO YOU SPEND TOGETHER PER WEEK (IN THE LAST 3 MONTHS)	WHAT ARE EXAMPLES OF THE TYPES OF THINGS YOU DO TOGETHER
<i>Carl</i>	<i>Brother</i>	<i>15</i>	<i>M</i>	<i>20 hours/week</i>	
1.					
2.					
3.					
4.					
5.					

APPENDIX H. CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION SCALE

(CES-D)

Rarely or None of the Time (Less than 1 day)	Some or a Little of the Time (1-2 days)	Occasion ally Or a Moderate Amount of Time (3-4 days)	Mostly or Almost all the time (5-7 days)
0	1	2	3

1. I was bothered by things that usually don't bother me.
2. I did not feel like eating; my appetite was poor.
3. I felt that I could not shake off the blues, even with help from family and friends.
4. I felt that I was just as good as other people.
5. I had trouble keeping my mind on what I was doing.
6. I felt depressed.
7. I felt that everything I did was an effort.
8. I felt hopeful about the future.
9. I thought my life had been a failure.
10. I felt fearful.
11. My sleep was restless.
12. I was happy.
13. I talked less than usual.
14. I felt lonely.
15. People were unfriendly.
16. I enjoyed life.
17. I had crying spells.
18. I felt sad.
19. I felt that people disliked me.
20. I could not get "going".

APPENDIX I. BURDEN ASSESSMENT SCALE

I am going to read a list of things which other people have found to happen to them because of their relative's illness. Would you tell me to what extent you have had any of the following experiences in the past six months.

1	2	3	4	9
Not at all	A little	Some	A lot	N/A

1. Had financial problems
2. Missed days at work (or school)
3. Found it difficult to concentrate on your own activities
4. Had to change your personal plans like taking a new job, or going on vacation
5. Cut down on leisure time
6. Found the household routine was upset
7. Had less time to spend with friends
8. Neglected other family members' needs
9. Experienced family frictions and arguments
10. Experienced frictions with neighbors, friends, or relatives outside the home
11. Became embarrassed because of (name's) behavior
12. Felt guilty because you were not doing enough to help
13. Felt guilty because you felt responsible for causing (name's) problem
14. Resented (name) because s/he made too many demand on you
15. Felt trapped by your caregiving role
16. Were upset about how much (name) had changed from his or her former self
17. Worried about how your behavior with (name) might make the illness worse
18. Worried about what the future holds for (name)
19. Found the stigma of the illness upsetting

APPENDIX J - FAMILY ATTITUDE SCALE

0	1	2	3	4
Never	Very Rarely	Some Days	Most Days	Every Day

1. It is good to have him/her around.
2. He/she makes me feel drained.
3. He/she ignores my advice.
4. He/she is really hard to take.
5. I shout at him/her.
6. I wish he/she were not here.
7. I feel that he/she is driving me crazy.
8. I lose my temper with him/her.
9. He/she is easy to get along with.
10. I am sick of having to look after him/her.
11. He/she deliberately causes me problems.
12. I enjoy being with him/her.
13. He/she is a real burden.
14. I argue with him/her.
15. I feel very close to him/her.
16. I can cope with him/her.
17. Living with him/her is too much for me.
18. He/she is infuriating.
19. I find myself saying nasty or sarcastic things to him/her.
20. He/she appreciates what I do for him.
21. I feel that he/she is becoming easier to live with.
22. I wish he/she would leave me alone.
23. He/she takes me for granted.
24. He/she can control himself.
25. He/she is hard to get close to.
26. I feel that he/she is becoming harder to live with.
27. I feel very frustrated with him/her.
28. He/she makes a lot of sense.
29. I feel disappointed with him/her.
30. He/she tries to get along with me.

APPENDIX K – FAMILY ENVIRONMENT SCALE (FES) COHESION

There are 9 statements on this page. They are statements about families. You are to decide which of these statements are true of your family and which are false. If you think the statement is *True* or mostly *True* of your family, circle “True”. If you think the statement is *False* or mostly *False* of your family, circle “False”.

1. Family members really help and support one another.
2. We often seem to be killing time at home.
3. We put a lot of energy into what we do at home.
4. There is a feeling of togetherness in our family.
5. We rarely volunteer when something has to be done at home.
6. Family members really back each other up.
7. There is very little group spirit in our family.
8. We really get along well with each other.
9. There is plenty of time and attention for everyone in our family.

APPENDIX L – STIGMA SCALE

Always	Often	Sometimes	Rarely	Never
5	4	3	2	1

1. Are you worried about what people will think of your son/daughter if they know about his/her problems?
2. Are you worried about what people will think of you if they know about your son/daughter's problems?
3. Are you worried that more people might find out about your son/daughter's problems?
4. Are you careful about telling people about your son/daughter because of what they might think of you?
5. When you meet new people, do you worry about how they will act if they find out about your son/daughter's problems?